Chapter 16 – Support and Counselling

Introduction

1 Support, counselling and, in the case of the death of a patient, bereavement services were available to parents of children who received paediatric cardiac care at Bristol, both at the BRI and the BRHSC during the period of the Inquiry's Terms of Reference. These services were provided by a variety of individuals and bodies. Many were UBH/T staff who did not have a defined, or named, role in providing support or counselling but who nevertheless came into regular contact with patients and their families.

2 Others had a defined role in providing this service, namely the Bristol & South West Children's Heart Circle, the UBH/T Chaplains, the Social Work Department and those responsible in the UBH/T for responding to bereavement. During the period of our Terms of Reference two posts were created at UBH/T. The first post, that of Counsellor in Paediatric Cardiology, was taken up by Mrs Helen Vegoda in January 1988. The second post, that of Cardiac Liaison Sister, was held by Miss Helen Stratton from November 1990 until February 1994.[1] As will be seen later in this chapter, Mrs Vegoda and Miss Stratton had different roles.

Terminology

3 The Inquiry commissioned a background paper from Dr Charlotte Humphrey.[2] She sought to set out the needs for care which parents of children in acute healthcare settings, such as those receiving paediatric cardiac care, might have. She wrote:

> '… "support" is defined as including all activities or arrangements within the health care environment which help meet the psychological and social needs of parents whose children are receiving care, whether or not they are specifically intended to fulfil this purpose. Support thus covers a wide range of issues from practical arrangements for parents to stay in hospital and help in their children's care to the giving of information, encouragement, advice and sympathy. …
>
> 'Given this broad definition of support, it follows that anyone involved in the provision or organisation of care at an individual or institutional level may have a part to play in ensuring that parents' needs are provided for and taken into account. Support may also be provided from sources outside the healthcare setting including self-help groups or facilitator-led support groups.'[3]
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> 'Within the broader framework of psychological and social support, counselling is the activity which occurs when a person (either regularly or temporarily in the role

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[1] The two posts were given various titles, see later in this chapter

[2] Charlotte Humphrey PhD, Professor of Health Care Evaluation, Florence Nightingale School of Nursing and Midwifery, King's College London, formerly Senior Lecturer in Sociology, Royal Free and University College Medical School, University College London: BRI Inquiry paper on support and counselling for parents of children in acute health care settings, December 1999, INQ 0025 0001 – 0023

[3] INQ 0025 0005; Dr Humphrey's paper

> of counsellor) offers time, attention and respect to another person or persons to explore their feelings and concerns …
>
> ‘Counselling skills, such as listening, reflecting and conveying empathy, are not exclusive to the counsellor. Almost all healthcare professionals need such skills in the course of their interactions with patients, for example in giving information, clarifying treatment options and helping people adjust to new and sometimes unwelcome circumstances. The difference between these generic skills and those of a formally defined counsellor (or psychologist or psychotherapist) is that the latter is expected to have advanced training and qualifications in their field and is likely to approach the counselling process within a specific theoretical framework …’[4]

4 Mrs Valerie Mandelson[5] defined ‘support’ as being: ‘… listening skills, empathy, being alongside a person at a time of great emotional stress and distress’, and ‘counselling’ as:

> ‘… something on a deeper level … something that is more formal, that is something that is entered into with the person who is the parent or the family, or the client …
>
> ‘Bereavement counselling actually provides a means of expressing grief in a much deeper way, and working on some of the tasks of mourning, facing the reality of the loss, perhaps experiencing the pain of that loss, and working with families in adjusting to daily existence without a very much-loved child and all the stresses that that might bring in terms of family stress, marital stress, self-esteem; and I guess, working with families, helping them find future direction …’[6]

5 In a letter to the Inquiry, Mrs Mandelson said:

> ‘There is debate amongst counselling professionals as to how we can usefully distinguish between support and counselling. I feel that many service users would be unlikely to be able to tell if they had been “supported” or “counselled”.’[7]

6 Mrs Vegoda told the Inquiry that by ‘support’ she meant:

> ‘I was with the parents when the child went into the catheter lab. When the child had actually gone in, if the parents wanted me to be around, I would come out with them, often take them back to my room and they were often upset. At that point I saw that as support, because I felt they just needed somebody with them.

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[4] INQ 0025 0005 – 0006. Dr Humphrey also referred to a paper (Bor R, Miller R, Latz M, Salt H. *‘Counselling in Health Care Settings’* (1998), London: Cassell) which identified four levels of counselling: information-giving, implications counselling, supportive counselling and psychotherapeutic counselling – and suggested that only the first two of these would routinely be provided by healthcare professionals responsible for patients’ care

[5] Manager and Senior Counsellor, Alder Centre, Alder Hey Children’s Hospital, Liverpool: Expert to the Inquiry on Support and Counselling Services and see later in this chapter

[6] T47 p. 180–1 Mrs Mandelson

[7] INQ 0026 0008; letter to the Inquiry

> They often were in tears, they needed someone to make them a cup of tea, and I think that was pure support.'[8]

7 As for 'counselling', Mrs Vegoda said:

> '… counselling might come in, for example, if I met a family where the child had been newly diagnosed and the parents, for example, were saying things like, you know, "It is my fault" and "I feel very guilty", or they were very angry about the child having a condition. Then I would try and use my counselling skills, because I would try and help them to see that that was not so … I felt the counselling was helping them to come to terms and accept what was normal, and also to deal with it.'[9]

8 Miss Stratton told the Inquiry:

> '… my personal definition of counselling is someone who has a professional qualification to carry that out.' [10]

The split site

9 The basic chronology of the split site contributes to an understanding of the split of support, counselling and bereavement services for paediatric cardiac patients between the BRI and BRHSC during the period 1984–1995. The salient facts are set out very briefly here.

10 In 1984 paediatric cardiology was based at the BRI. Open-heart surgery was also performed at the BRI, paediatric patients being cared for, along with adult patients, in Ward 5 at the BRI. However, closed-heart surgery was performed at the BRHSC, paediatric patients being cared for in Ward 33.

11 In 1987 the cardiac catheterisation suite opened at the BRHSC. Cardiology was based there, along with closed-heart surgery, but open-heart surgery remained at the BRI.

12 In October 1995 the paediatric cardiac services were united at the BRHSC. Thus, throughout the period of the Inquiry's Terms of Reference, until October 1995, the paediatric cardiac service was split between the BRI and the BRHSC, with many paediatric cardiac patients being transferred between sites for treatment, resulting in a split in the provision of support, counselling and bereavement services.

Priority

13 The priority attached to the support, counselling and bereavement services by UBH/T management and staff, in terms of the provision of funding, time and interaction with those providing the service, will be a recurring theme.

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[8] T47 p. 95–6

[9] T47 p. 96 Mrs Vegoda

[10] T46 p. 53–4 Miss Stratton

14 The Directorate of Surgery stated in its document *'Services for Patients'*:

> '… a positive and happy atmosphere is maintained throughout the department, and to this end counselling of patients and their relatives before and after surgery, is a priority'.[11]

15 A number of witnesses to the Inquiry commented on the priority they felt was attached to the service.

16 Mrs Jean Pratten[12] told the Inquiry:

> 'I am certain that children's paediatric surgery at the Bristol Royal Infirmary was never properly resourced and funds eventually only became available when the crisis arose.'[13]

17 She told the Inquiry that the Bristol and South West Children's Heart Circle raised in the region of £1,000,000 for projects at the UBH/T:[14]

> 'I would have to say that the financing of the support and counselling services was inadequate. Even when posts were created through funding from the Heart Circle, the posts were still effectively "supernumerary" as reflected by the relatively low priority afforded to support and Counselling Work by the Trust Management generally.'[15]

> 'I have throughout felt that the psychological and social needs of families was never made a priority by the Trust and that the combined lack of management support and co-ordination often hindered and complicated the support that we tried to make available.'[16]

18 Mr James Wisheart, consultant cardiac surgeon, said:

> 'Against a background of historic under-funding and under-provision, I am in no doubt that for most of the period under review the priority of the clinical staff was for the development of the resources for the basic medical service … Only in recent years has there appeared to be a resource available for purposes of this type.'[17]

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[11] HAA 0097 0007 – 0010; *'Services for Patients'*, July 1991

[12] Jean Ruth Pratten, Justice of the Peace, first Secretary of the Bristol and South West Children's Heart Circle from 1972 until 1989, and Chairman from 1989 to 1997

[13] WIT 0269 0011 Mrs Pratten

[14] See later in this chapter

[15] WIT 0269 0011 Mrs Pratten

[16] WIT 0269 0011 – 0012 Mrs Pratten

[17] WIT 0120 0238 Mr Wisheart

19 Mr Janardan Dhasmana, consultant cardiac surgeon, said:

> 'Although they [management] accepted in principle, finding the money and resources was always a problem.'[18]

20 Dr Freda Gardner[19] told the Inquiry that she became involved in Wards 5A and 5B in conducting her research:[20]

> 'It is only possible for me to comment on psychological care of children and their families. In my view the psychological care of children was never given a high enough priority at the BRI by UBHT. In spite of staff making great efforts this problem was further complicated by the fact that the majority of patients on Ward 5 were adults. There is no doubt that the Heart Circle made enormous efforts to provide for the needs of children. Without the resources they provided, there would have been very few facilities for the paediatric patients and their families.'[21]

She stated that she was also aware of: 'numerous frustrations experienced by Mrs Jean Pratten in her exhaustive efforts to help managers, staff, parents and patients on both sites for many years.'[22]

21 In Dr Gardner's view, 'Support and counselling were never a priority' for management and clinical staff.[23]

22 Graham MacIntosh[24] stated in his evidence to the Inquiry:

> 'My impression is that the support and counselling work needed as part of the practice of the clinical area of cardiac surgery for children was at best seen as an added luxury. As with all large organisations and institutions on occasions counselling can be seen as a method whereby compliance is achieved rather than as an empowerment process for the individuals concerned to grow in their self awareness and capacity to take responsibilities upon themselves.'[25]

23 By contrast, Kathryn Hale[26] stated in her evidence to the Inquiry:

> 'Counselling and support within BRHSC was given a high priority and was regarded as part of the case management. In this sense it did not present as a separate discipline, but was seen as an integral part of the entire care process for

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[18] WIT 0084 0104 Mr Dhasmana

[19] Dr Freda V Gardner PhD CPsychol, went to Bristol in 1990 to continue a PhD thesis on mother-infant interaction in infants with cardiac disease, and became a British Heart Foundation Clinical Research Fellow in 1993 in the academic unit of the University of Bristol headed by Professor Gianni Angelini; WIT 0534 0001

[20] WIT 0534 0001 Dr Gardner

[21] WIT 0534 0005 Dr Gardner

[22] WIT 0534 0005 Dr Gardner

[23] WIT 0534 0007 Dr Gardner

[24] Social Worker, BRI from 1997

[25] WIT 0401 0006 Mr MacIntosh

[26] Senior Nurse, BRHSC, October 1983–June 1989

> each child in which all members of the clinical team had a part to play. This meant that, whilst from a financial point of view, counselling itself did not feature particularly highly in specific fund allocation, it was given high priority in respect to the ongoing training given to nursing staff "on the job", in order that they felt competent to support and counsel the families in their care.'[27]

24 Janet Gerrish[28] said:

> 'I realised the importance of support and counselling and considered it high priority in supporting the parents of children undergoing paediatric cardiac surgery.'[29]

25 However, Graham Brant[30] told the Inquiry:

> 'I do not believe this was a priority but an added extra, some nurses were better at supporting and counselling parents than others.'[31]

26 Mrs Vegoda commented on the priority given to counselling:

> 'I felt that particularly once Julie Vass[32] was in place, that management and the Trust did support and was aware of counselling and support needs of families.
>
> 'But I am also aware … that maybe where there was not a priority was in not allowing some space within the cardiac team to make room for looking at the needs, the emotional and psychological needs of families.
>
> 'So I think the Trust personally did support the posts.'[33]

27 Whilst some parents who gave evidence to the Inquiry were given support and counselling,[34] others felt that they had received neither support nor counselling during their child's treatment.

28 Erica Pottage, mother of Thomas:

> 'Looking back, I felt the care we received as parents was appalling … I felt very alone in a strange town … I did not receive any counselling and had nobody to talk to about my worries and concerns.'[35]

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[27] WIT 0180 0037 Ms Hale

[28] Director of Nursing Services, Central Unit 1982–1986, and Hospital Manager, BRI 1986–1989

[29] WIT 0150 0043 Miss Gerrish

[30] Charge Nurse, Ward 5B from 1993, formerly a Staff Nurse, BRI 1991–1993

[31] WIT 0513 0016 Mr Brant

[32] Julie Vass (formerly Crowley), line manager of Helen Vegoda

[33] T47 p. 169 Mrs Vegoda

[34] See witnesses' comments later in this chapter

[35] WIT 0260 0004 Erica Pottage

29 Others, whose children died, felt that they had received no support or counselling after the death.

30 Antonio Chiarito, father of Maria:

> '[The staff] said that they had taken Maria to the Chapel of Rest, if we wanted to see her again. We went to see her … but she had already been taken away. We both found this distressing … Since I have taken up my new employment, as a psychiatric nurse, I now understand how to treat people during times of emotional crisis. I do not think the staff at the BRI knew how to do so. I think that someone should have taken the time to explain things, and to answer our questions. As it was, I got the impression they were covering up for some mistake.'[36]

31 The UBHT responded to Mr Chiarito's comments:

> 'Evidence has been given to the Inquiry as to the bereavement and counselling facilities made available by the Trust.
>
> 'Unfortunately, they were insufficient to meet the needs of some parents.'[37]

32 Rosemary Walker, mother of Ryan:

> 'After Ryan died, we did not really see anyone in the hospital. We did not know what to do, or where to go. We were not even offered a cup of tea or coffee – there was certainly no offer of counselling.'[38]

33 Paul Bradley, father of Bethan:

> 'We did not receive the option of any bereavement counselling. No help was offered to us to know how best to cope, discharge and manage grief positively. It would have meant a great deal to us if someone still expressed an interest …'[39]

34 Jean Sullivan, mother of Lee:

> 'The lack of aftercare which was shown to me also caused me considerable distress. Had I received some counselling it may have helped me to come to terms with Lee's loss … I was not given any assistance whatsoever to cope with what had happened and I feel that when I look back on the manner of Lee's death and the dreadful scene which I witnessed I am filled with bitterness.'[40]

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[36] WIT 0291 0015 Antonio Chiarito

[37] WIT 0291 0022 UBHT

[38] WIT 0458 0013 Rosemary Walker

[39] WIT 0229 0020 Paul Bradley nonetheless spoke of the assistance he received from Mrs Pratten and Mrs Vegoda, see later in this chapter. He also told the Inquiry that, with Mrs Vegoda, he and his wife produced a booklet entitled *'Remembering Your Child',* sponsored by the Bethan Amanda Bradley Fund set up in his daughter's name and designed to assist other parents in knowing how to remember and grieve for their child. See T53 p. 38–9 Paul Bradley

[40] WIT 0016 0014 Jean Sullivan

35 Lorraine Pentecost, mother of Luke:

> 'Nobody had said anything to me. When I was outside the hospital I realised that I did not know what I had to do. I therefore went back to the Intensive Care Unit and asked a doctor who told us that the hospital needed to do a post-mortem to establish why Luke had died. I remember being told to go home and have another baby. I said that a baby was not something you went out to get from a supermarket … I was sent an appointment card for Luke to have a check-up. The date of his examination fell a few days after his funeral.'[41]

36 Others told the Inquiry that after the death of their child, not only were they not offered support, but also staff appeared anxious for them to leave the hospital.

37 Rosemary Riddette-Jones, mother of Luisa:

> 'One thing which I felt very strongly about was that we were not supposed to speak to the other parents on the general ward. One just didn't speak about the death of one's child.'[42]

38 In response, the UBHT commented:

> '… the Trust's policy was for the parents to get home as soon as possible, and for the General Practitioner to be informed of the situation immediately so that appropriate support could be given locally…'[43]

39 Karen Meadows, mother of Sarah:

> 'We went back to the hostel and picked up our stuff. We drove the hundred miles back to Torquay in despair. We felt that once our child had died the hospital ceased to feel that we had any medical needs …'[44]

40 Malcolm Curnow, father of Verity:

> 'Both my wife and I felt under pressure to leave the hospital. We were not given adequate time to mourn, or to be left alone. I felt as if we were on a conveyor belt. One of the nursing staff asked us to clear our room …'[45]

41 Philippa Shipley, mother of Amalie:

> 'We were told that we would have to leave the hospital as our presence there would upset other patients and their families.'[46]

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[41] WIT 0267 0014 – 0015 Lorraine Pentecost

[42] WIT 0421 0012 Rosemary Riddette-Jones

[43] WIT 0421 0019 UBHT

[44] WIT 0415 0009 Karen Meadows

[45] WIT 0004 0009 Malcolm Curnow

[46] WIT 0392 0020 Philippa Shipley

Longer-term support and counselling

42 Many of the organisations or individuals, including UBH/T employees, involved in the provision of counselling and support continued to provide, or offer to provide, this service once the family returned home after the discharge or death of a child, whether by maintaining personal contact, or through support groups and remembrance services.

43 However, it was the policy of the UBH/T not to offer longer-term counselling, but to make arrangements for this to be provided locally.

44 Tracey Morgan, mother of Daniel:

> 'The hospital did not offer us any counselling. I think it would have been helpful if they had been able to do so. I have since received psychiatric treatment, but this had to be arranged through my GP.'[47]

45 In response, the UBHT confirmed its policy at that time on bereavement counselling:

> 'It was not the practice of the hospital to offer any counselling but to advise the General Practitioner immediately of the death of the child so that appropriate assistance could be arranged locally …'[48]

46 Mrs Vegoda and Miss Stratton confirmed that it was part of their roles to make contact with local support services to facilitate this longer-term support and counselling.[49]

47 Helen Johnson, mother of Jessica, said that Mrs Vegoda had arranged for her to be visited when she returned home by a health visitor. Her evidence included this exchange:

> 'Q. I think it is right, is it not, that there was some follow-up support which Helen Vegoda took some steps to organise?
>
> 'A. Yes.
>
> 'Q. In particular, with the Social Services department?
>
> 'A. Yes.

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[47] WIT 0288 0011 Tracey Morgan

[48] WIT 0288 0012 UBHT

[49] See later in this chapter

> ‘Q. And I think it is not necessary to go to the correspondence, but you are aware of correspondence, for example, in 1993, between Helen Vegoda and the Social Services department?
>
> ‘A. Yes, that is true.
>
> ‘Q. And that Helen Vegoda was in contact also with your GP and health visitor?
>
> ‘A. Yes.
>
> ‘Q. Did the health visitor continue to visit you and Jessica after her discharge from hospital?
>
> ‘A. Yes.
>
> ‘Q. How did you find that? Was that of assistance?
>
> ‘A. I found that of assistance, yes.’[50]

Role and responsibilities of UBH/T staff

48 As has been seen, it was not only staff who were specifically responsible for counselling and support that came into contact with distressed and bereaved families.

Surgeons

49 The surgeons received no formal training or support. They spoke of their practices in dealing with bereaved families.

50 Mr Wisheart said:

> ‘I, together with a nurse and/or the counsellor, always talked with the parents of a child who died as soon as possible after that death …
>
> ‘I invited the parents to meet with me again when the stress and emotion was less immediate. I normally suggested that six weeks or later would be appropriate …’[51]

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[50] T44 p. 137 Helen Johnson

[51] WIT 0120 0234 – 0235 Mr Wisheart

51 Mr Dhasmana told the Inquiry:

> ‘I always made a point of talking with parents after a bereavement, or if the child had suffered a permanent disability … I always offered to see the parents again, if they desired. …[52]
>
> ‘In the case of a child suffering a disability i.e. neurological damage, I would talk with the parents and inform them of the problem. Unfortunately the information I could provide was incomplete, as the extent of neurological injury and permanent disability would not be known for a few weeks post-operatively.’[53]

Cardiologists

52 In his written evidence to the Inquiry, Dr Joffe said that:

> ‘On occasions, when I learned that a patient of mine at BRI was critically ill, I made every effort to see the parents. If a child died, I was always ready to arrange to talk to the parents at a mutually suitable time, if requested by the surgeons or the parents themselves.’[54]

And:

> ‘At BCH, as far as I am aware, the majority of staff were sensitive and understanding of parents who were under stress ...’[55]

In his oral evidence he touched on bereavement while dealing with the issue of communication with parents:

> ‘I believe it comes with experience of being with people and unfortunately I have had to be part of the process, not only of informing people of the total picture but also of being present at bereavement situations and inevitably there will be a difference of opinion about how that should be handled. But I think one does one’s best in one’s own perception of the requirement.’[56]

And then the following exchange:

> ‘Q. You mentioned the question of bereavement and what one says in respect of bereavement which puts the clinician dealing with bereavement in a very difficult position because you do not know really how to deal with the news, I suspect,

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[52] WIT 0084 0103 Mr Dhasmana
[53] WIT 0084 0103 – 0104 Mr Dhasmana
[54] WIT 0097 0317 Dr Joffe
[55] WIT 0097 0318 Dr Joffe
[56] T91 p. 36 Dr Joffe

> except by having done it in a number of distressing circumstances over a period of years?
>
> 'A. Yes.
>
> 'Q. The fact of death must, I suspect, be distressing to the clinician even if not as distressing as it is to the parent?
>
> 'A. Undoubtedly, yes.'[57]

53 Dr Houston, consultant paediatric cardiologist and Expert to the Inquiry, added:

> 'I think nowadays the students get some training in this, but certainly when I qualified we did not, we worked with our colleagues and you would know how various colleagues put things and you would learn from that and decide how you did it yourself.'[58]

Nursing staff

54 The nursing staff were involved with children and their families throughout their care.

55 Unlike the clinicians, they received some training. Barbara Sherriff[59] told the Inquiry:

> 'From approximately 1980, the training department ran a 2 day counselling course and a 5 day course entitled "Caring for Dying Children" for nursing staff …
>
> 'The training department ran a specific course for nursing staff entitled "Talking to Relatives" from 1984.'[60]

56 Julia Thomas[61] stated:

> 'The hospital offered basic and advanced counselling courses for nurses and many of the senior ITU nurses had undertaken one or both of these. The nurses in ITU had a supporting role, but did not always have time to look after both the ill child and the carers. This is where Helen Stratton's role became indispensable as she would support the families, leaving the nurses more time to nurse the patients.'[62]

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[57] T91 p. 38 Dr Joffe

[58] T91 p. 40 Dr Houston

[59] Nursing Officer/Clinical Nurse Manager/Unit Manager, BRHSC, 1981–1991, Service Development Manager 1991–1992, Assistant General Manager from 1992

[60] WIT 0234 0026 – 0027 Ms Sherriff

[61] Sister-in-charge of the Cardiac Surgery ICU 1982–1988 and Clinical Nurse Manager of the Cardiac Unit 1988–1992

[62] WIT 0213 0049 Julia Thomas

57 Canon Charmion Mann[63] stated:

> ‘It was clear when I began in 1985 that the nursing staff were not always aware of the particular religious requirements of other faiths in the treatment of patients and a deceased person … I undertook the preparation and presentation of a training session for BCH nursing staff to explain the impact of different customs and religious beliefs in the care of patients and treatment of the families. This training session took place with every intake of nurses …’[64]

Support for nursing staff

58 Staff were offered support by the Chaplains at UBH/T, and by Mrs Vegoda and Miss Stratton.

Staff generally

59 Ms Joyce Woodcraft[65] told the Inquiry:

> ‘Some nurses and doctors will find it very difficult to hide their own emotions on the death of any patient. This is particularly true of a baby or child that has been “specialed” by a nurse for a long period of time. A more senior nurse may take over parental support if this was deemed necessary, but did not happen frequently in my experience.’[66]

60 The Reverend Robert Yeomans,[67] in common with others, stressed the demands placed on staff working in paediatric cardiac care. He told the Inquiry:

> ‘I felt staff showed immense sensitivity when dealing with parents and were supportive every step of the way. They provided comfort throughout and became involved in all cases. Staff too, were upset when patients died, and may have found it difficult because of their own grief or lack of experience, to give parents what they wanted at the time. It can be very difficult to anticipate and give what bereaved parents want in their grief, distress and anger, when, at that moment of time, they may be inconsolable.’[68]

61 The Reverend Yeomans explained that, whilst ordinarily the work of hospital chaplains is supported by volunteers, this was not felt to be appropriate for Ward 5:

> ‘Volunteers are seen as the vanguard of the Chaplaincy services, to ensure that everyone is visited on every ward where possible. It was felt that volunteers were needed to assess both spiritual and religious needs and they thus were an important part of the process …

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[63] Assistant Anglican Chaplain 1985–1988 and Chaplain to the BRHSC 1988–1994
[64] WIT 0273 0013 Canon Mann
[65] Senior Sister, BRHSC ICU 1985–1994
[66] WIT 0121 0020 Ms Woodcraft
[67] Spiritual and Religious Advisor to UBH/T
[68] WIT 0274 0009 Rev Yeomans

> 'We did not have any volunteers on Ward 5 during the period to [the] end of 1995. I felt that the particular demands, both in respect of experience and skills would be too demanding …'[69]

62 Likewise Mr MacIntosh told the Inquiry:

> 'I have no recollection of any specific instance when I was aware of feeling a concern about the sensitivity of staff dealing with such parents. I would however, be very surprised if there were not occasions when the stress and severity of the situation blunted the capacity of staff to give sufficient time in order to be sensitive.'[70]

63 Sarah Appleton[71] said:

> 'My impression was that nurses were caring towards parents and children within the context of working in a highly stressed environment …'[72]

64 Julia Thomas said:

> 'I cannot rule out the possibility of occasional personality clashes which may have interfered with the counselling process, but if a nurse was finding certain parents difficult to relate to they would hand their support over to another staff member, involving one of the two Helens in the situation …
>
> 'I believe our staff shows great sensitivity in their dealings with parents of very ill children. As a manager, I had no complaints about individual nurses. I received many thank-you letters and I believe many nurses had letters from families they had supported.'[73]

65 Mrs Pratten said:

> '… in my experience … I did not ever witness instances of insensitivity … on the part of nurses or of doctors. Some situations were certainly very upsetting for the medical staff … my overall impression was that even in the circumstances that could be difficult for all concerned the staff were genuinely giving of their best.'[74]

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[69] WIT 0274 0005 – 0006 Rev Yeomans

[70] WIT 0401 0006 Mr MacIntosh

[71] Social Worker, BRI 1989–1994

[72] WIT 0385 0007 Ms Appleton

[73] WIT 0213 0051 – 0052 Julia Thomas

[74] WIT 0269 0012 Mrs Pratten

The Bristol and South West Children's Heart Circle

Background

66 Mrs Pratten was the founder of the Bristol and South West Children's Heart Circle. She told the Inquiry that the Heart Circle was founded in 1972 'to help parents of children with Heart Disease help one another, particularly when faced with the problems of Cardiac Surgery' and 'to provide amenities and equipment not funded by the NHS'.[75]

67 She stated in her evidence to the Inquiry that in 1969, when her daughter underwent open-heart surgery at the BRI:

> 'There was minimal support for parents and at that time no specialised Cardiac Unit. Children were admitted to a Paediatric Orthopaedic Ward and Intensive Care was a two-bedded side ward attached to a Women's Surgical Ward.'[76]

68 She went on:

> 'In 1970 I started discussions with medical staff to look into the viability of such a group and became the first secretary …'[77]
>
> 'Membership of the Heart Circle is open to all families who wish to be on the mailing list, and in 1997 there were over 1,000 families … There is no subscription. The Heart Circle also helps all families whether or not they are members.[78]
>
> 'Local branches were set up[79] so that families could meet together locally. Social and fundraising activities were organised and medical staff from Bristol visited each group from time to time to speak on their speciality to help families gain more understanding of the problem and feel more involved with Bristol.'[80]

69 She explained how, initially, it was she who provided support and counselling to families:

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[75] WIT 0269 0001 Mrs Pratten

[76] WIT 0269 0001 Mrs Pratten

[77] WIT 0269 0001 – 0002 Mrs Pratten

[78] WIT 0269 0002 Mrs Pratten

[79] The branches were in Cornwall, North Devon, South Devon, Somerset, Wiltshire, Gloucestershire and Mid-Glamorgan

[80] WIT 0269 0002 Mrs Pratten

> ‘Following the opening of the Cardiac Surgery Unit in 1972 I was invited to visit the unit at least once a week to talk to families and staff, and this continued at the Bristol Children’s Hospital until I retired. Certainly at this stage the role of providing the care and support to the families was something that I undertook on my own … I was able to talk through issues with the parents and ensure that particular areas of concern were appropriately addressed by relevant medical staff. I was also able to identify parents’ needs. Frequently I had parents in my home on the day of their child’s surgery to while away the time, and this continued until the volume of work increased and the first accommodation for parents was opened in 1978 …’[81]

70 She referred to the commencement of the involvement of social workers:

> ‘In the late 1970s Mrs Edna Culverhouse was appointed full-time Medical Social Worker on Ward 5. Her personal commitment to families was outstanding. She could be found on the Unit at any time of the day or night when the need arose. She continued in post for some five years or so, and after she left, there was only part-time social work support due to lack of resources, and her high standard was never again matched.’[82]

Financial and other support provided by the Heart Circle

71 Mrs Pratten said:

> ‘Although fundraising has never been or never will be the primary aim of the Heart Circle, money raised by children, parents, friends and medical staff has made an extremely important contribution to the Cardiac Surgery Unit … and the Bristol Children’s Hospital. It is impossible for me to calculate in retrospect the amount of money involved in projects initiated by the Heart Circle at BRI and BCH but it must be in the region of £1,000,000, all of this money being raised voluntarily by members of the Heart Circle.’[83]

72 She gave examples of the support provided by the Heart Circle:

> ‘We provided small items of equipment if they were considered to be for the improved care of children and beyond the budget of the NHS. In 1992 Dr Jordan asked if we would make a substantial contribution to the purchase of a Doppler/Echo Machine. We agreed to provide £25,000 …’[84]

73 Mrs Pratten subsequently provided the Inquiry with a breakdown of the sums raised by the Heart Circle.[85] She pointed out that the administration costs of the Heart Circle during the period were minimal as no office accommodation was rented nor staff employed.

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[81] WIT 0269 0002 – 0003 Mrs Pratten

[82] WIT 0269 0003 Mrs Pratten

[83] WIT 0269 0011 Mrs Pratten

[84] WIT 0269 0009 Mrs Pratten

[85] WIT 0269 0504 – 0505; letters dated 26 June and 12 July 2000

1984	£16,000	1990	£55,000	
1985	£22,000	1991	£70,000	
1986	£34,000	1992	£114,000	
1987	£26,000	1993	£96,000	
1988	£52,000	1994	£86,000	
1989	£56,000	1995	£81,000	Total: £708,000

74 The Heart Circle also bought and insured a portable Doppler machine for the cardiologists to take to peripheral clinics. Mrs Pratten said:

> ‘… they would take it down to Treliske or Taunton or wherever with them, so they had a better means of diagnosis. That was an important piece of equipment that we felt was not going to be funded by any other source …
>
> ‘Nobody else was prepared to fund it. So if we felt that a Doppler … was a better means of diagnosis in the peripheral clinics and would save families having to come all the way to Bristol, then that was a worthwhile piece of equipment to buy.’[86]

75 They provided accommodation for parents. Mrs Pratten explained that, prior to assistance from the Heart Circle, families of children undergoing surgery had stayed in bed and breakfast accommodation:[87]

> ‘The first major project undertaken by the Heart Circle was to identify a property where parents could stay while their child was in hospital. It took Dr Jordan and I almost six years of discussion with hospital management before they accepted the need but in 1978 a small house belonging to the hospital was given over. This was completely refurbished and furnished by the Heart Circle and opened in 1978 and I believe was the first such accommodation in the country.
>
> ‘Demand for this was so great that a year later the house next door was similarly opened and shortly after that a third house, making twelve rooms in all.
>
> ‘In the early years these houses were managed by the Warden of the Nurses Home … However, later the management was taken over by the Children’s Hospital which meant that parents on that Unit were not given the priority intended and I had to undertake hard negotiations to enable the six bedroomed house to be handed over for families on the Cardiac Surgery Unit.

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[86] T47 p. 59 Mrs Pratten

[87] WIT 0269 0007 Mrs Pratten

> 'The Heart Circle continued to keep these houses in good maintenance although later the two smaller houses were little used by the Children's Hospital as the Heart Circle had been instrumental in the provision of two purpose-built blocks of bedrooms and the refurbishment of other accommodation in the Children's Hospital itself. However, the largest house continued to be used for parents on Ward 5 until the transfer. We also negotiated the provision of two bedrooms along the corridor from the Unit for parents at the time of surgery and again all costs were undertaken by the Heart Circle.'[88]

76 However, she went on to say:

> 'It was understood that as the houses were hospital property there could not be exclusive use … but because they were funded by the Heart Circle, and our families had particular problems, they would be given some priority. This was the original agreement under which the Heart Circle funded these rooms but regular changes in their management at Bristol Children's Hospital meant that this principle was not followed …'[89]

77 The Heart Circle provided play facilities and, when the unit at the BRHSC was upgraded in 1986, obtained a small room for play, again fitted out and equipped by the Heart Circle. A Hospital Play Therapist, Helen Passfield, was appointed with the support of Julia Thomas, and funded by the Heart Circle.

> '… not only did she prepare children for surgery through play, spend time with them in Intensive Care if they were there for a long time, but she was also a great support for parents. This post continues in Bristol Children's Hospital and is still being funded by the Heart Circle.'[90]

78 Mrs Pratten told the Inquiry:

> 'I think the hardest job there was to get a room assigned for play, because the hospital did not see the need for a separate area for play away from the "nursery" as it was called, where the sleeping beds were …'[91]

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[88] WIT 0269 0006 – 0007 Mrs Pratten
[89] WIT 0269 0007 Mrs Pratten
[90] WIT 0269 0008 Mrs Pratten
[91] T47 p. 58 Mrs Pratten

79 The Heart Circle also gave grants to families with significant need,[92] for example, where their child had a prolonged stay in intensive care; provided furniture for a nursery;[93] negotiated the conversion of a store room into a quiet room for parents and provided furniture;[94] set up a kitchen for parents and provided a washer-dryer;[95] and within Intensive Care, made a designated area for children and provided cots and other furniture and portable telephones;[96] published an information booklet for parents with the support of Children in Need;[97] provided two caravans at Burnham-on-Sea to allow parents or families to take subsidised or free holidays;[98] and made a video for parents to introduce them to the Unit.[99],[100]

The posts of Helen Vegoda and Helen Stratton

80 The Heart Circle played a major role in the development and funding of the posts of Mrs Vegoda and Miss Stratton. Mrs Pratten stated in her evidence to the Inquiry:

> ‘In about 1986 Dr Joffe approached me about setting up the post of Family Support Worker based at Bristol Children’s Hospital. The Heart Circle agreed to fund the first year’s salary (£15,000) and then £5,000 per annum over the next three years.
>
> ‘Helen Vegoda was appointed and the Heart Circle set up her office in the Bristol Children’s Hospital.’[101]

Asked about the Heart Circle’s annual income at that time, she estimated it would have been £50,000–£60,000.[102]

81 Mrs Pratten stated that with the assistance of Julia Thomas:

> ‘In 1990 a further post was set up in the BRI for Ward 5, namely that of Cardiac Liaison Sister. There was an obvious need for a suitably qualified nurse on the unit to whom parents can turn to discuss their anxieties and receive good information. Helen Stratton was appointed on a three-year contract, later extended by six months, which was fully funded by the Heart Circle at a total cost of over £70,000. The management of this post was under the Unit, but again it did not fit into any established structure.’[103]

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[92] WIT 0269 0008 Mrs Pratten

[93] WIT 0269 0009 Mrs Pratten

[94] WIT 0269 0009 Mrs Pratten

[95] WIT 0269 0009 Mrs Pratten

[96] WIT 0269 0009 Mrs Pratten

[97] WIT 0269 0010 Mrs Pratten

[98] WIT 0269 0010 Mrs Pratten

[99] WIT 0269 0006 Mrs Pratten

[100] See also the 1988 Annual Report for the BRHSC and BRI at HAA 0138 0003 which records that the play room and two parents’ rooms at the BRI had been furnished by funding from the Heart Circle; and the first edition of the Bristol and South West Children’s Heart Circle *‘Newsletter’* at UBHT 0213 0069 – 0093, November 1989, reporting that caravans were provided for the use of Heart Circle families

[101] WIT 0269 0003 Mrs Pratten

[102] T47 p. 4 Mrs Pratten

[103] WIT 0269 0003 – 0004 Mrs Pratten

82 She went on:

> ‘It was always understood that when Helen Stratton’s contract terminated the post would be taken over by the NHS but this was not to be. I was very concerned that all the experience and knowledge that had been gained by Helen’s work would be lost. I therefore approached Dr Freda Gardner, Consultant Clinical Psychiatrist and Senior Lecturer in Mental Health, and commissioned a report on the *“Needs of Children with Heart Conditions and their Families”* because I was devastated that there was no longer a designated sister on the Unit.
>
> ‘Dr Gardner’s document[104] was produced in 1995 and Professor Angelini charged the Heart Circle £11,000 for Dr Gardner’s time.[105]
>
> ‘The Heart Circle again agreed to fund the post of Cardiac Liaison Sister and this proved so successful that after six months the funding was taken over by the NHS. The report had made the precise needs of families more explicit and this contributed to the increased acknowledgement by senior medical and managerial staff that such a post was vital.’[106]

83 Mrs Pratten told the Inquiry that when the paediatric cardiac service was united at the BRHSC, the UBHT would not allow the Doppler machine, part funded by the Heart Circle, to be transferred to the BRHSC as it was being used for research. The Trust offered the Heart Circle £4,000 in respect of their financial contribution.

84 Mrs Pratten wrote to Mrs Rachel Ferris, General Manager of the Directorate of Cardiothoracic Serices, UBHT, on 6 November 1995:

> ‘… you give a total amount of £4,000 with no breakdown and I have not been given an inventory of what has been taken up to BCH and what remains on Ward 5. I should be grateful, therefore, if you could indicate how this £4,000 is made up and what percentage relates to the echo machine. When it was purchased, the Heart Circle donated £25,000 …
>
> ‘This information will have to be supplied to the Charity Commissioners, who in 1994 expressed their concern to us about the purchase of equipment for hospitals.’[107]

85 Mrs Ferris replied to Mrs Pratten on 5 December 1995:

> ‘Professor Vann Jones and I are keen to acknowledge the huge commitment made by you and the Heart Circle in paediatric surgery at the BRI over the last 23 years. We know that the equipment that you have purchased totals many many thousands

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[104] WIT 0269 0013 – 0066 Mrs Pratten; see also paras 20 and 21

[105] WIT 0269 0005 Mrs Pratten

[106] WIT 0269 0006 Mrs Pratten

[107] UBHT 0225 0010; letter from Mrs Pratten to the UBHT

> of pounds, and that the purchase of equipment has been just one aspect of the support you have given. It would be helpful if you would let me have a list of some of the things that you have done so that they can be included in our presentation.'[108]

86 Mrs Pratten commented in evidence:

> 'It was jolly good to get £4,425 at that stage. They kept saying they did not have the money anyway and eventually it came out of the special trustees and what was done instead of money passing hands, they bought a machine for the new cardiac intensive care in the Children's Hospital.'[109]

Comment on the service provided by the Heart Circle

87 Witnesses to the Inquiry were unanimous in their praise for the assistance and contribution of the Heart Circle.

88 The UBHT stated in its evidence to the Inquiry:

> 'The Trust greatly appreciates the financial and human support that The Heart Circle has provided over the years to acknowledge the limitations of the non-clinical aspects of the paediatric cardiac service that could be provided from NHS funds.'[110]

89 Marion Stoneham[111] stated:

> 'The South West Heart Circle was a very well established voluntary body when I took up post. The leader of this was an extremely active worker across the region. The South West Heart Circle offered great support to parents and families of the patients …'[112]

90 Dr Susan McMullen[113] stated:

> 'The work of Jean Pratten and the Heart Circle was extremely valuable and was valued very highly by the staff themselves. Their work was valued not only by Social Workers whose work was complemented by the Heart Circle, but also by nursing staff.'[114]

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[108] UBHT 0225 0003, T47 p. 62–3 Mrs Pratten

[109] T47 p. 63 Mrs Pratten

[110] WIT 0269 0503 Mrs Pratten

[111] Manager of the Children's and Obstetric Sub Unit from 1986

[112] WIT 0149 0002 Miss Stoneham

[113] Team Manager, Social Services, BRI 1987–1992

[114] WIT 0487 0012 Dr McMullen

> 'I believe that members of the Heart Circle worked extremely well and very effectively with the Social Workers, throughout the period, to provide support for patients and families.'[115]

91 Julia Thomas, writing in the first edition of the Bristol and South West Children's Heart Circle *'Newsletter'*, thanked the Heart Circle for its generosity to Ward 5:

> 'Without you, I believe, we would still be in the situation we were in in 1976'.[116]

92 Parents expressed only positive comments regarding the work of Jean Pratten and the Heart Circle in general. Many parents expressed their appreciation of the personal support given by Mrs Pratten.

93 Susan Warburton, mother of Sam:

> '… found her extremely kind and motherly'.[117]

94 Tony Collins, father of Alan:

> 'Jean Pratten of the Bristol Heart Circle also came to see us on the day of Alan's admission to offer any help or assistance she could whether in material or financial terms.'[118]

95 Jayne and Richard Leonard, parents of Katie:

> '… Jean Pratten of the Bristol and South West Children Circle also arrived on Intensive Care and asked us if we needed any help at all.'[119]

96 Richard Lunniss, father of William, explained that he:

> '… had an immediate affinity with Jean because I trusted her as she had a daughter who had also gone through heart surgery'.[120]

97 One mother told us:

> 'When I first arrived at the Bristol Maternity Hospital I was seen by Jean Pratten within minutes of my arrival. She was absolutely wonderful with me and gave me a great deal of encouragement.'

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[115] WIT 0487 0014 Dr McMullen
[116] UBHT 0213 0083; Heart Circle *'Newsletter'*
[117] WIT 0416 0003 Susan Warburton
[118] WIT 0021 0009 Tony Collins
[119] WIT 0367 0005 Jayne and Richard Leonard
[120] WIT 0516 0003 Richard Lunniss

98 Paul Bradley, father of Bethan:

> 'The chairperson from the local charity Heart Circle, Jean Pratten, visited us on the ward. She gave us a very useful booklet concerning children with congenital heart disease and what we as parents might expect in the next few years. This was very useful information on the new circumstances we suddenly found ourselves in.'[122]

99 Alison Leeming, mother of Jamie:

> 'When we arrived at the Children's Hospital we were very impressed with things. We were given a room in the hostel run by the Heart Circle. We thought the hostel was very friendly and we liked it very much.'[123]

100 Another parent stated:

> 'I felt very alone with my sick child, so it was good to be able to communicate with other parents, and share our concerns.'[124]

The Children's Heart Circle in Wales

101 David Brokenshaw provided a statement to the Inquiry about the treatment and death of his daughter Alys. He and his wife met Helen Vegoda when Alys was first treated at the BRHSC. Alys was transferred to the BRHSC in March 1989, and until her operation in May, Mr Brokenshaw commuted between Rhondda and Bristol.

102 He told the Inquiry:

> 'Whilst I was commuting … a cheque arrived from The Children's Heart Circle in Wales. Until the arrival of this cheque I had not heard of the organisation. I assumed that Helen Vegoda had contacted them on our behalf. The fifty pounds was gratefully received as it contributed towards the petrol and bridge expenses of travelling back and forth …'[125]
>
> 'Following Alys' death about a year later we received a letter from the CHCW [Children's Heart Circle in Wales] requesting support. I attended a meeting and was elected to the committee. The following year I stood for Secretary and was elected. We spent a good few years running the charity and giving grants … However, once the National Lottery started funds dried up.'[126]

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[122] WIT 0229 0004 Paul Bradley

[123] WIT 0537 0004 Alison Leeming

[124] WIT 0264 0014. This parent was one of a number of parents who gave a witness statement to the Inquiry and gave only partial consent to publication of the statement, as they did not wish to be publicly identified

[125] WIT 0514 0003 David Brokenshaw

[126] WIT 0514 0005 David Brokenshaw

UBH/T Chaplaincy

Organisation and role

103 One of those involved in counselling both at the BRI and the BRHSC during the period of the Inquiry's Terms of Reference was the Spiritual Advisor to the UBH/T. The Reverend Michael Jarvie held this post until his death in 1992, and was succeeded by the Reverend Yeomans in 1993. The role involves acting as full-time Anglican Chaplain to the BRI, and overseeing other chaplains.

104 The Reverend Yeomans stated:

> 'In 1993 when I joined the UBHT I felt that the Chaplaincy services were very good and I still do … With the Trust's agreement, I organised the pattern of Chaplaincy provision – obtaining funding to develop the service and appoint more staff, modify leaflets and notices. However, the basic service remained the same.'[127]

He produced for the Inquiry a plan of the structure of the chaplaincy services, showing the other chaplains in post.[128]

105 In 1993 he drafted a booklet[129] on hospital chaplains for the hospitals' staff, setting out the role of a chaplain and contact names. He told the Inquiry that it was the first leaflet of its kind. The booklet has gone through a number of amendments, and the current version[130] provides detail of how patients of different faiths[131] will wish to be treated, and their attitudes to death, disposal of bodies, post-mortems and organ donation.

106 The Reverend Yeomans described his role:

> 'My job description specified that I was to respond to the spiritual and religious needs of patients, their families, carers and staff. I am employed full time, i.e. 6 days a week.'[132]

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[127] WIT 0274 0006 Rev Yeomans

[128] WIT 0274 0019. These were as follows. Full-time Anglican Chaplains to the BRHSC and St Michael's: Reverend Charmion Mann (1985–1994), Reverend (now Canon) Helena Cermakova (1995 onwards). Part-time Free Church Chaplains to BRHSC and St Michael's: Reverend A Howell (1983–1993), Reverend J Pye (1988–1993), Reverend M Pullan (1993 onwards). Part-time Free Church Chaplains to the BRI: Reverend Will Minnis (1976–1995), Reverend Bill Welch (1995–1997). Part-time Catholic Chaplains for both sites: Father Francis Collins (1981–1987), Father William Webb (1988), Father John Fairhurst (and while he was on secondment, Father Claudio Rossi) (1989–1990), Father Bernard Charles (1991–1996)

[129] UBHT 0270 0002; *'Hospital Chaplains Booklet'*

[130] WIT 0274 0021 – 0065 Rev Yeomans

[131] Baha'i, Buddhist, Chinese, Christian of various denominations, Hindu, Humanist, Jain, Jehovah's Witness, Jewish, Muslim, Pagan, Rastafarian, Sikh and Zoroastrian

[132] WIT 0274 0001 Rev Yeomans

107 In relation to the paediatric cardiac service, he stated that he visited Ward 5 as often as possible:

> ‘I made it a high priority to mingle with those on the ward and to befriend not only the parents but also the children. I would make it known to parents who I was, and that I was available to discuss anything they wanted with them.[133]
>
> ‘… I visited everyone regardless of denomination, faith or no faith … The Catholic Chaplain and the Free Church Chaplain came to the BRI one session a week …’[134]

108 He also explained his role in providing support for staff:

> ‘In addition to supporting parents I would occasionally sit down with staff to discuss what happened and debrief them.’[135]
>
> ‘When a child died I was always careful to ensure that the staff had attention too. Sometimes I would speak individually to staff, as well as to staff collectively. Staff as well as parents were upset when a child died. It has to be acknowledged that the death of a child has a particular effect on everyone involved.’[136]

109 In 1987 Canon Mann, who worked principally at the BRHSC and St Michael’s Hospital (a maternity hospital), set up the body known as ‘Friends for Patients’ to provide day-to-day support and to befriend parents whose children were sick but not seriously ill: ‘Essentially they gave practical help wherever possible.’[137]

110 In her statement to the Inquiry she said:

> ‘The Cardiac Counsellor for BCH and I set up a Bereavement Support Group for parents from 1992–3. This was found to meet a deep need for those parents who attended …
>
> ‘I also provided support to staff who, naturally, also became upset when a child was ill or died … We also set up a support group (I think this began in 1988) for staff working in Casualty and ITU at the BCH, and in St Michael’s … Marion Stoneham, the General Manager at St Michael’s and the BCH, was very supportive and agreed to fund outside speakers to speak at seminars on bereavement.’[138]

Canon Mann told the Inquiry that she also attended functions of the Heart Circle whenever possible.[139]

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[133] WIT 0274 0003 Rev Yeomans
[134] WIT 0274 0004 – 0005 Rev Yeomans
[135] WIT 0274 0005 Rev Yeomans
[136] WIT 0274 0008 Rev Yeomans
[137] WIT 0273 0010 Canon Mann
[138] WIT 0273 0009 – 0010 Canon Mann
[139] WIT 0273 0011 Canon Mann

111 Canon Mann was succeeded in February 1995 by the Reverend Helena Cermakova. The Reverend Cermakova stated:

> 'Once a year there was a remembrance service arranged by Helen Vegoda specifically for children who had died following cardiac surgery. I believe this had started in 1994. I first helped to organise the remembrance services when I joined in 1995.'[140]

Funding and support for the Chaplaincy Service

112 The hospital chaplains were appointed and paid by the UBH/T.[141] They had line managers within the UBH/T.[142]

113 The Reverend Cermakova stated:

> 'There was (and is) a Chaplaincy budget which covers items such as wages, books … Ian Barrington[143] … is responsible for that budget with me.'[144]

However:

> 'In respect of the "Friends for Family" Group, this was partly funded by the Mothers' Union and by UBHT.'[145]

114 Commenting on the support which the chaplains received from the UBH/T, the Reverend Yeomans said:

> 'Clinicians and staff were very supportive of our services. We worked closely with the surgeons, especially Mr Wisheart and Mr Dhasmana. Nursing staff would be closely involved, and would often attend the funeral if a child died. The management were also welcoming to the Chaplaincy and supported us.'[146]

115 Father Bernard Michael Charles[147] (who had little contact with paediatric cardiac patients or their families) stated:

> 'I think that the Personnel Manager [at the BRHSC], Mr Ian Stone, was responsible for Chaplaincy as a whole in the hospitals and that, since I was a member of the Chaplaincy team, he was my Manager … I am satisfied that the hospital management did give high priority to support and counselling work, and that the Personnel Department at least saw the hospital Chaplaincy as an important aspect

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[140] WIT 0272 0010 Rev Cermakova

[141] See, for example, the evidence of the Reverend Cermakova, T46 p. 31

[142] For example, the Reverend Yeoman's line manager was Janet Maher, WIT 0274 0001

[143] General Manager, Children's Services from 1991

[144] WIT 0272 0011 Rev Cermakova

[145] WIT 0272 0012 Rev Cermakova

[146] WIT 0274 0008 Rev Yeomans

[147] Catholic Hospital Chaplain, 1991–1996

> of the support and counselling structures in the hospitals and that because of this, our work was much appreciated.'[148]

116 The Reverend Will Minnis[149] did not recall being called to see paediatric cardiac surgery patients or their families on Ward 5, but in relation to the Chaplaincy service generally, stated:

> 'I felt staff were very supportive of Chaplaincy services.'[150]

The effect of the split site

117 The chaplains who gave evidence to the Inquiry did not express concern that the split site affected their ability to provide counselling.

Comment on the service provided by the Chaplaincy

118 Parents gave evidence about the support provided by the Reverend Cermakova and the Reverend Yeomans.[151]

119 Sharon Peacock, mother of Andrew:

> 'Since I have lost Andrew, I have received much support from Helen Vegoda … and Helena Cermakova, the hospital chaplain. Helen helped me to prepare for my meetings with Dr Martin, and talked with me about all the questions that I wished to ask. She also helped with the fertility treatment appointments that I underwent, and would visit me to give support both before and after my operations. Helena and I have meetings often, and speak on the telephone regularly. I do not think I could have coped without their help and support. Helena conducted Andrew's funeral service, and has always been very supportive.'[152]

120 Carol Kift, mother of Steven:

> 'No member of staff came to see us after Steven died. The only person who had been supportive, the hospital chaplain, was away over the weekend so we did not see her either. She had helped us to organise Steven's baptism and had been supportive for us whilst we were at Bristol. We were touched when she wrote to us to offer her condolences after Steven's death.'[153]

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[148] WIT 0277 0006 Father Charles

[149] Free Church Chaplain, 1976–1995

[150] WIT 0282 0009 Rev Minnis

[151] See, for example, Lesley Smith, mother of Katherine; WIT 0286 0014

[152] WIT 0011 0031 Sharon Peacock

[153] WIT 0461 0005 – 0006 Carol Kift

Bristol City Council Social Services Department

Organisation, accountability and funding

121 Dr McMullen was Principal Medical Social Worker (Teaching) (PMSW(T)) at the BRI from 1975 to 1987, and Social Work Team Manager at the BRI from 1987 to 1992.

122 In her written statement to the Inquiry she explained how changes to the structure and accountability of social services in 1974 and 1987 had affected the role of social workers, and caused a move away from their performing a role as counsellors.

123 Prior to 1974 social workers (then 'Medical Social Workers') had been employed by the hospitals and paid by the health authority. In 1974 the responsibility for the management of, and payment for, social workers passed to local authorities, in this case to Avon County Council.

124 Dr McMullen stated:

> 'Medical Social Workers are trained to support patients and families, and they form part of the treating team. It was my experience that the changes in 1974, when responsibility for payment and management of Social Workers in hospitals moved from the Health Authority to Local Government, started a process that had a far reaching impact on the counselling role of Social Workers in hospitals. Management of Social Workers became the responsibility of Social Services provided by local authorities in 1974. Many of these managers had little comprehension of the function of a hospital Social Worker. This change began the erosion of Social Workers' ability to provide counselling in hospitals. Gradually, the role of the Social Worker in a hospital became much more focussed on carrying through the legislative duties imposed on Local Authorities, with far less emphasis on counselling.'[154]

125 She also highlighted changes brought about in 1987:

> 'In the restructuring of 1987, Social Services Management was entirely separate from that of the hospital, there was an inevitable lack of understanding by management of the work needed to be undertaken by Social Workers in a hospital setting. Statutory functions imposed on the Social Services Department of the Local Authority recognise the work of Social Services in dealing with: adults and children at risk; identifiable social problems, for example inadequately housed people, benefits entitlement and (in co-operation with health staff) planning the patients' discharge into the community. This change in perception, which I believe was driven by the change in the statutory role of Social Workers, coincided with a

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[154] WIT 0487 0008 Dr McMullen

> greater recognition by others involved in healthcare of the role and value of counselling during the mid-1980s.'[155]

126 Dr McMullen explained that, in the 1987 restructuring, the post of PMSW(T) was abolished, and she was then appointed Team Manager for the Social Work team covering the BRI and the oncology centre, and was responsible to the local authority Social Services manager.

127 She stated that, as a result of the restructuring in 1987, although contact between team managers was maintained through informal networking, there were no structural links between the Health District and the Social Services Department and as a result social workers in different hospitals would be managed by different Social Services areas.

128 The Social Work team at the BRI reported to Bristol North Social Services, and the team at the BRHSC reported to Bristol Central. The General Hospital team reported to Bristol South Social Services:[156]

> 'At this period, it was clear that Social Services Headquarters management did not value hospital social work nor the co-operation with health staff that was inherent in it. There was therefore continuous pressure to reduce the number of social workers in the team and to reorganise work along lines that more closely fitted a locality team model rather than a health one. My task therefore seemed to be to protect the essential nature of hospital-based work while changing that which could be changed without too much damage. There was much greater understanding and value given to the role of the hospital social worker by staff and management within the hospital than there was from social services management.'[157]

> 'My work was structurally separated from the Social Work Team manager at the Bristol Children's Hospital …'[158]

129 Mr MacIntosh, Social Worker at the BRI throughout the period of the Inquiry's Terms of Reference, and Acting Team Manager at the Social Work Department from January 1997 to November 1998, also commented on the changes in the role of the hospital social worker. He stated that until 1990/91 social workers within the BRI Social Work Team were employed as generic social workers. Following the Children Act 1989 and the NHS and Community Care Act 1990 it was recognised that this was no longer viable:[159]

> 'The expectations of Social Workers in hospital to provide medical counselling as a general part of their work with individuals was historically established and there

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[155] WIT 0487 0008 Dr McMullen

[156] WIT 0487 0009 Dr McMullen

[157] WIT 0487 0004 Dr McMullen

[158] WIT 0487 0006 Dr McMullen

[159] WIT 0401 0002 Mr MacIntosh

> was a general expectation that this continued until the changes had started to take place in the late 1980s. Social Workers were at that time funded by Avon County Council.'[160]
>
> 'My recollection is that there were considerable managerial, political and financial constraints on providing Social Work staff to meet needs related to healthcare treatments (both locally and nationally). I believe that the inability of the Social Work Team in the BRI to take on additional work created by an expanding service of Cardiac Surgery (as with other areas of specialised clinical practice) resulted in prioritisation of work towards statutory duties and responsibilities only. These constraints continue to this day.'[161]

Role and training

130 Dr McMullen did not herself have regular day-to-day contact with Ward 5, but managed the social worker who was directly responsible for it:[162]

> 'The emotional impact of such work on the individual would be high …'[163]

Their role was 'to identify, by a number of means, that appropriate referral [to Social Services] of patients and their families had taken place and then to offer the help the family wanted if this was possible … ensuring that, on discharge, the patient and their family had available to them and were aware of appropriate support from Social Services.'[164]

131 Of the first social worker to be attached to Ward 5, she said:

> 'I am aware that Edna Culverhouse had considered it part of her counselling function as a Social Worker to be with a family whose child was undergoing surgery and to provide support … there was increasing pressure from Social Services for Social Workers in the hospital environment not to undertake this sort of generalised supportive work.'[165]
>
> 'After surgery and by prior arrangement, the Social Worker on Ward 5 sometimes made contact with appropriate Support Services in the home area. To some extent this was dependent on outcome … Usually there was little contact … It was much more usual for such contact to be made in the case of … those who needed some form of aftercare in the form of the provision of accommodation and support after discharge from hospital. If, however, the child died, the family often left Bristol very rapidly.'[166]

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[160] WIT 0401 0002 Mr MacIntosh

[161] WIT 0401 0002 – 0003 Mr MacIntosh

[162] Social workers responsible for Ward 5 were: Edna Culverhouse (1974–1983), Patrick Smith (1987–1988), Sarah Appleton (1989–1994), Robin Dunford (1994 onwards)

[163] WIT 0487 0009 Dr McMullen

[164] WIT 0487 0010 Dr McMullen

[165] WIT 0487 0011 – 0012 Dr McMullen

[166] WIT 0487 0012 Dr McMullen

132 Mr MacIntosh stated:

> 'To the best of my knowledge and since I started in 1984 there was no involvement by BRI Social Workers in providing information, support and counselling before or during surgery … Support given to families with children receiving surgical cardiac care by the BRI Social Work Department was, in my understanding, responsive to circumstances rather than as a planned method of addressing a stressful and potentially damaging time for all parties involved.'[167]

133 He went on:

> 'I cannot recall an instance of a family being newly referred to the Social Work Department who had lost a child, or whose child had suffered permanent disability.'[168]

134 The move away from the traditional counselling role for social workers was also confirmed by the social workers attached to Ward 5 from whom the Inquiry received evidence.

135 Mr Patrick Smith, a social worker at the BRI, was attached to Ward 5 (and three other wards) from February 1987 to November 1988.[169] He stated:

> '… referrals or requests for [social work] services were received by me at any time during the working week … 9.00 a.m. to 5.00 p.m. …
>
> 'Additionally, I met the senior nurse on duty on a weekly basis on Ward 5, to discuss the patients on the Ward and to screen any referrals or patients which may have benefited from social work assistance.'[170]
>
> 'As well as responding to referrals, I would also introduce myself to parents/families on the Ward. I considered that it was very important to build a relationship with the families, and that they knew who I was and that I was available to talk or help whenever they wished.
>
> 'I had an office close to Ward 5 which meant parents or patients could find me.' [171]

136 His role as social worker, he explained, involved a range of tasks:

> '… providing information and advice, for example about welfare benefits, transport, the Heart Circle, etc. At other times … negotiating services on behalf of parents, for example obtaining financial help towards subsistence, transport, bills,

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[167] WIT 0401 0005 Mr MacIntosh

[168] WIT 0401 0005 Mr MacIntosh

[169] WIT 0402 0001 Mr Patrick Smith

[170] WIT 0402 0004 Mr Patrick Smith

[171] WIT 0402 0004 Mr Patrick Smith

> etc., as a result of the additional expenses incurred due to the admission to hospital … via Social Services or from organisations like Heart Circle … to discuss leave arrangements with employers, housing problems, childminding arrangements or transport problems.'[172]

137 The Social Services Department, he explained, kept the keys to the accommodation provided for parents by the Heart Circle and provided a list of bed and breakfast and hotels.[173]

> 'On my visits to the Ward I would check the progress of a child post operation … If things had not gone as well as expected then I would meet the parents to see if there was anything I could help with.'[174]

138 Ms Appleton joined the Social Work Department at the BRI in January 1989, and was the link social worker to Ward 5 from then until 1994. She explained her role in relation to parents as being:

> '… if they required support over and above what was given by Helen Stratton or Helen Vegoda, i.e. it was not a counselling role'.[175]

139 She described her role as being largely concerned with families having financial difficulties, for whom she carried out tasks outlined by Patrick Smith. These included: liaising with housing associations to seek a change of accommodation if current accommodation was not suitable for a child recovering from surgery; assisting parents to claim DSS benefits; liaising with employers about compassionate leave for parents; identifying charitable sources which could provide financial relief, such as the Heart Circle, the Guild of Friends and the Samaritan Fund. Additionally, the Social Work Department within the BRI kept the keys to the accommodation for families funded by the Heart Circle and the Ward Clerk informed families that this accommodation was available to them:

> 'A small charge was made for each night's stay, although this was sometimes waived.'[176]

140 Subsequently, her role changed:

> 'As a response to the implementation of the NHS and Community Care Act and the Children Act 1989, responsibility for children and adults was split, and I then dealt with adults.'[177]

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[172] WIT 0402 0004 – 0005 Mr Patrick Smith
[173] WIT 0402 0005 Mr Patrick Smith
[174] WIT 0402 0005 Mr Patrick Smith
[175] WIT 0385 0002 Ms Appleton
[176] WIT 0385 0006 Ms Appleton
[177] WIT 0385 0002 Ms Appleton

141 Mr Robin Dunford was employed as a childcare social worker responsible for covering all wards and departments of the BRHSC from April 1990 to April 1994. In May 1994 he took over from Ms Appleton as (adult) social worker for Ward 5.

142 He stated to the Inquiry that he worked very closely with Mrs Vegoda. They would have weekly meetings, but she referred families to him only if they needed practical assistance, such as assistance with travel expenses or accommodation. Mr Dunford stated:

> ‘On occasion if covering for Helen Vegoda I would accompany parents to a pre-op visit to the Bristol Royal Infirmary as this was part of the orientation process.’[178]

143 Mr Dunford also explained that he liaised with Miss Stratton in Mrs Vegoda’s absence, and liaised with Ms Appleton when they were both in their respective posts at the BRI and the BRHSC, particularly in relation to patients being referred back to the BRHSC post-operatively, and to avoid duplication if families needed financial support.

Support for the social work team

144 Members of the social work team commented on how they believed other UBH/T staff saw their role.

145 Mr Dunford told the Inquiry:

> ‘There were occasions when I needed to discuss cases with consultant cardiologists or surgeons … All … I spoke to were very approachable and helpful.’[179]

146 Mr Smith stated:

> ‘I recall that the clinical staff, the sisters, staff nurses, consultants and ancillary staff were all supportive of Social Services and made appropriate referrals.’[180]

147 Ms Appleton commented:

> ‘I never quite felt part of the multidisciplinary team. My feeling was that the general staff excluding Helen Stratton regarded my role as peripheral…’[181]
>
> ‘Although the nursing staff respected my role and were supportive and made referrals when necessary they didn’t see it as particularly central to the running of the ward.’[182]

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[178] WIT 0384 0003 Mr Dunford
[179] WIT 0384 0003 Mr Dunford
[180] WIT 0402 0006 Mr Patrick Smith
[181] WIT 0385 0003 Ms Appleton
[182] WIT 0385 0007 Ms Appleton

Comment on the split site

148 In addition to the organisational effects of the split site on the Social Services Department set out earlier, social workers also commented on the effect of the split site on their work.

149 Mr Smith:

> 'I do not recall any significant problems with the split site in relation to discharging my responsibilities.'[183]

150 Mr Dunford contrasted facilities at the two sites:

> 'At the Children's Hospital parents had accommodation and support of other families. It was a child centred environment. This was not available for them at the Bristol Royal Infirmary. It was difficult for parents if children were admitted straight to the Bristol Royal Infirmary as they appeared to miss out on some of the pre-operative preparation.'[184]

151 Dr McMullen:

> 'We tried to liaise between the BRI social work team and the BCH team – usually but not always successfully. I think the difficulties resulted from the amount of pressure everyone was under. I remember that the BRI social workers had a far more limited amount of Samaritan Fund money to give to families than these same families were used to receiving from the BCH social workers and they were sometimes made to feel they were seen as unhelpful by some families.'[185]

UBH/T bereavement services

152 The Inquiry heard that, at the BRI, parents whose children had died were assisted through the various practical steps by Diane Kennington, who became the Patient Affairs Officer at the BRI in 1983.

153 She told the Inquiry that her duties in 1983 were very much the same as they are currently:

> 'My role is to see relatives through a very difficult time, immediately following the death of a patient in hospital. At that time there are requirements of the registration

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[183] WIT 0402 0003 Mr Patrick Smith
[184] WIT 0384 0006 Mr Dunford
[185] WIT 0487 0015 Dr McMullen

> of death, arrangements for the funeral and obtaining the signature on the consent form for a hospital post mortem …'[186]
>
> 'I was often called to the Ward 5B immediately following a death so that I could give some help regarding the necessary procedure and formalities. I was asked to register the death of a child for parents who very often lived perhaps in Cornwall or Wales … Other parents were given my name and telephone number in the usual way so that I could give information regarding the Coroner and again offer any help I could at this time. Helen Stratton was Cardiac Support Nurse and she passed the care of the parents over to me which provided the continuity which was felt to be important.'[187]
>
> 'I speak to all the bereaved families. They are told to ring me the day after the death has occurred and I can then give them information about the Coroner's involvement …'[188]

154 Catherine Warren[189] informed the Inquiry that after a child died at the BRI:

> 'Before the parents left the unit, we would provide them with the contact number for the Patient Affairs Officer at the BRI (Diane Kennington) … We would also give them a leaflet called *"After your Child has Died"*,[190] which was specific to Ward 5.'[191]

155 Mrs Kennington's only previous post in the NHS had been that of a cashier. Her role in seeking 'consent' for hospital post-mortems is considered in the Inquiry's Interim Report.[192]

156 The Inquiry heard that, at the BRHSC, hospital porters filled the role played by Mrs Kennington. Mr Frank Long worked at the BRHSC at various times and in various positions between 1984 and 1994.[193] In about 1989 the Head Porter at the BRHSC retired and in the 6–12 months before a replacement was found, Mr Long and his colleagues (Mr Graham Milkins[194] and Mr Leonard Dudridge) split the responsibilities of Head Porter, which included responsibility for bereavement services, between

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[186] WIT 0214 0001 Mrs Kennington

[187] WIT 0214 0014 – 0015 Mrs Kennington

[188] T43 p. 95 Mrs Kennington

[189] Senior Staff Nurse, Paediatric Intensive Care Unit from 1995

[190] WIT 0483 0033 – 0034; *'After Your Child has Died'*

[191] WIT 0483 0006 Ms Warren

[192] Interim Report: *'Removal and Retention of Human Material'*, COI, May 2000. See Annex C for the full Interim Report

[193] Mr Long began as a kitchen porter at the BRHSC in about 1984, shortly afterwards becoming a full-time relief porter at the maternity hospital and the BRHSC. He worked as an auxiliary nurse from about 1986 to 1988–89, before returning to his post as full-time relief porter at the BRHSC

[194] Mr Milkins previously worked as a porter at the BRHSC in the early 1980s. Following employment as a driver and cleaner, he took up the post of porter at the BRHSC in September 1993, and became Head Porter at the BRHSC in February 1995 with full responsibility for bereavement services there. See WIT 0276 0001

them. Mr Milkins and Mr Dudridge were responsible for bereavement services at the BRHSC and Mr Long at St Michael's. Given the split site, Mr Long stated that he had:

> '… very little contact with families whose child had undergone paediatric cardiac surgery …'[195]

157 Mr Long stated:

> 'My involvement in bereavement services varied over the years and depending on which post I held.'[196]

But once he became Portering Manager in 1991, he was then:

> '… fully responsible for an important aspect of bereavement services at both St Michael's Hospital and the Children's Hospital … In about 1993 I split and restructured the portering services so that there was a dedicated team for each hospital. From then onwards I dealt with bereavement services only at the Children's Hospital.'[197]

158 He explained his role:

> 'My overall responsibility for bereavement services was to provide information to parents about their legal responsibilities, and how they could meet them (e.g. registration of the death); to give practical advice about, for example, making funeral arrangements; and to act as liaison between the hospital, parents and undertakers …
>
> 'I was contacted soon after a death had occurred, by the nursing staff. They would arrange a time for me to speak with the parents.[198]
>
> 'I worked very closely with the nursing and Chaplaincy staff at BRHSC and St Michael's in order to provide as supportive a service as possible.'[199]

159 As for support and training for him in his role, he stated that when he took up his post as Head Porter he was sent 'on a counselling skills course for 4 days at the BRI'[200] and that his first line manager, Ian Barrington 'was very supportive of the bereavement services', as were his subsequent line managers.[201]

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[195] WIT 0368 0007 Mr Long
[196] WIT 0368 0003 Mr Long
[197] WIT 0368 0003 Mr Long
[198] WIT 0368 0004 Mr Long
[199] WIT 0368 0006 Mr Long
[200] WIT 0368 0008 Mr Long
[201] WIT 0368 0008 Mr Long

Comment on the service provided by UBH/T bereavement services

160 Miss Stratton said of Mrs Kennington:

> 'Diane was always extremely kind and sensitive to parents and adult relatives, often going out of her way to help parents who often lived some distance away.'[202]

161 Dr Ashworth, consultant paediatric pathologist at the UBHT, was asked:

> 'Q. Did you know who Diane Kennington was?
>
> 'A. I did not, no.
>
> 'Q. Or what her role was?
>
> 'A. I understand what it is now, but I did not know then, no.'[203]

Helen Vegoda and Helen Stratton

162 Two posts were created during the period of the Inquiry's Terms of Reference, those of Mrs Vegoda and Miss Stratton. Although both posts were created and funded with the assistance of the Heart Circle, both women were employees of the UBH/T.

163 Although Mrs Vegoda and Miss Stratton maintained contact with Mrs Pratten, their line management, or supervision, was by staff employed by the UBH/T.

Helen Vegoda

Background to the appointment

164 Dr Joffe, consultant paediatric cardiologist, informed the Inquiry:

> 'In the mid 1980s, I became aware of the need for counselling of cardiac patients and their families at BCH during times of crisis. This occurred when the diagnosis of serious congenital heart disease was first confirmed, especially in newborn babies; and when children were admitted for cardiac catheterisation or closed-heart surgery. I anticipated that a counsellor could also support families with children

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[202] WIT 0256 0009 Miss Stratton

[203] T54 p. 25 Dr Ashworth

> undergoing open-heart surgery. With the financial support of Mrs Jean Pratten and the Bristol and South West Children's Heart Circle, the post was developed and advertised.'[204]

165 Ms Stoneham wrote to Mr John Watson[205] in March 1987,[206] enclosing a paper entitled *'Counsellor in Paediatric Cardiology'*[207] setting out a proposal for the establishment of this post. She had already discussed the proposal with Mr Graham Nix, Director of Finance and Deputy Chief Executive of the UBHT. The proposal was that the funding of the post for the first two years was to be undertaken by the Bristol and South West Children's Heart Circle.

166 The proposal was that if, after two years, it was shown to fill a real need, an application would be made to the DHSS, through the SWRHA for funding (the salary for the post being £12,500) on a permanent basis as part of the supra regional service.

167 Ms Stoneham stated:

> 'As I recall, at this time, funding constraints prevented managers from allowing such developments. The Cardiac Counsellor post, however, was initially to be funded by voluntary monies from The Heart Circle. Nevertheless, I had to seek the permission of John Watson, Central Unit Manager, before recruiting for this appointment. Once in post it was very probable that a cardiac counsellor would become part of the established service, which would ultimately have to be funded by the Authority.[208]
>
> 'This was not the top priority but it was high on the agenda. It was recognised as being necessary as there was an increasing concern about the amount of stress people were under. This did not just relate to the cardiac unit, but to the hospital as a whole.'[209]

168 Mr Watson replied to the proposal on 18 May 1987.[210] He stated that he was only prepared to accept the proposed post if the Heart Circle funded it in full. Referring to Ms Stoneham's letter, he told the Inquiry that it, and a letter from Dr Marianne Pitman[211] to Mr Nix dated 10 July 1987,[212] brought the need for a counsellor and the question of funding to his attention:

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[204] WIT 0097 0316 Dr Joffe

[205] Management Consultant and Business Psychologist; he was General Manager of the Central Unit, B&WDHA, from February 1986; from late 1989 to early 1990 he acted as leader of the DHA purchaser team; he moved to the Avon FHSA, becoming its Chief Executive in March 1990. He was the budget holder for the Central Unit; see WIT 0298 0002. Hospitals in his charge included the BRI and the BRHSC. He met his hospital managers at least once a month, including Ms Stoneham as manager of the BRHSC; see WIT 0298 0005 Mr Watson

[206] UBHT 0278 0347; letter dated 12 March 1987

[207] UBHT 0278 0335 – 0338; *'Counsellor in Paediatric Cardiology'*

[208] WIT 0149 0029 Ms Stoneham

[209] WIT 0149 0029 Ms Stoneham

[210] UBHT 0062 0307; letter dated 18 May 1987 from Mr Watson to Ms Stoneham

[211] Specialist in Community Medicine/Consultant in Public Health Medicine, 1980–1996, SWRHA

[212] UBHT 0062 0323; letter dated 10 July 1987 from Dr Pitman to Mr Nix

> 'This was eventually achieved through liaison with the South West Heart Circle, who gave us the go-ahead for funding for such a counsellor. This reinforced the work already done on an informal basis by the nursing staff.
>
> 'I was predominantly dependent upon people such as Marion Stoneham to bring to my attention an assessment of the need for such a counsellor, partly by virtue of liaising with staff and parents about the needs of parents and families with sick children in the Unit.'[213]

169 On 18 June 1987 Mr Nix wrote to Dr Pitman providing details of the counsellor post and stating that unless a permanent arrangement could be made with the DHSS for funding, it had been decided that the appointment could not proceed.[214]

> 'Dr Pitman replied on 10 July 1987, that the cost of a counsellor had been included in the 1988–1989 bid for neonatal and infant cardiac surgery.[215]

170 The draft annual programme for B&WDHA confirmed that the counsellor was to be appointed: 'costing £12,000 per annum'. [216]

171 The need for the post was stressed in the BRHSC and BRI *'Annual Report'* for 1987[217] that recorded that the post of counsellor was 'finally' established at the end of 1987 to address the 'urgent need for emotional and psychological support'. It was reported to be the first such post in the country, and made possible through a donation from the Heart Circle and funding from the Supra Regional Services budget.

Qualifications

172 Mrs Vegoda told the Inquiry that she first qualified as a teacher. She then took a qualification as a social worker and worked for nine years in the Child and Family Psychiatric Unit in a hospital in the West Midlands where she had been seconded. She told the Inquiry that this work was very much 'hands on' work with families.[218]

> 'I worked very closely with both adults and children … the expression that was used was a "therapist" … the children were actually referred, because they had some sort of psychiatric or psychological problems … I worked as one of a team of people doing an assessment of what the problems were and the family background, and then working with either the parents or the children, often in very long-term commitments … That was the main part of the work.'[219]
>
> 'I also worked with parents or children who may have been bereaved …'[220]

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[213] WIT 0298 0031 Mr Watson

[214] UBHT 0062 0319; letter dated 18 June 1987 from Mr Nix to Dr Pitman

[215] UBHT 0062 0323; letter dated 10 July 1987 from Dr Pitman to Mr Nix

[216] HAA 0055 0002; draft annual programme, B&WDHA, August 1987

[217] HAA 0137 0011; BRHSC and BRI *'Annual Report'*, 1987

[218] T47 p. 88 Mrs Vegoda

[219] T47 p. 89 Mrs Vegoda

[220] T47 p. 91 Mrs Vegoda

173 Between 1981 and 1986 she undertook training in child psychotherapy at the Tavistock Clinic in London whilst also employed as a trainee child psychotherapist in Bristol. She explained that the training that she undertook at the Tavistock Clinic was part-time and she did not obtain a qualification in child psychotherapy as she did not complete the course. She stressed to the Inquiry, however, that she underwent a considerable amount of training during the course.[221] She then spent two years working with the mental health charity Mind, as a Regional Administrator for the South West.

174 She stated she had a diploma in sociology from London University.[222] She told the Inquiry that she had also been on a bereavement course organised by Cruse[223] and subsequently became a member of the West Midlands Institute of Psychotherapy and she took a qualification with them.[224] She was also a member of the Bristol Association of Psychotherapy.[225]

Funding

175 Mrs Pratten explained the funding of Mrs Vegoda's post, as set out above. Mrs Vegoda commented:

> 'Whilst I have always considered myself to be an employee of the Health Authority and then the Trust, I was aware that my post was partially funded by the Heart Circle for up to two years following the instigation of my post.'[226]

Appointment

176 Mrs Vegoda told the Inquiry:

> 'I in fact knew Dr Joffe and he telephoned me one day and discussed the idea that he wanted to help create a post that would support the needs of parents, of families. I believe he asked whether I would come in [for] a meeting with Jean Pratten. I think Professor David Baum as well. This was a fairly informal meeting, just to look at the idea of setting up such a post.
>
> 'I did that. … Then there was the formal application and the formal interview. I always understood that the post was, I believe, part funded by the Heart Circle for, I think, two years, but was also part funded by the Health Authority …
>
> 'My understanding was that Dr Joffe had already discussed the idea of having some sort of support counselling role, which I believe he had already discussed with Jean

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[221] T47 p. 87 Mrs Vegoda
[222] WIT 0192 0001 – 0002 Mrs Vegoda
[223] Cruse is a national voluntary organisation which offers free bereavement counselling services
[224] T47 p. 90 Mrs Vegoda
[225] T47 p. 91 Mrs Vegoda
[226] WIT 0192 0006 Mrs Vegoda

> Pratten, and possibly other people. I think he was really picking my brains at that stage. I do not even know whether he was aware that I might apply for it.'[227]

177 Mrs Vegoda took up post in January 1988.[228]

178 Mrs Pratten, who was on the interview panel, told the Inquiry:

> 'I … felt that Helen Vegoda did not have the necessary qualifications for the job, but at the end of the day, we did not take part in the voting for the job because we felt it very difficult, as a voluntary organisation that had never become part of the politics of the hospital, to give our vote … Though we were going to fund the post, we were not going to employ the post.'[229]

Asked what qualifications she felt the post required she said:

> 'Certainly hospital experience. I would have thought nursing experience, or certainly awareness of a cardiac situation, of cardiac children and their needs, and the stresses that the parents go through.'[230]

179 However, she did not criticise Mrs Vegoda's approach to the job. She said:

> 'Helen Vegoda played a very useful part in supporting families. There were families who certainly were helped by knowing her, but the qualifications for that post were not met … I would not criticise her dedication in any way.'[231]

Role

180 The way in which the appointment of Miss Stratton affected the role of Mrs Vegoda will be addressed later in this chapter, in the context of Miss Stratton's developing role.

181 There was also some divergence of evidence as to the role to be filled by Mrs Vegoda. The proposals for Mrs Vegoda's post referred to a 'Counsellor in Paediatric Cardiology'. However, Mrs Pratten told the Inquiry:

> '… when Helen Vegoda was appointed she was a family support worker.'[232]

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[227] T47 p. 103–4 Mrs Vegoda
[228] WIT 0192 0002 Mrs Vegoda
[229] T47 p. 5 Mrs Pratten
[230] T47 p. 5 Mrs Pratten
[231] T47 p. 28 Mrs Pratten
[232] T47 p. 18 Mrs Pratten

182 Once in post, Mrs Vegoda introduced herself in the Heart Circle newsletter *'Heart South West'*[233] in November 1989:

> 'Although I am officially called the Cardiac Counsellor, I prefer to introduce myself as a Heart Family Support Worker.'

183 Mrs Vegoda stated that during the period 1988–1990, she worked with families whose children had congenital heart defects and who came to the BRHSC, the BRI and the Bristol Maternity Hospital.[234] She was based at the BRHSC and also covered Ward 5 at the BRI which meant that she visited the BRI often once or twice a day to see families and to be available at key times such as surgery and admission.

184 She told the Inquiry that she saw the main aspect of her job when she took it in 1988 as being to provide emotional and psychological support and counselling to families and to give information:

> 'It involved being there as a very general support at times of stress. It involved what I would have called "orientation", helping parents to know what facilities were around in the Children's Hospital in Bristol. It had a liaison element to it in terms of the community …'[235]

185 She stated:

> 'I provided emotional and other support at key times during the child's admission, for example, being available to parents accompanying the child to theatre or the catheter lab and supporting them whilst they awaited the child's return. Some of my support was to liaise with parents' employers to obtain leave of absence, give information about voluntary organisations such as the Heart Circle and the Downs Heart Group, and help make preparations for discharge by contacting other agencies, e.g. Social Services, GPs and Health Visitors …
>
> 'On occasions I would sit in with cardiologists and surgeons when a diagnosis was made or when details of surgery were given to the parents. This allowed me subsequently to carry out a supportive role.'[236]

186 Mrs Vegoda informed the Inquiry that she would usually try to ascertain whether a parent understood what treatment or surgery entailed following their meeting with the cardiologists or surgeons, and if it was apparent that they needed clarification, she

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[233] UBHT 0213 0086; *'Heart South West'*, Issue Number 1, November 1989

[234] WIT 0192 0002 Mrs Vegoda

[235] T47 p. 86 Mrs Vegoda

[236] WIT 0192 0002 – 0003 Mrs Vegoda

would ask the consultant or registrar, or one of the nurses to meet the parents to explain the procedures again. She stated:

> ‘I would never explain the medical aspect of any procedure to a parent as I was not qualified to do so. I could provide the details of the process and place of treatment only.’[237]

187 In relation to bereaved families she said:

> ‘At the time of death my support could include staying with the parents until they were ready to go home, accompanying the parents to register the child’s death, meeting them if they returned to the hospital to see their child in the Chapel, and liaise with and be present at meetings with the Surgeon or Cardiologist, usually after the post mortem report was available.
>
> ‘I sent out regular cards to parents on the anniversary of their child’s death and birth, and instigated and organised an annual Remembrance Service for Cardiac families for three years,[238] each attended by over 150 people including medical and nursing staff who took an active role.’[239]

188 She also described her ongoing support for bereaved parents:

> ‘My contact with bereaved parents was open ended, and in some instances continued for several years.’[240]

189 Mrs Vegoda spoke of the need for her to be proactive in establishing her role:

> ‘… one of the things that I was aware of was that I do not know how much the post had been discussed with all members of the cardiac team … both surgeons, consultants, nursing staff or anybody else … possibly had there been more of a cardiac team structure that met very regularly, that looked at non-clinical issues, then possibly I might have slotted into the team as opposed to a professional background.’ [241]

190 She said:

> ‘My memory is that I had to be very proactive in seeing where I was needed. By that I mean the cardiologists and surgeons would not necessarily have brought me in at the diagnostic stage … When I discussed that with Dr Jordan, they were very happy for me to do that and to be there, but it did not happen routinely, and somehow I felt I was always having to be proactive.’[242]

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[237] WIT 0192 0003 Mrs Vegoda

[238] 1994–1996

[239] WIT 0192 0006 Mrs Vegoda

[240] WIT 0192 0005 Mrs Vegoda

[241] T47 p. 114–15 Mrs Vegoda

[242] T47 p. 117 Mrs Vegoda

Communication between Mrs Vegoda and others

191 Mrs Vegoda stated that her job involved liaison within the hospitals with other professionals and voluntary groups, and with services in the community, to obtain services for the families. Her job included: acting on the families' behalf with their employers, council departments, schools and the DSS, for example, to obtain leave of absence or grants, discussing the availability of resources; providing information and 'TLC', the provision of a listening ear, a place of refuge, a cup of coffee both at times of crisis and on a daily non-eventful basis; attending Tribunals at a parent's request to prevent them losing a job, or to appeal against refusal of disability living allowance; and carrying a dead child to the mortuary, having helped to dress him or her.[243]

192 Ms Lorna Wiltshire[244] stated:

> 'The role for Helen Vegoda (BRHSC) was not only to provide support, but also to arrange more practical issues such as transport, accommodation etc.'[245]

193 However, as was set out earlier[246] a number of these tasks was at that time already being carried out by social workers.

194 In April 1988 Dr McMullen wrote to Mr Dhasmana[247] enclosing a copy of a document seeking to clarify how Mrs Vegoda and social workers could work together on Ward 5. The paper set out some general principles:

> 'It is important to work towards clarity about roles for 3 reasons:
>
> 'a. to minimise confusion for the families of the patients;
>
> 'b. to enable staff to know to whom to refer/with whom to continue discussion;
>
> 'c. so that the activity of the 2 workers fits together rather than overlaps.'[248]

195 The paper suggested that both Mrs Vegoda and Mr Smith, the social worker then attached to Ward 5, would take referrals from any source. Mrs Vegoda would, it suggested, meet some families around the time of the diagnosis, she would become involved with some families at BRHSC with whom she would continue to work when they transferred to the BRI, and her counselling would focus on emotional and relationship difficulties related to the child's illness and treatment. Mr Smith, the paper suggested, would work with families where there were statutory responsibilities, he would take referrals from Mrs Vegoda to respond to families' particular needs,

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[243] WIT 0192 0244 Mrs Vegoda

[244] Night Nursing Officer at the BRI from April 1981 to April 1990 when she took the post of Nurse Manager of the Cardiac Unit; Nurse Manager, Cardiac Unit, 1990; and Assistant General Manager, General Surgery, 1990–1993

[245] WIT 0330 0028 Ms Wiltshire

[246] See paras 121–51

[247] UBHT 0160 0004; letter 25 April 1988 from Dr McMullen to Mr Dhasmana

[248] UBHT 0160 0005; paper on counselling

in which cases Mrs Vegoda would continue her involvement with the family, and wherever their roles overlapped significantly, this would be discussed between them. This way of working together was to be achieved by regular meetings.

196 Mrs Vegoda also explained to the Inquiry that her role involved liaison with the Chaplaincy and voluntary bodies. She described the bereavement support group set up in 1992:

> '… Charmion Mann, the then Chaplain to the hospital, and myself, who worked quite closely together, were very aware that there possibly was a need to offer that type of support. We were both offering individual support and support in other ways to bereaved parents, but what was not available from the point of view of the hospital was some sort of group, and we both felt that parents might benefit from being able to talk to other bereaved cardiac families.'[249]

She went on to say that six or eight sessions were held in the evening; they reviewed the situation, and then had another six sessions, but these were not very well supported:

> 'A number of families said they would like to but they could not because of the distance, so in the end, we actually felt that they were not particularly well supported.'[250]

197 She stated:

> 'I also directed families to voluntary organisations offering bereavement support such as Compassionate Friends and CRUSE.'[251]

198 Mrs Vegoda commented on the split site and its effect on the attitude of the nurses on Ward 5 to her. She said:

> '… one of the difficulties of the split site and the fact that I was going down to Ward 5 was that I did not really get to know the nurses well … So I do not think I necessarily developed a sort of close rapport with the nursing staff.'[252]

Support for Helen Vegoda

199 Mrs Pratten stated in her evidence to the Inquiry:

> 'I was concerned that this new post did not fit into any established structure, and none was established for her. In addition there was no clinical supervision provided for this post during The Heart Circle's involvement with it.'[253]

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[249] T47 p. 155 Mrs Vegoda

[250] T47 p. 155–6 Mrs Vegoda

[251] WIT 0192 0006 Mrs Vegoda

[252] T47 p. 138 Mrs Vegoda

[253] WIT 0269 0003 Mrs Pratten

200 Mrs Vegoda agreed:

> 'There were difficulties about the post because … I did not fit into social work and I did not fit into nursing and I did not fit into psychology … From that point of view, it was isolated. There was no peer system that I slotted into … certainly, there was not that peer support.'[254]

201 She told the Inquiry that when the post was first set up she was not part of any formal management structure within the Health Authority. That came into place in 1991 or 1992 when Julie Vass[255] came into post and became her line manager. A formal management structure was put in place:

> 'I do not really think that aspect of the role was discussed until Julie Vass came into post, I think it was around 1991, and I mean, I was certainly aware that I was trying to "find my feet" with the post. What I think I did was focus in on the needs of families, which I was beginning to understand and felt I was making headway with, but I think probably what I was not doing was looking at the whole wider area of how it fitted in with the cardiac team and things like that. That aspect probably was not looked at until I had professional managerial input.'[256]

202 She told the Inquiry that in all matters of clinical responsibility and accountability Dr Joffe supervised her and she saw herself as being accountable to Dr Joffe and the Health Authority.[257] Mrs Vegoda stated that she received good support from Mrs Vass, and regular supervision from Dr Joffe.[258] Of Dr Joffe she said:

> 'I felt he was very aware of his families. I think he was very aware of the emotional and the stress factors on them. That is what we talked about. We obviously talked about different children's conditions and who was coming in and what the needs of those families were, but we were really looking at the emotional content.'[259]

203 Asked whether there was anyone else who could look at her performance as a counsellor, discuss with her areas in which her skills might need to be strengthened or developed, or discuss critically the sorts of initiatives she was taking, Mrs Vegoda replied:

> 'What I did, because I think I was aware that there were gaps, is I went to see Paul Burroughs, who was a child psychotherapist, because I did discuss with Dr Joffe right at the beginning supervision outside the role with him, and talking to Paul Burroughs was quite helpful in terms of how I felt I was dealing with things, but again, I did not feel it was quite appropriate for this post, because he was a very good child psychotherapist, but that was really not what the main thrust of the

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[254] T47 p. 113–14 Mrs Vegoda

[255] Assistant General Manager, BRHSC

[256] T47 p. 107–8 Mrs Vegoda

[257] T47 p. 105 Mrs Vegoda

[258] WIT 0192 0007 Mrs Vegoda

[259] T47 p. 107 Mrs Vegoda

> job was about. I did also see Madeline Dunham who was or is the principal psychologist at the hospital, and she, again, was very helpful.
>
> 'So I think I was getting people to look at aspects of my work, but whether either of those two people were actually aware of how I was performing, other than what I said, I do not know.'[260]

204 Mrs Vegoda said that in the first two years, while her post was part-funded by the Heart Circle, she met Mrs Pratten regularly, although Mrs Pratten's role was supportive and informative rather than supervisory. [261]

205 Mrs Pratten said:

> 'I tried to help her because I realised she did not have an understanding of the needs of children or their relatives. I gave a lot of time to trying to help her to understand the needs of these families and the children.'[262]

206 Mrs Mandelson[263] told the Inquiry that notwithstanding that Mrs Vegoda was not a member of the British Association of Counsellors, nor an accredited counsellor through the British Association of Counsellors, the Code of Practice and Ethics, setting out accepted practice for counsellors, would have required her to have 'outside supervision'.[264]

207 In addition to formal lines of accountability to Dr Joffe and Mrs Vass and contact with other professionals, Mrs Vegoda was asked what other forms of support she had in her role. She explained that a support group was set up specifically for people like her with isolated jobs, in order to support them.[265] She said:

> 'It was a very stressful job, and I think I was aware right at the beginning that I was going to need help … that was part of my reason for seeing Paul Burroughs and then Madeline Dunham, but a number of years after that, and I cannot date it, a support group was set up in the hospital, in fact there were two support groups. One was convened by Charmion Mann, who was the Chaplain to the hospital. That was helpful but it was not terribly structured. About six years ago, a support group was set up by Ann Dent, who has done a lot of work in bereavement research, and that is ongoing. That has been invaluable.'[266]

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[260] T47 p. 108–9 Mrs Vegoda

[261] T47 p. 105 Mrs Vegoda

[262] T47 p. 9 Mrs Pratten

[263] Manager and Senior Counsellor, Alder Centre, Alder Hey Children's Hospital, Liverpool: Expert to the Inquiry on Support and Counselling Services

[264] T47 p. 170 Mrs Mandelson

[265] T47 p. 111–12 Mrs Vegoda

[266] T47 p. 111–12 Mrs Vegoda

208 Despite having an 'isolated job', however, Mrs Vegoda told the Inquiry that when she made suggestions for improvements, she got a response:

> 'For example, I helped to produced … three booklets and Dr Joffe was one of the people that helped to produce them … I got a lot of support for that sort of initiative. I got a huge amount of support for organising the study days for the whole team. I mean, both surgeons and the cardiologists and others involved with cardiac surgery were very, very supportive, and gave their time, and they were very successful. So I feel that when I came up with an idea or initiative, it was supported.'[267]

Comment on the service provided by Helen Vegoda

209 The 1987 *'Annual Report'* for the BRHSC and BRI recorded that Mrs Vegoda and her counselling service had become:

> '… an integral and most valued part of the unit'. [268]

210 Mr Wisheart commented on Mrs Vegoda's contribution:

> 'She played an invaluable role in supporting the parents in many different ways.'[269]

211 As to the reaction of the parents to her role, she said that she received continued feedback which was appreciative, including over 200 letters which:

> '… suggest that my support to cardiac families, both met many of their needs, and was valued and appreciated'.[270]

212 Mrs Vegoda was asked about the survey that she conducted in the first half of 1993,[271] in which she studied the level of information and support being given to families attending, specifically, for catheterisation at the BRHSC. The findings[272] were that at the time of initial diagnosis, 45% responded that they did get support from the hospital source, 53% did not, and of those who did not get support, 25% said they would have liked it. Counsel to the Inquiry asked whether the document painted a picture of parents who, in 1993, were still not gaining access to, or were not aware of, the support that Mrs Vegoda could give them within the BRHSC.

213 She replied:

> 'Clearly it must do, and I can only surmise, looking back at this stage, that that could have been for a number of reasons. It could be that there were some families

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[267] T47 p. 146 Mrs Vegoda
[268] HAA 0138 0006; BRHSC and BRI *'Annual Report',* 1987
[269] WIT 0120 0230 Mr Wisheart
[270] WIT 0192 0246 Mrs Vegoda
[271] WIT 0192 0065 Mrs Vegoda
[272] WIT 0192 0072 Mrs Vegoda

> who had not been to Bristol before and either were not aware that I existed or possibly were sent a leaflet and did not take particular note of it. There may have been other reasons, but, yes, clearly there were families who were not aware.'[273]

214 The study recommended[274] that professionals and families be made more aware of the counsellor, that information be posted at the BRHSC, and that the availability of counselling should be more widely advertised. In evidence, Mrs Vegoda spoke again about the need for her to be proactive. She said:

> 'I have to say that most of the impetus [in advertising the post] would have been left to me. I had to be very proactive about finding ways in which health professionals or parents or voluntary organisations knew about my existence, and I do certainly remember feeling slightly overwhelmed by the fact that the South West was a very large area … I was very aware that there was not necessarily a consistent structure by which I could make sure that all GPs or all health visitors, for example, knew that my post existed. That actually felt rather overwhelming, outside my grasp.'[275]

215 Parents commented on the support they received from Mrs Vegoda whilst at the UBH/T.

216 Jayne and Richard Leonard, parents of Katie:

> 'We do recall that Helen Vegoda, a Cardiac Counsellor at BCH, came to see us to help with anything she could. She advised us on reading material and made it quite clear that she was always available for chats if we felt we needed to speak to her.'[276]

217 Amanda Evans, mother of Joshua:

> 'Helen Vegoda … talked about the hospital in very positive terms, and gave us confidence in the establishment. She helped us to sort out some forms, and went through various details of our stay with us. She said that, if we needed anyone, she was there for us.'[277]

218 Another parent stated:

> I found [Helen Vegoda] extremely patronising and not at all supportive.'[278]

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[273] T47 p. 141 Mrs Vegoda

[274] WIT 0192 0078 Mrs Vegoda

[275] T47 p. 142–3 Mrs Vegoda

[276] WIT 0367 0004 – 0005 Jayne and Richard Leonard

[277] WIT 0417 0009 Amanda Evans

[278] WIT 0408 0007. This parent was one of a number of parents who gave a witness statement to the Inquiry and gave only partial consent to publication of the statement, as they did not wish to be publicly identified

219 Marie Edwards, mother of Jazmine:

> ‘I found her extremely irritating, patronising and unhelpful.’[279]

220 Kenneth and Susan Darbyshire, parents of Oliver:

> ‘Helen Vegoda … was there from day one giving us moral support at all times. Also she would do the ward rounds with the doctors, every single morning, Monday to Friday. She had this uncanny knack of always popping up when parents were feeling stressed out. She was a real tower of strength to all the heart baby parents.’[280]

221 Alison Leeming, mother of Jamie:

> ‘We also met Helen Vegoda who we thought was an excellent counsellor and a lovely woman.’[281]

222 Michelle Cummings, mother of Charlotte:

> ‘Helen Vegoda was available at all critical times throughout Charlotte’s stay in the BRI and the Bristol Children’s Hospital … her support and assistance and comfort were tremendous.’[282]

223 Robert Briggs, father of Laura:

> ‘… she was helpful. One thing she did was to arrange for us to meet with the parent of a child who had had similar surgery and who had come through successfully, and again this was reassuring to us.’[283]

224 Robert Langston, father of Oliver:

> ‘On the day that Oliver died, Helen Vegoda was there for us all the time. She was brilliant all the way through. She helped me get everything in perspective, and also helped us practically with things like arranging the death certificate.’[284]

225 Many parents commented positively about Mrs Vegoda’s cards and telephone calls after they had left the hospital(s).[285]

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[279] WIT 0414 0008 Marie Edwards

[280] WIT 0125 0006 Kenneth Darbyshire

[281] WIT 0537 0004 Alison Leeming

[282] WIT 0123 0025 Michelle Cummings

[283] WIT 0136 0004 Robert Briggs

[284] WIT 0184 0012 Robert Langston

[285] See, for example, Tracey Morgan, mother of Daniel, WIT 0288 0011 and Alison Havenhand, mother of Victoria, WIT 0244 0014

226 Lynne Lloyd, mother of Kate:

> 'Helen Vegoda … sent me a "Thinking of You" card for the next five years on Kate's birthday and the anniversary of her death. I found this very comforting.'[286]

227 Paul Bradley, father of Bethan:

> 'Helen Vegoda kept in regular contact with us … For several years, she remembered to send a card on the anniversary of Bethan's death. She also invited us to a Heart Children's Remembrance Service held once a year. This was deeply appreciated.'[287]

Helen Stratton

Background to the appointment

228 Dr Joffe stated to the Inquiry that a year or two after the appointment of Mrs Vegoda:

> '… it became clear that the overall service was insufficient for the demand with, I believe, the split site proving a barrier to full communication with the BRI. The Heart Circle, once more, gave financial assistance for a second cardiac counsellor post, based at the BRI, and Ms Helen Stratton was appointed and commenced service in January 1991. I was not involved in the development of this post.'[288]

229 Ms Wiltshire told the Inquiry:

> 'In 1990 the full-time chaplain [Michael Jarvie] was covering numerous hospitals. It was felt that we needed one full-time member of staff designated solely to the cardiac unit who had time to liaise with parents. I spent a considerable amount of time with Jean Pratten (South West Heart Circle) in setting up this post and was included in the interview panel. The post was partly funded by the Southwest Heart Circle and partly by the hospital. We employed Helen Stratton in October 1990.'[289]

Qualifications

230 Miss Stratton informed the Inquiry that she qualified as a registered nurse in 1982, working in intensive care and accident and emergency, and studied for the ENB course in intensive care at the BRI in 1986–1987 following which she began work at the BRI in the Accident and Emergency Department. In late 1988 she was appointed

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[286] WIT 0225 0011 Lynne Lloyd

[287] WIT 0229 0023 Paul Bradley

[288] WIT 0097 0316 Dr Joffe

[289] WIT 0330 0028 Ms Wiltshire

Regional Transplant Co-ordinator for the South West, based at the Renal Unit at Southmead Hospital, a post which she held for two years.[290]

231 She told the Inquiry that she had no professional qualification in dealing with bereavement:

> 'I had experience as a nurse of dealing with bereaved relatives, but no professional qualifications.'[291]

232 Asked whether she had any training in counselling she said:

> 'Not official, formal training, no. My understanding was that it was not part of the criteria for this particular job.'[292]

Miss Stratton stated that her post, as advertised, did not require the holder to be a registered sick children's nurse nor even a nurse, although a nursing background was said to be advantageous.[293]

Funding and employment status

233 Miss Stratton said that she saw Mrs Pratten as her 'boss', who had appointed her to the post, and thought that she was paid through the UBH/T simply for administrative purposes.[294] She said:

> 'I perceived that Jean Pratten, the Chairman of the Heart Circle, was my boss, as the Heart Circle were paying my salary, or funding the post, so I saw her as someone to refer to as a reference. I do remember having a discussion with her that she did not feel it was appropriate for me to have the senior nurse on the cardiac unit as my direct report because I was not actually nursing patients or children, I was not clinical hands-on. So that might have been inappropriate. But I think, suffice to say, it was quite unclear, apart from my perception of it being Jean Pratten because the Heart Circle were paying my salary and for day-to-day things going on the unit, I would probably refer to Fiona Thomas, or Julia Thomas in the beginning of my job, but I cannot remember that ever being formalised. That was just something that I did.'[295]

234 However, Mrs Pratten stressed:

> '… whereas her post was funded by the Heart Circle, she was not at any time employed by the Heart Circle nor regarded as an employee of the Heart Circle …

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[290] WIT 0256 0001 Miss Stratton

[291] T46 p. 35 Miss Stratton

[292] T46 p. 35 Miss Stratton

[293] WIT 0256 0002 Miss Stratton

[294] T46 p. 38–9 Miss Stratton

[295] T46 p. 38 Miss Stratton

> she would have been employed by the NHS Trust, and all employment responsibilities and duties lay with the Trust.'[296]

Appointment

235 As to her reasons for applying for the post, Miss Stratton said:

> 'I had worked with distressed and bereaved relatives, and I wanted to develop my career in another area.
>
> 'When I saw the advert for the new cardiac liaison post at the BRI, I thought this was a good opportunity to use my clinical background and to gain an insight into working for a charity.'[297]

236 Helen Stratton was appointed as Cardiac Liaison Nurse in October 1990, and took up the post in November 1990.

237 In her written statement Miss Stratton told the Inquiry that she did not know whether Mrs Vegoda had been made aware of her role before her appointment:

> '… I am unclear as to whether this new role had been discussed with her prior to my appointment. At my interview I was told that there was a paediatric counsellor at the BCH and I did not know that she was specifically a cardiac children's counsellor until after I was appointed and went to the BCH to meet the cardiac nursing staff. I met Helen Vegoda and had thought that she covered the whole of the BCH. It was only then that I discovered that she only covered the cardiac children and parents. She seemed quite defensive and questioned me about what exactly I would be doing. In retrospect she may have felt threatened by my appointment, and both she and I were somewhat confused by our respective roles and where the boundaries of these lay.'[298]

238 She subsequently told the Inquiry:

> '… when I met Helen Vegoda, she probably did not have an accurate understanding of what my role was going to be, and I perhaps had a misperception of what her role was at the time. I was told there was a counsellor at the Children's Hospital who looked after the parents before I commenced the job …'[299]

239 By contrast, Mrs Vegoda told the Inquiry of various discussions she had with Miss Stratton prior to Miss Stratton's appointment. She said:

> 'I cannot remember the details of our conversations. I do remember that Helen Stratton contacted me. I did not know her. She contacted me because she had

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[296] WIT 0256 0106 Mrs Pratten

[297] WIT 0256 0001 Miss Stratton

[298] WIT 0256 0005 Miss Stratton

[299] T46 p. 44–5 Miss Stratton

> either seen the job advert, or I am not even sure it was not before the job advert came out, and she wanted to talk about my role and she wanted to know about cardiac services in the Children's Hospital generally and on Ward 5.
>
> 'I cannot remember whether we talked very specifically about how the two posts would marry together, but I do know that we met, I think, a few times and we also talked about her actual interview and the areas that she might be asked questions on.'[300]

She stated in her written evidence:

> 'Helen Stratton first contacted me in July 1990 and there are several entries in my diary for June, July, September and October 1990 referring to meetings or contact with her, all prior to her interview and taking up her post … Helen Stratton would therefore have been fully aware of my role in BCH/BRI with cardiac children and their families. I welcomed Helen Stratton's selection for interview, gave her support prior to this, and was enthusiastic about her appointment.'[301]

240 Miss Stratton was referred to Mrs Vegoda's diary that had an entry for 20 July 1990:[302] '11:30, Helen Stratton'. Miss Stratton's evidence included the following exchange:

> 'Q. Did you speak to her by phone before you took that appointment?
>
> 'A. I cannot recall meeting her, and I cannot recall a phone call.
>
> 'Q. She says it happened. Is that probably right?
>
> 'A. I cannot comment. I cannot remember it.
>
> 'Q. The next diary extract that she gives us, she tells us that she spoke to you or saw you before October … "1:00pm. Helen S in room" … So very shortly after, if you began on the Monday, which you might have done, two days later, did you, do you think, meet Helen Vegoda?
>
> 'A. Yes, probably, because I probably thought it was important that we had an opportunity to discuss our roles'.[303]

241 Although Mrs Vegoda had asked whether she could assist in preparing Miss Stratton's job description or sit in on her interview, she was told that this was neither appropriate nor possible.[304] She said that she was not formally consulted about the creation of

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[300] T47 p. 121 Mrs Vegoda

[301] WIT 0256 0015 Mrs Vegoda

[302] WIT 0256 0016 Mrs Vegoda

[303] T46 p. 80–1 Miss Stratton

[304] T47 p. 123 Mrs Vegoda was unable to confirm, for certain, who told her it was inappropriate

Miss Stratton's post or about her appointment, but when she became aware that the post was being set up she was both surprised and concerned:

> 'I asked to see Jean Pratten because I was concerned. I felt quite confused and I did not quite understand what was going on. I went to see Jean, she was very clear that this post was going to be based on Ward 5. The person appointed would have a nursing background, and therefore the two posts would complement one another, but we would be doing very different jobs, on different bases and with different professional backgrounds. I was very satisfied with that.'[305]

242 On that basis Mrs Vegoda said:

> '… there was no question in my mind that there would be any difficulty about the post marrying in.'[306]

Role

243 The Inquiry heard different interpretations of Miss Stratton's role and particularly whether she was to work only at the BRI, or to work at the BRI and the BRHSC.

244 Dr Joffe referred to Miss Stratton as the:

> '… second cardiac counsellor … based at the BRI.'[307]

245 Mrs Vegoda had understood Miss Stratton's role to be 'based at' the BRI. Miss Stratton said:

> '… I got the impression that Helen Vegoda felt that my role was based at the Bristol Royal Infirmary and was not to be at the Bristol Children's Hospital at all, and that was a problem.'[308]

246 Further, Miss Stratton spoke of a general perception that her role would be the same as that of Mrs Vegoda, but at the BRI. She said:

> 'I think there was a perception and I obviously feel wrongly, that I would do the same role that Helen Vegoda did at the Children's Hospital at the Bristol Royal Infirmary. This was an underlying perception that I gradually over months and years realised that people had.'[309]

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[305] T47 p. 118–19 Mrs Vegoda
[306] T47 p. 123 Mrs Vegoda
[307] WIT 0097 0316 Dr Joffe
[308] T46 p. 45 Miss Stratton
[309] T46 p. 89 Miss Stratton

247 However, Mrs Pratten envisaged that Miss Stratton's role would involve attending at the BRHSC. She told the Inquiry that when Miss Stratton's post was created:

> 'It was supposed to be a cardiac liaison post, a Sister post, to liaise between the community and the unit, and to enable parents to liaise with her, so that they had somebody to whom they could turn … it was hoped originally that she could have gone to the outpatients appointment prior to surgery, but that did not work out because it was in the Children's Hospital and I do not think she was made very welcome.'[310]

248 Miss Stratton told the Inquiry that she believed she had had a formal job description but did not have it nor did she recall exactly what it had said.[311] She told the Inquiry that she had not, until she gave evidence, seen the description of the respective roles of Mrs Vegoda and herself as set out in the *'Annual Report'* for the BRI and BRHSC for 1989:

> 'The nursing team on Ward 5 now includes about 75 nurses … supported by Mrs Helen Vegoda, Counsellor to the families of the children and Miss Helen Stratton who has a similar but wider counselling role supporting any families in need and also the staff.' [312]

249 Asked whether there was uncertainty or lack of definition in the role that she was expected to do, Miss Stratton said:

> 'Yes. I clearly had a perception and I had my brief from Jean Pratten of what she wanted. But, you know, in hindsight, I would say that the hospital, the Bristol Royal Infirmary and the staff there, did not have the same perception. Whether that was a communication issue, I cannot be sure.'[313]

250 Miss Stratton was referred to a sample of a standard letter that she sent to parents that described her as a 'Support Nurse Specialist'. In the letter she describes her job as giving: '… any support and advice you may need regarding your child's operation and your stay in Ward 5.'[314] She said:

> 'At the beginning of my job I was Support Nurse Specialist and by the time I had been there a few months it was decided, because of the grading of the post and things, that I should be called Cardiac Liaison Sister.'[315]

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[310] T47 p. 14 Mrs Pratten

[311] T46 p. 36 Miss Stratton

[312] UBHT 0167 0076; BRHSC and BRI *'Annual Report'*, 1989

[313] T46 p. 85 Miss Stratton

[314] WIT 0074 0589; T46 p. 83 Miss Stratton. See also the report from the Secretary of the Heart Circle which refers to the appointment of Miss Stratton as the 'Support Nurse Specialist', who was to help families to understand the medical aspects of their child's problem, as well as undertaking research into the needs of families on Ward 5; UBHT 0213 0016, May 1991

[315] T46 p. 84 Miss Stratton

251 In the letter she describes Mrs Vegoda's role as that of a 'Family Support Worker'. She said:

> 'At the beginning of my job, I thought that was her title. Then she was called the "paediatric counsellor"…'[316]

252 Miss Stratton stated that her role was broad and included working with the Heart Circle in fund-raising activities and attending meetings in the regions which covered the South West.

> 'My understanding of the role was to bring together the BCH paediatric/cardiac activities with those of the BRI. The aim was to ensure the smooth transition for parents and children from the BCH to the BRI. This would include corresponding with the child's health visitor and/or GP. I also had to ensure that parents had accommodation and had practical information on the child's admission to the BRI and their forthcoming stay. This would include advice on transport … I would work in a very practical way with the parents … My understanding was that I was there to support the parents so that when the child was in surgery or in intensive care the liaison nurse could spend time explaining for example why the child was on a ventilator and what the lines were for, and the reason for sedation. The nurses caring for the child often did not have the time to spend with the parents and explain at length what was happening'.[317]

253 Miss Stratton explained how she approached parents:

> 'At the beginning of every month I would get a theatre list with all the adult and children's names on it along with the referring GP. I would write to the parents and introduce myself and say that they may have met Helen Vegoda at the BCH and that my role was to provide support and care while they were at the BRI, in conjunction with Helen Vegoda. I would tell them that I was employed by the Heart Circle.'[318]

254 In relation to bereavement she stated:

> 'Where a child died, I would notify the Health Visitor and would tell them how the parents had reacted and their plans for returning home.'[319]

255 She said:

> '… I kept a red book with patients' names and addresses, the name of the health visitor, how often I had spoken to the health visitor, the name of the GP and other information like whether I had referred the family to the social worker … had the

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[316] T46 p. 85 Miss Stratton

[317] WIT 0256 0002 Miss Stratton

[318] WIT 0256 0008 Miss Stratton

[319] WIT 0256 0008 Miss Stratton

> parents received any support from the social worker and had they received any financial support from the Heart Circle …
>
> 'It had the date of the operation, the date the child was extubated or taken off the ventilator, the date they were moved through to the nursery, the date they went home and the date they died …'[320]

256 In her written evidence, Helen Stratton said in her first year at the BRI:

> 'I discussed with Jean [Pratten] and some of the senior nurses the idea of taking a hand or footprint of the baby or a lock of hair from a baby that had died. The parents could take this away or I would send this to them when they were ready to receive it. Sometimes they would ask for this six months later. The Heart Circle bought a Polaroid camera and I would take a photo of the baby in a Moses basket which again the parents could take away or ask for later. Appropriate cards were purchased by the Heart Circle to place the hair or photo or print in.'[321]

Development of Helen Stratton's role

257 Miss Stratton stated that her role was evolving. She continued to go to Great Ormond Street to establish links with Mary Goodwin, whom she described as carrying out a similar role to her:

> '… and to look at what improvements I could bring to BRI. During my visits to GOS [Hospital] I met with a number of paediatric cardiac nurses of all levels and we decided that it would be beneficial to set up a forum for paediatric cardiac nurses to come together to share ideas and information. It was envisaged that nurses from all over the UK in this speciality would want to join. We had nurses from Birmingham, Liverpool, Ireland, the Brompton, Newcastle, etc. I saw this as an ideal opportunity for the nurses at both the BCH and the BRI to exchange experiences and ideas. The group was called the Paediatric Cardiac Nurses Association. I became the Secretary and wrote the monthly newsletter. We also managed to get a nursing session tagged onto the paediatric/cardiology conference held annually at the Brompton [Hospital]. I took part in getting an agenda together and got Freda Gardner to speak about her research. Martin Elliott, a Consultant Paediatric Cardiac Surgeon [at GOS] came along to talk. I encouraged nurses at both the BRI and the BCH to join so that they could make a contribution and learn from other centres. One sister from the BRI joined and I think that 3–4 of the staff nurses joined from BRI. The nurses at the BCH thought this was a brilliant idea but most of them already belonged to paediatric associations and as they were not solely cardiac paediatric nurses they did not feel it was a priority.'[322]

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[320] T46 p. 161 Miss Stratton

[321] WIT 0256 0007 – 0008 Miss Stratton

[322] WIT 0256 0006 Miss Stratton

> ‘Another initiative that I brought back from GOS was the idea of parents going to theatre with the child if they wanted. Before I arrived I think they could go down as far as the door of the theatre … I wanted the parents to have the choice of coming into the anaesthetic room … From then on I always offered this as a choice to the parents …
>
> ‘Another idea I implemented was that the older children could paint their theatre gown prior to the operation and get the surgeon, anaesthetist and nurses to sign this for them to take it home …
>
> ‘I had come across a book at GOS called *“Heart Children”* … which had concise and easy to understand explanations of commonest cardiac conditions with diagrams.’ [323]

258 Miss Stratton arranged via the Heart Circle for copies of this book to be made available to parents. She said:

> ‘… I was evolving a job given what was happening at Great Ormond Street, but I think in a typical nursing fashion, I was trying to fill gaps where I thought there were gaps in the provision of looking after parents and children at the Royal Infirmary. So if I felt it was appropriate to talk to parents on the unit, I would do that. So it was rather unstructured to start with, because I did not have an awful lot of guidance, apart from what I was learning at Great Ormond Street, to go on.’[324]

259 She also took on a role that was not performed by Ms Goodwin at GOS. She told the Inquiry that Ms Goodwin did not, as a general rule, make herself available to parents during and after surgery. Miss Stratton said:

> ‘I think what happened is that whilst I tried incredibly hard to do the liaison job, the job that I had been tasked with doing, I found that I was filling gaps and doing things that Mary Goodwin did not do, but just because there was a need and someone had to meet that need.’[325]

260 She informed the Inquiry that in her second year she wrote and published an information pack for parents which outlined the process for admission to the BRI for surgery, providing details of accommodation, useful telephone numbers and what would take place during the pre-surgery preparation. She also produced a leaflet for bereaved parents providing the name of Mrs Kennington together with useful telephone numbers and information.[326]

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[323] WIT 0256 0006 – 0007 Miss Stratton

[324] T46 p. 50–1 Miss Stratton

[325] T46 p. 52 Miss Stratton

[326] WIT 0256 0009 Miss Stratton

261 Miss Stratton spoke of her role in supporting staff:

> 'I suppose quite early on when I was evolving the post, I thought it would be helpful, given the high levels of stress that nurses were experiencing on the unit, to give them the opportunity to have half an hour or forty-five minutes where they could discuss those concerns and although it was never, although I cannot recall, but I cannot remember it ever being pointed out as a large part of the job, I felt that by supporting the nurses they in turn would be able to support the parents more effectively, and some would argue that I took on a role that … was not part of my initial job, but it was important because I had empathy with the nurses who were giving extremely good care in sometimes almost impossible conditions.'[327]

262 Miss Stratton stated:

> 'Two Sisters at BCH … had become tutors for an ENB course in paediatric intensive care. They asked me to speak on the role of supporting parents to nurses who were doing the course. The nurses at BCH were always receptive to my role and ideas throughout my time as a liaison nurse. They were more receptive to change and new ideas than the nurses at the BRI. The senior nurses at the BRI tended to have a perception that a suggestion for change was a personal criticism of what they were already doing.'[328]

263 Miss Stratton stated that in the third year she was in post she:

> '… organised a cardiac study day sponsored by the Heart Circle for all nurses involved with cardiac patients …'[329]

264 Miss Stratton said:

> '… I was also aware that there was this cavern between the nurses at the BRI and the nurses at the Children's Hospital and I wanted in some small way to see how that could be improved, whether that was through communication, whether that was through going to the Children's Hospital and speaking with people informally, and setting up the Paediatric Cardiac Nurses' Association, which I did whilst I was there as well.'

She continued:

> 'I think there were territorial issues in as much as if I suggested that perhaps somebody came down to Ward 5 from the Children's Hospital to spend some time down there with the nurses, there was a sort of, "Oh, no, you have got adults down there" and, you know, "No, we do not want to go down there". And vice versa, the

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[327] T46 p. 167–8 Miss Stratton

[328] WIT 0256 0013 Miss Stratton

[329] WIT 0256 0012 Miss Stratton

> children's nurses on the BRI unit did not want to go up to the Children's Hospital because "No, they do not understand what we are doing down here".
>
> 'So I thought that was quite sad, really, and there was very much, "This is my territory. Why would I want to go up to the Children's Hospital to find out what they were doing up there?"'[330]

Communication between Helen Stratton and others

265 Miss Stratton described some of the initiatives she took:

> 'I set up a strong link with the social work department at the BRI which was mirroring the set-up at GOS. I met with Sarah Appleton, the social worker who was assigned to the cardiac unit and discussed my role. We worked well together … We decided to meet once a week to discuss parents/children who were either on the unit or were likely to come in … This link worked extremely well and she developed a rapport with the social worker at the BCH which enhanced the service we could deliver.'[331]

266 Miss Stratton expressed concern at the amount of time the social worker was able to give to Ward 5. She said that Ms Appleton was only allocated five hours a week to the unit to respond to the needs of children and adults:

> 'I did express my concerns to Fiona Thomas, who was also very concerned that the social worker was given five hours for the unit … I know for Sarah, that she was incredibly stretched and I certainly would not have asked her for more hours because she just did not have that time to give me.'[332]

267 Miss Stratton stated that in her second year:

> 'I had also started to arrange support meetings for the theatre and intensive care nurses at the BRI giving them an opportunity to talk about how difficult and upsetting it was for them to look after a child that had died. Sarah the social worker came to facilitate the meetings and the Chaplain sometimes came along as well … The feedback that I had was that the meetings were very helpful and allowed them to offload before going home.'[333]

Issues of 'territory' between Helen Vegoda and Helen Stratton

268 A number of witnesses commented on the way Mrs Vegoda and Miss Stratton appeared to relate to each other.

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[330] T46 p. 96–7 Miss Stratton

[331] WIT 0256 0005 – 0006 Miss Stratton

[332] T46 p. 58 Miss Stratton

[333] WIT 0256 0010 Miss Stratton

269 Ms Joyce Woodcraft, Senior Sister BRHSC ICU 1985–1994, said:

> 'I do not think the relationship between the two counsellors over the years was particularly warm, although I do not believe that this had an adverse impact on the information or support given to the parents.'[334]

270 However, Mrs Pratten told the Inquiry:

> 'It was clear soon after the appointment of Helen Stratton that the two support positions did not function in a complementary manner and neither post, therefore, fulfilled its full potential. This was exacerbated by the problems of the split site with different managements and a general lack of co-operation.'[335]

271 Sheila Forsythe, mother of Andrew, described how she perceived the relationship between Mrs Vegoda and Miss Stratton:

> 'I had a professional relationship with Helen Vegoda. I felt that parents either liked or disliked her – there were no half measures. At a later date Helen Stratton was appointed as a cardiac nurse. My understanding was that Helen Vegoda would deal with the parents in the Bristol Children's Hospital when they were to be counselled or diagnosed of their child's cardiac defect and Helen Stratton would deal with them in the BRI. When questions of a practical day-to-day medical nursing nature could be answered I was aware that there was tension between Helen Vegoda and Helen Stratton but equally I was not aware that this affected the care the parents received.'[336]

272 However, David Charlton, father of Hannah, spoke of meeting both Mrs Vegoda and Miss Stratton. He stated:

> 'We felt that we were into "territory issues" between them.'[337]

273 Miss Stratton was asked in evidence whether she and Helen Vegoda disagreed as to what their respective roles should be: 'I think so. I mean, we never discussed it in detail.' But she continued: 'It never affected our professional relationship that we had differences.'[338]

274 One point of difference between Mrs Vegoda and Miss Stratton was Miss Stratton's wish to attend the BRHSC so as to provide support to parents at the time of diagnosis.

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[334] WIT 0121 0006 Ms Woodcraft

[335] WIT 0269 0005 Mrs Pratten

[336] WIT 0515 0006 – 0007 Sheila Forsythe

[337] WIT 0539 0008 David Charlton

[338] T46 p. 46 Miss Stratton

275 Miss Stratton stated that following meetings at GOS with Ms Goodwin and others:

> '… I think the key thing that came across for me was that I should meet the parents at the earliest possible stage, either when they were meeting the cardiologist at the BCH, or when they saw the surgeon at the BCH.'[339]
>
> 'I also discussed this with Helen Vegoda and she did express some concern as she felt that this was quite a large part of her role. I was quite surprised at this, as I thought there were some clinical aspects which could arise from the meeting that she would not be in a position to explain. For example, if the cardiologist or surgeon had used language or referred to procedures that the parents did not understand, then I felt I would be in a better position to be able to explain this to them.'[340]

276 When Miss Stratton began to go to the BRHSC:

> '… Helen Vegoda asked me what I was doing there. I had discovered that she was not happy about my appointment as she felt that care of the parents on both sites had been part of her role.'[341]

277 Mrs Vegoda said that the fact that Miss Stratton envisaged that her role would involve regular attendance at the BRHSC was not discussed formally with her:

> 'I actually went down to outpatients one day and she was actually there, and I remembered being very confused about why she was there and why she had not said she was going to be there. There were other instances that happened where I understood from nursing staff that she had come up to the ward of the Children's Hospital to see families, or … to look at notes.
>
> 'Although we did have meetings, I tried to clarify and to raise this issue, and somehow it just was not possible to do that. It did not seem possible to have a discussion as to, you know, why she had been in outpatients and her involvement with the Children's Hospital.'[342]

278 In her written statement, Mrs Vegoda stated:

> 'I became aware of a video produced by the Heart Circle which was made available to families prior to their attendance at the BRI hospital. I was advised that the video related to Ward 5 only. I was concerned when Helen Stratton indicated on the video that she would be available to parents from the point of diagnosis to the time the family left the hospital. This was factually incorrect.'[343]

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[339] WIT 0256 0003 Miss Stratton

[340] WIT 0256 0003 Miss Stratton

[341] WIT 0256 0004 Miss Stratton

[342] T47 p. 123–4 Mrs Vegoda

[343] WIT 0192 0249 Mrs Vegoda

279 Mrs Vegoda agreed that it would have been helpful to have a cardiac liaison nurse available to families at the BRHSC, but said:

> 'I think that the difficulty was that there was a gradual breaking down of communication between Helen and myself at a point where it was not possible to discuss how our two roles were merged … I had no idea, in fact, until her statement [to the Inquiry] came out or I sat in on the Inquiry, that she saw that as part of her role and that she was very unhappy about the way in which her role was perceived. Somehow it was not possible to sit down and say, "Well, yes, that makes sense, that you sit in outpatients, so maybe we sit together, or you refer families to me". The communication was not there. I found it increasingly very difficult and very stressful.'[344]

280 Mrs Vegoda stated in her written evidence:

> 'In 1990 Helen Stratton was appointed as cardiac liaison sister and was based at the Bristol Royal Infirmary until she left in 1993. As a qualified and experienced nurse, Helen's role was focused on information, support and counselling to families in respect of the child's condition, diagnosis and prognosis whilst at the BRI.'[345]

She stated that following Miss Stratton's appointment, she [Mrs Vegoda] spent most of her time in the BRHSC unless she was asked to visit families in the BRI. She and Miss Stratton would hand over counselling roles when the child was transferred from one hospital to the other.[346]

281 She estimated that prior to Miss Stratton's appointment she would go to Ward 5 at the BRI approximately twice and sometimes three times per day. Asked whether she thought that Miss Stratton, or someone in Miss Stratton's post, by taking over her work at the BRI, was diminishing or reducing the importance of her role, she said:

> 'No, I really did not. I was very aware that first of all I felt being in two places, it was very far from ideal. I was very aware that I could not work on Ward 5 in the way that I liked working with families in the Children's Hospital, which was a mixture of quite a formal approach with just saying, "This is my room, if you want to come and knock on the door, you are welcome".
>
> 'I also felt that I did not have the background to help families with the information and I felt that it needed somebody down there, apart from the fact that I was very busy and it was quite difficult trying to meet the needs of families down on Ward 5 because of open-heart surgery, which was a very, very stressful time, and obviously

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[344] T47 p. 124–5 Mrs Vegoda

[345] WIT 0192 0004 Mrs Vegoda

[346] WIT 0192 0004 Mrs Vegoda

> bereavements as well, dealing with the families at the BRHSC. I welcomed that post.[347]
>
> 'My understanding of her post was that she was I thought an experienced, qualified nurse; that she would be based down on Ward 5; that she would be there to both support the parents at the time when the child entered Ward 5, just pre-operatively, and would be there to keep them informed about the child's medical condition or could be a contact with medical staff, nursing staff. I was not particularly aware of the liaison role with GPs and health visitors routinely.'[348]

282 Mrs Vegoda said that she had not been aware, until Miss Stratton gave evidence to the Inquiry, that Miss Stratton had felt that her appearance at the BRHSC was seen as encroaching on or threatening Mrs Vegoda's role:

> 'I can only say that it is with great sadness, because I feel that we were not able to communicate but we could have been mutually supportive, had that been the case, but her way of behaving with me was just very, very undermining, and I could not deal with that …
>
> 'I am not suggesting that her work with the families was not, but her actual professional relationship with me, her personal relationship with me, was I think bordering on not being professional, and I think it was more than cold.'[349]

283 Mrs Vegoda prepared a note in 1991[350] for an informal meeting with Mrs Vass, entitled 'Areas of Concern'.[351] This note lists concerns about her relationship with Miss Stratton, such as:

> 'Being told it was inappropriate for me to visit a family on Ward 5 whom I knew longer than her …
>
> 'Not wanting me to know that she was on holiday, and asking that this information be withheld from me.
>
> 'Talking to staff on the Ward about not thinking it appropriate that I visit Ward 5.
>
> 'Refusing to discuss differences or points of disagreement, and cancelling our arranged weekly meetings on several occasions at the last moment by getting someone else to say that she was not available when in fact she was.
>
> 'Lack of communication about families at the unit whom I knew …

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[347] T47 p. 120 Mrs Vegoda

[348] T47 p. 122 Mrs Vegoda

[349] T47 p. 133–4 Mrs Vegoda

[350] The note was not dated and the precise date is not known

[351] WIT 0192 0248 and WIT 0192 0250 Mrs Vegoda

> ‘Not communicating about the progress or welfare of children or important information regarding dates of operation even though it had been agreed that she would.
>
> ‘Lack of communication on her research, or her role in setting up a support group for nurses on ITU at the BCH.
>
> ‘Not replying to notes referring to patients visiting Ward 5.’

Meeting on 9 January 1992

284 As a result of the perceived differences in roles, and of working difficulties, discussions were held in an attempt to resolve the position. Evidence to the Inquiry focused on a meeting on 9 January 1992 that resulted in a separation and delineation of the two roles.

285 Miss Stratton said:

> ‘I did express concerns [prior to the meeting] that I had a problem accepting that Helen Vegoda, who had a very different role to mine in my perception, was doing a job at the Children’s Hospital which, for some reason, did not allow her to come and do that job at the Bristol Royal Infirmary …
>
> ‘I had this slightly idealistic view that both our roles, in my perception of what they were, could have worked very well together if she had carried out her role at the Children’s Hospital and at the Bristol Royal Infirmary, and I had carried out my liaison role at the Bristol Royal Infirmary and Children’s Hospital.
>
> ‘But because of the strong feeling that I could not go to the Children’s Hospital and Helen Vegoda could come to the BRI but, I think, as it says here, only to visit families she already was involved with, I found that was an issue.’[352]

286 Mr Wisheart stated:

> ‘The background to this meeting was that Helen Vegoda was established as a paediatric cardiac counsellor in the BRHSC and the BRI. Helen Stratton was newly appointed as a Paediatric Cardiac Liaison Nurse based mainly at the BRI. The two Helens needed to set out how they would work together in order to fulfil their professional responsibilities. Instead, there was a clash of personalities and some polarisation of viewpoint between them. This led to the meeting … the object of which was to help Helen Vegoda and Helen Stratton resolve their differences and reach a working understanding.

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[352] T46 p. 88 Miss Stratton

> ‘It was not my role to reinforce the polarisation by adopting one of the entrenched positions, rather to facilitate the development of a working understanding by supporting *both* counsellors.’[353]

287 Miss Stratton stated:

> ‘Mr Wisheart chaired the meeting. I put forward my understanding of my role and the outcome of my visit to GOS and how I thought it would be beneficial for both of us to work on this as my perception was that my role was very different from her role. I do not recall that there was any support from either Julia [Thomas] or Mr [Wisheart] and I think that they felt that if Helen Vegoda was unhappy with me going to outpatients, then I should not go there … They agreed that things should stay as they were and that I should meet on a weekly basis with Helen Vegoda to discuss the parents and children who were coming to BRI …’[354]

She confirmed that after the meeting they had weekly meetings.[355]

288 She told the Inquiry:

> ‘… I think there were mixed feelings and possibly an indifference to my role which made me quite a weak player in the framework of everything.[356] And I just got the distinct impression that if I had voiced a view or an opinion … [it] would be treated with some indifference or, after my experience of trying to get to go to the Children’s Hospital, where I felt quite strongly I was “put back in my box”, for want of another expression, I was not keen to go down that road again.’[357]

289 Following the meeting, Mrs Vass wrote to Mrs Vegoda and Miss Stratton to review their discussions. The letter is addressed to: ‘Helen Vegoda, Family Support Worker, BCH’ and ‘Helen Stratton, Family Support Worker, BRI’.

The letter said:

> ‘To recap on our discussions to date, the team covering both Ward 5 and the Bristol Royal Hospital for Sick Children … have been aware of a difficulty in achieving smooth free-flow communications and in generally understanding and accepting each others’ roles.
>
> ‘In previous talks we have sought to assist you both in defining your individual roles … It was agreed that Helen Vegoda would only visit families she was already professionally well involved with, on their admission to Ward 5, once, and then “hand over” the supportive care to Helen Stratton. This would be a rigid

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[353] WIT 0256 0110 Mr Wisheart (emphasis in original)

[354] WIT 0256 0004 Miss Stratton

[355] T46 p. 92 Miss Stratton

[356] Commenting on Miss Stratton’s description of herself as a ‘weak player’, Mr Wisheart said: ‘This was not my impression of her as a senior nurse, a sister and an assertive person’; see WIT 0256 0115

[357] T46 p. 77–8 Miss Stratton

> understanding unless the family or either of you felt strongly that it should be otherwise, in which case further visits are acceptable. It was also agreed that Helen Vegoda would not make enquiries regarding families on Ward 5, of the nursing staff, as they found this time consuming, but would speak to Helen Stratton …
>
> ‘In return Helen Stratton would do the very same and families transferred to the Bristol Royal Hospital for Sick Children would be “handed over” to Helen Vegoda’s care unless any party involved felt strongly that Helen Stratton should continue to visit …
>
> ‘Both of you have ample workload in your respective areas. It has been agreed all round that these roles are “similar but extremely different” and because of this, the need for good communication is essential.’[358]

290 This demarcation was agreed, despite the fact that both appeared to agree that there was a role for Miss Stratton at the BRHSC. Mrs Vegoda agreed that it would have been helpful for the Cardiac Liaison Nurse to attend the BRHSC. But she said:

> ‘My memory of that period was that the level of non-communication from Helen to myself was really quite extreme and there was also certainly in a sense for me, that I was undervalued professionally and personally … by Helen, and I can only imagine that that solution was because we could not, sadly, work in a joint role together, or actually be together at that period …’[359]

291 Mrs Vegoda said that whilst she and Miss Stratton continued to have weekly meetings, those meetings were probably to discuss families, rather than the greater issue of their inability to work together:

> ‘I can only say that it was a gradual breakdown of communication in the sense that Helen seemed to be doing things, arranging meetings, without me being aware of this, and certainly I was completely unaware of the fact that she clearly, from what she was saying yesterday [in evidence to the Inquiry], was under a lot of stress and very confused about and felt very unsupported in the role. We did not look at her role and my role at all. Somehow – I do not want to sound personal because it is maybe not the arena to do that, but I just found her manner to me impossible.’[360]

292 Of the suggestion that their roles were ‘similar but extremely different’ Mrs Vegoda said:

> ‘Helen was a nurse, and I think an extremely experienced nurse, and my background was obviously different. I think there would have been an area in the middle where we would both have had a role in supporting, … “counselling” families. Helen, obviously with her nursing background would have meant she was

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[358] WIT 0192 0110 – 0111; letter dated 14 January 1992 to Mrs Vegoda and Miss Stratton

[359] T47 p. 127 Mrs Vegoda

[360] T47 p. 128 Mrs Vegoda

> there helping families with the medical nursing aspect. I was more on the emotional, psychological side. But in the middle there would have been some common area, for example, maybe perhaps information giving, perhaps an element of liaison with the community, or preparation to go into the community. And the support aspect. So although our jobs were very different, inevitably, because we were dealing with families, there must have been some common ground.'[361]

293 Mr Wisheart stated in his evidence to the Inquiry:

> 'Helen Stratton expresses the view that because her wishes did not prevail at the meeting, the others present had a wish to continue doing things the way that they had always been done. I disagree with that view. Her own appointment was one of the innovative steps we took as the service evolved.'[362]

Support for Helen Stratton

294 Miss Stratton described the room provided to her within the BRI:

> 'I did not have an office when I started my job, and the BRI gave me a linen cupboard which the Heart Circle painted and furnished with a desk and some comfortable chairs for parents to use.'[363]

295 Michael Parsons, father of Mia, referred to the room as:

> '… a small box room which was full of all sorts of stuff and had a small settee. It was effectively a junk room'.[364]

In his evidence to the Inquiry he stated:

> 'The whole sequence of events that had transpired since we had been told of Mia's death was deeply upsetting … there was being placed in a junk room where we were expected to say goodbye to Mia and finally I got the distinct impression that we were being rushed out of the hospital before we were ready to go … I must stress that all this took place in the box room and Mia was still lying in the Moses basket.'[365]

296 Asked whether she found herself being pushed into acting as a counsellor, Miss Stratton said:

> 'I think increasingly it did become that, … My personal definition of counselling is someone who has a professional qualification to carry that out. I recognised I did not have that qualification. That is when I sought advice and help from Dr Gardner

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[361] T47 p. 129 Mrs Vegoda

[362] WIT 0256 0115 Mr Wisheart

[363] WIT 0256 0010 Miss Stratton

[364] WIT 0010 0008 Michael Parsons

[365] WIT 0010 0008 – 0009 Michael Parsons

> as to how I should support, counsel these parents, given that I did not have a mental health background or counselling, and I took advice from her.
>
> '… but there was nobody else to do it, I felt I could not just walk away from that role.'[366]

297 Mrs Pratten stated:

> 'Sister Julia Thomas was responsible for setting up this post with The Heart Circle … After [she] resigned as Nurse Manager, I never felt that the management of the Unit appreciated the importance of the post of Liaison Sister, and with voluntary funding considered the post to be supernumerary. They did not give Helen Stratton the support she needed in such a demanding and emotionally draining position. Helen was on call for parents almost twenty-four hours a day and she also gave support to the nursing staff.'[367]

298 Miss Stratton told the Inquiry of her meetings with Mrs Pratten:

> 'I used to meet with her two or three times a week at her house and we would sit and discuss issues, but we never had minutes or a formal agenda …'[368]

299 She stated that she began to be concerned both about the time that children spent in the operating theatre and in intensive care,[369] and about the hours that she was working:

> 'I also found I was spending an increasing amount of time dealing with bereaved parents and I asked Mary Goodwin [from Great Ormond Street] how she coped with dealing with bereaved parents on such a regular basis and in particular working late into the evening. I told Mary that I would start a shift at 7.30 am going down to the theatre with the parents and often be there until as late as 11.00 pm waiting for the child to come back from theatre.'[370]

300 She compared her role with that of Ms Goodwin and of Susie Hutchinson, the Cardiac Liaison Nurse at Birmingham Children's Hospital:

> 'Neither … went with the parents to surgery on a regular basis and did not consider it their role to be there when the child returned. Both of them told me that children with similar operations in their units would be back at lunchtime or early afternoon in their hospitals … Both Susie and Mary could call on a strong multi-disciplinary team for support. This included a dedicated accommodation officer, social worker and psychiatric support if necessary.'[371]

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[366] T46 p. 53–4 Miss Stratton

[367] WIT 0269 0004 Mrs Pratten

[368] T46 p. 155 Miss Stratton

[369] See paras 301 and 306 for details of Miss Stratton's concerns about the paediatric cardiac surgical service

[370] WIT 0256 0010 Miss Stratton

[371] WIT 0256 0011 Miss Stratton

301 She stated:

> 'The switch programme started in early 1992. I cannot be precise about the date.[372] It was a combination of the deaths from this programme together with the other concerns that led me to ask Jean [Pratten] if Dr Freda Gardner could supervise my work, help me cope with the extreme exposure to distressed parents, and also help me manage my time better. I think I was beginning to feel out of my depth in my ability to deal on such a regular basis with distressed parents and other demands on the unit. Freda said that I couldn't spend my time seeing distressed parents all day every day because that made me less effective. She pointed out to me that my role was not that of a psychologist or of a bereavement counsellor but that's what I seemed to be spending the majority of my time doing.'[373]

302 Of the support she received from Dr Gardner[374] she said:

> 'I sought supervision from Dr Gardner, in essence because, without a counselling qualification, I felt that I was dealing with often situations that I was unqualified to deal with, and whilst there was nobody else to do it, I went to her for advice and support. I felt, along with trying to support the theatre nurses and the nurses on the unit, I needed to have some support myself.'[375]
>
> 'She helped me in coping … both by giving me advice on how to deal with parents who were extremely distressed, but also advice and help on how to deal with my own feelings, and part of that was to remain always very professional, always to do my job to the best of my ability, and if I thought for one minute that I was unable to do that, I was to withdraw from the ward and the situation, which is what I did.'[376]

303 She stated that by the third year of her post:

> '… I felt unable to continue going to theatre with the parents and children as I was emotionally drained. I ensured that one of the other nurses in the nursery was able to carry out this task.'[377]

304 In her written statement Miss Stratton dealt with her decision to leave Bristol:

> 'Around June/July 1993, I told Jean that at the end of the funding for my post in November I would be looking for other employment. I was beginning to make enquiries about other jobs …[378] Jean was kind enough to say that the Heart Circle

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[372] Mr Dhasmana clarified the reference: 'I think she probably means the neonatal Switch programme, which started in January 1992'; WIT 0256 0109 Mr Dhasmana

[373] WIT 0256 0012 Miss Stratton

[374] She explained that she was introduced to Dr Gardner by Mrs Pratten, and acted as a liaison between Dr Gardner and parents for the purposes of Dr Gardner's PhD thesis. See T46 p. 56 Miss Stratton

[375] T46 p. 101 Miss Stratton

[376] T46 p. 137 Miss Stratton

[377] WIT 0256 0012 Miss Stratton

[378] In a later statement to the Inquiry Helen Stratton stated: 'I do recall that in early May 1993 I attended for a job interview at the Churchill Hospital in Oxford. It is possible that my interview took place on 6 May.' See WIT 0256 0126 Miss Stratton

> would continue the funding of my post if I hadn't found a job in November. In the event, I found a job in February 1994 and the Heart Circle employed me until then. I felt a great loyalty to the Heart Circle and Jean Pratten, and I was determined to see out the 3-year funding …'[379]

305 She also explained:

> 'I remember that in the Summer of 1993 I took two periods of 2 weeks annual leave in fairly rapid succession. I have reason to remember this because it was very unusual to take so much annual leave in so short a period; it used up my entire annual leave entitlement for that year … I think there is a real likelihood that I was on annual leave for the two weeks beginning Monday 5 July 1993 and ending Friday 16 July 1993 … My second period of annual leave that summer took place in early August …'[380]

306 Miss Stratton appeared in a BBC Television *'Panorama'* programme screened on 1 June 1998. In the interview she said:

> 'We would get a call from theatre to say that they were ready and we would go down … a very, very emotional difficult time for parents, incredibly difficult … and we'd go down to the theatre and they'd normally go into the anaesthetic room and they'd have an opportunity to give the baby a kiss and say a few words, etc. …
>
> 'There was always this thought in the background that they were clinging onto the fact that they would see their baby later – that in eight hours' time their baby would be coming back …
>
> '… I think you have to understand that in a situation that is so emotionally charged like that, where people have put their trust, faith and hope in the surgeons there, that if I had in that situation actually said, "I think we should go back upstairs and take the baby back upstairs …" Yes, of course it was what I wanted to say. I wanted to pick the baby up and just run out of the operating theatre, bundle it into the car with the parents and take them anywhere else.'[381]

307 Describing her approach towards the end of her post she said:

> '… I think it is fair to say that on advice from Dr Gardner, I had withdrawn my input to a level where I was not enthusiastic …'[382]

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[379] WIT 0256 0013 Miss Stratton

[380] WIT 0256 0126 – 0127 Miss Stratton

[381] WIT 0256 0108 Miss Stratton

[382] T46 p. 131 Miss Stratton

Comment on the service provided by Helen Stratton

308 Paula Jordan, mother of Joe, said that she 'developed a close relationship with the "Cardiac Liaison Sister" Helen Stratton, whose job was to explain things to me and keep me informed of what was happening.'[383]

In her oral evidence the following exchange took place:

> 'A. When I first heard I was going to the BRI, I was slightly daunted in that we had always been to the Children's Hospital and I knew where I was, I knew where the sandwich machine was and I knew where I slept and I knew where the wards were, so I felt quite comfortable being there. They told me this was at the BRI and I felt slightly daunted, I do not know where I have to go and all that. But I had a letter before with a contact name and number of someone I could ring, so I rang up a few days before and introduced myself and said I was coming up. She expected me, and she reassured me about the hospital and when we got there, I felt a lot happier, having had the contact before.
>
> 'Q. Contact with whom? Who was showing you around or assisting you there?
>
> 'A. A cardiac liaison, I do not know if they call her a sister, officer or nurse, Helen Stratton.
>
> 'Q. What was her role?
>
> 'A. She was basically a go-between, between medical staff and parents, so if there is anything you did not know or did not understand, you could ask her and if she did not know or could understand, she would find out for you.
>
> 'Q. Was that helpful?
>
> 'A. Absolutely wonderful.'[384]

309 Michael Parsons said in his oral evidence:

> 'Helen [Stratton], I must say, worked very, very hard and had a very difficult job to do.'[385]

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[383] WIT 0026 0006 – 0007 Paula Jordan

[384] T4 p. 27–8 Paula Jordan

[385] T2 p. 94 Michael Parsons

310 Phillip Wagstaff, father of Amy, said that he was shown around the ICU by Helen Stratton the night before the operation. He was asked as to his understanding of her role:

> ‘A. I understood she was actually employed by the Children’s Heart Circle, which is a charity and her role really was to sort of help parents through the ordeal, really, to liaise with the parents and the hospital staff.
>
> ‘Q. Was that a helpful exercise, being shown around the ITU?
>
> ‘A. Yes, it was.
>
> ‘Q. Why?
>
> ‘A. I think it really prepared us for the shock of seeing Amy with all the tubes and pipes and everything coming out of her, so at least we knew what to expect the following day.’[386]

311 Mrs Pratten stated:

> ‘On reflection I believe a three-year contract was too long for the emotional demands on any one person. Because of the absence of clinical supervision and professional support, I asked Dr Freda Gardner if she would provide this for Helen on behalf of the Heart Circle, and she agreed to do so …’[387]

312 Mr Graham Brant, Senior Staff Nurse, BRI, 1991–1993, stated:

> ‘Helen Stratton had an extremely difficult job providing support and liaison between the parents and staff. She had to spread her time evenly which meant that at times she was unavailable when needed. She would hold debriefing sessions for staff after a child died, but these often did not take place until two or three days later which reduced the debriefing effect. Helen tried to see all the parents and children pre and post op but often had little time to spend with them. Helen liaised with Helen Vegoda at the BRHSC but I felt there was often a tension between their personalities.’[388]

313 Dr Gardner stated:

> ‘Helen Stratton provided an extremely professional service. She made enormous efforts to educate herself when she first came to the post. She found quite early on that her own form of support was very different from that of Helen Vegoda. It soon became clear that the difference in approach made it almost impossible for co-operative working. I was asked by Mrs Jean Pratten to offer supervision to

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[386] T2 p. 27 Phillip Wagstaff

[387] WIT 0269 0005 Mrs Pratten

[388] WIT 0513 0005 Mr Brant

> Helen Stratton, which I did … The situation over time became very stressful. There were times when Helen Stratton was out of her depth (it is fair to say that anyone without significant experience in mental healthcare would have found the situation similarly impossibly difficult). I have no doubt that in these situations she always did her best, and sometimes that was to withdraw from some families …
>
> ‘I believe it to be the case that it would have been impossible for her to have provided a better service given the demands at that time.’[389]
>
> ‘She left the service extremely distressed and I have no doubt that it may be some time before she recovers from what she experienced as a profoundly distressing period of her life.’[390]

314 David Charlton, father of Hannah who was operated on at the BRI in November 1992:

> ‘… Helen Stratton was quite supportive in a practical, but not personable or approachable way … She was going through what I imagine were deemed to be effective procedures, but without any real sympathy.’[391]

315 Stephen Willis, father of Daniel who was operated on at the BRI in May 1993, referred to discussions with Miss Stratton whilst Daniel was in surgery:

> ‘I have no alternative but to say that the way Helen Stratton handled that interview was insensitive and distressing … and indeed was the worst moment that we were to experience other than being told that Daniel had died.’[392]

316 Kenneth and Susan Darbyshire, parents of Oliver who was operated on at the BRI in July 1993:

> ‘She’s supposed to be a counsellor, but she really did not know how to strike up a chord with parents. One thing that came across with her was a very strong *lack of empathy*…
>
> ‘Looking back on it now, I have often wondered whether her approach towards parents was deliberate, to stop parents from seeing her, or bothering her. Because it worked with us.’[393]

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[389] WIT 0534 0006 Dr Gardner

[390] WIT 0534 0007 Dr Gardner

[391] WIT 0539 0010 David Charlton

[392] WIT 0285 0010 Stephen Willis

[393] WIT 0125 0016 Kenneth Darbyshire (emphasis in original)

317 Erica Pottage, mother of Thomas who was operated on at the BRI in July 1993:

> 'Helen Stratton said most parents in these circumstances want to go home straight away, so we packed up our belongings and my husband drove us back to Teignmouth.'[394]

318 Paul Bradley, father of Bethan who was operated on at the BRI in August 1993:

> '… Helen Stratton did not readily make herself available and was not very proactive. She did not warrant our confidence as someone to confide in. She seemed uneasy with us and with the situation we were in. It was as if she was not sure what to say … She did not command our confidence as a friend or someone who could counsel us through this traumatic period … It was not clear who we could direct our concerns to and if there was such a person it wasn't clear to us who that person was. Our stay at Bristol Royal Infirmary was a deeply lonely experience.'[395]

Split site

319 Commenting on the effect of the split site Miss Stratton said:

> 'I was also aware that there was this cavern between the nurses at the BRI and the nurses at the Children's Hospital and I wanted in some small way to see how that could be improved … I think there were territorial issues …'[396]

320 In answer to a question from Mrs Howard as to whether the split site compromised children's care, she said:

> 'I think the split site meant that there was a communication problem … not between Helen Vegoda and I in as much as we met on a regular basis, but I think with the nursing staff, just because they were not both in the same hospital, there were inevitably communication problems.'[397]

321 She continued:

> '… I think if you asked parents whether, at the times of diagnosis they would have benefited from having a nurse there who could explain the condition to them, could explain what the surgery would involve, could start to prepare them for intensive care and what that meant, I think that most parents would say yes.'[398]

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[394] WIT 0260 0003 – 0004 Erica Pottage

[395] WIT 0229 0020 Paul Bradley

[396] T46 p. 96–7 Miss Stratton

[397] T46 p. 164–5 Miss Stratton

[398] T46 p. 165–6 Miss Stratton

After the departure of Helen Stratton

322 Asked what happened to Miss Stratton's post between her departure in February 1994 and when the paediatric cardiac service was united at the BRHSC in October 1995, Mrs Pratten told the Inquiry:

> 'The post went, and I was concerned that there was no thought of putting it back in place, and I was very concerned that all that she had achieved would be lost … I spoke to Dr Gardner and asked her to do research on the needs of families and children, because although I was saying that I thought she had done a good job by and large … I had no documentation to prove it, and I felt that the only way forward, really, was to get a research document looking appropriately at the needs of children and their families.'[399]

323 Dr Gardner produced a report, *'Assessment of the Psychosocial Needs of Children with Heart Disease and their Families',* based on questionnaires completed by 150 parents. The paper considered the effectiveness of the services then being offered and suggested areas of improvement.

324 The report concluded:

> 'The survey revealed the parents' need for more information from medical or nursing staff. They expressed the need for additional reassurance and information, and advice on the care of their child before surgery and following discharge.
>
> 'At an emotional level, parents described periods of great distress and expressed the need for help which was in some cases met and in others not.
>
> 'Practical community-based advice was also needed such as information about financial support and help with other children at home.
>
> 'There was also evidence that children are discharged from hospital without adequate provision in advance made for psychological, emotional and in some cases practical support.'[400]

325 Dr Gardner recommended:

> 'The need for information however, requires the appointment of a Cardiac Liaison Nurse Specialist which would also bring the service in line with the Department of Health guidelines and other supra regional cardiac services throughout the United Kingdom. Many centres provide specialist nurses who provide information and explanation and provide a liaison service and co-ordinate community care. This is a service that Bristol currently lacks and the evidence for its need is compelling.'[401]

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[399] T47 p. 40 Mrs Pratten

[400] WIT 0269 0052; Dr Gardner's report

[401] WIT 0269 0052; Dr Gardner's report

326 In the report she stated that it could be presumed that all parents would require the skills of the Cardiac Liaison Nurse Specialist at the time of diagnosis and surgery, and recommended that referrals be made at that stage. She recommended that additional emotional and practical support could be given by the Family Support Worker, and financial or social support by a social worker. She stated:

> 'It is important to distinguish between the roles of the Cardiac Liaison Nurse Specialist and Family Support Worker. The Cardiac Liaison Nurse Specialist is primarily involved with all medical information and counselling concerning the condition of the child. In this way the Family Support Worker is released to offer emotional and practical support to the many families who need this form of care.'[402]

327 Dr Gardner also emphasised the continued need for a play therapist.[403]

328 In distinguishing between the two posts, she recommended that the Cardiac Liaison Nurse Specialist:

> '… would be responsible for providing parents with medical and nursing information throughout the period from the initial referral to the first outpatient appointment following corrective surgery. The nurse would be able to reinforce, repeat and supplement the information from the consultant involved with the care of the child, presenting it over a greater period of time and in terms that parents will clearly understand. They would also liaise between hospital and community, planning appropriately for admission and discharge.
>
> 'Some parents need additional help beyond that period and the cardiac nurse specialist would be able to assess any need and refer the family to an appropriate community professional. It is these important services, as described by the Department of Health, that are currently not provided in Bristol and diminish the quality of care … There is clear evidence from other centres such as Birmingham, Great Ormond Street and Southampton of the success of such a post.'[404]

329 As regards the post of Family Support Worker, she recommended:

> '… it is absolutely clear from our survey that the support provided by this service is of great value to some parents …
>
> 'In releasing the post holder from the medical aspects of care (such as preoperative talks) the many services that are currently not consistently provided can be fulfilled.

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[402] WIT 0269 0053; Dr Gardner's report

[403] WIT 0269 0054; Dr Gardner's report

[404] WIT 0269 0053 – 0054; Dr Gardner's report

> '… it was evident that many families were seeking counselling in conjunction with information as distinct from social and emotional support. This was particularly true at the time of diagnosis and in intensive care. This need for information cannot be met by the Family Support Worker. Removing this expectation from the post would release considerable time for the vitally important emotional and practical support that is needed by many families.'[405]

330 Dr Gardner also recommended:

> 'Any professional providing psychosocial support should in turn be supported and provided with professional supervision. There is currently no provision for this.
>
> 'Support for all other members of staff should be available either formally or informally. The benefits of staff support are well documented and should be provided, particularly for nurses in intensive care.'[406]

331 Describing Dr Gardner's paper, Mrs Pratten said that it:

> '… proved clearly that the post was needed … As a result of that research we offered to fund a post in the Children's Hospital [where the service had by then moved], which we did, and after 6 months of that post, the Trust took it over, so it is now a National Health Service post.'[407]

332 Mrs Pratten explained that Kathy Selway initially took the new post, and was the conflation of the posts previously held by Mrs Vegoda and Miss Stratton.[408]

333 Dr Gardner also stated:

> 'Towards the end of 1995, Rachel Ferris … made it clear that she wanted a part-time psychology service for the cardiac unit. I became formally clinically involved from then.'[409]

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[405] WIT 0269 0054; Dr Gardner's report

[406] WIT 0269 0055; Dr Gardner's report

[407] T47 p. 42 Mrs Pratten

[408] T47 p. 44. Mrs Vegoda told the Inquiry that in September 1996 she took on a new role at the BRHSC. She said: 'In 1996 I took on a new role in the Children's Hospital of Counsellor in Child and Family Support, offering counselling and support to families of children not previously receiving counselling. A cardiac liaison nurse was appointed to the cardiac team.' See WIT 0192 0005. Mrs Vegoda described her present role in which she provides child and family support throughout the hospital, although she does not cover oncology and cardiac services as they now have their own support systems, and that it was the intention of her present post to offer some support and counselling and help to families where counselling had not previously been provided. See T47 p. 99. In relation to facilities currently available at the BRHSC Cardiac Unit she said: 'There is a cardiac liaison nurse in place. … Having said that, I am occasionally specifically asked by either nursing staff or somebody in the hospital to see a particular cardiac family, either because they have requested counselling, or because the nursing staff feel that they need more psychological emotional input than can then be provided.' See T47 p. 172–3

[409] WIT 0534 0001 – 0002 Dr Gardner

Guidance and expert evidence on support and counselling

Governmental guidance

334 In her paper for the Inquiry, Dr Humphrey provided a brief summary[410] of published guidance during the period of the Inquiry's Terms of Reference. She wrote:

> 'The 1959 Platt Report on the welfare of children in hospital led to radical changes in, among other things, access and provision for parents …
>
> 'Over the past few years there has been an increasing consensus between government, professional and voluntary organisations on the benefits of parental participation in "family-centred" care. More recent government guidelines in this area published in 1984,[411] 1991,[412] and more recently the 1996 "Children's Charter"[413] reflect this philosophy, giving considerable attention to enabling parents to be with their children in hospital and ensuring access to information and improved contact with hospital staff to facilitate this involvement … In contrast, there appears to be relatively little detailed advice or recommendations specifically about the provision of psychosocial support or counselling for parents of children in hospital except in the context of life-threatening illness (which is not defined) and bereavement. The 1991 report on the welfare of children and young people in hospital represents the first comprehensive set of recommendations from the Department of Health in this area since the Platt report.'[414]

1991 guidance – *'The Welfare of Children and Young People in Hospital'*

335 Dr Humphrey noted the terms of the guidance issued by the DoH in 1991. She wrote that this:

> '… specifies that "Every children's hospital or children's division of a district general hospital must provide facilities to enable the mother and other members of the family to sustain the normal relationship to which the child is accustomed at home", such as accommodation and the use of a sitting room and kitchen, and recommends that "… hospitals collaborate with voluntary organisations helping families … which might also be able to provide accommodation for families near regional centres in some specialties."'[415]

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[410] INQ 0025 0012 – 0017; Dr Humphrey's paper

[411] DHSS. *'Hospital Accommodation for Children'*, Health Building Note 23, HMSO, 1984

[412] DOH. *'The Welfare of Children and Young People in Hospital'*, HMSO, 1991

[413] DOH. *'Services for Children and Young People'*, NHS Executive, 1996

[414] INQ 0025 0012; 'Platt Report', Ministry of Health (Chairman H Platt): *'Report on the Welfare of Children in Hospital'*, HMSO, 1959

[415] INQ 0025 0013; Dr Humphrey's paper

336 She noted that the guidelines also advised hospitals to:

> '… ensure that the Hospital Travel Costs Scheme is publicised within the children's department and that a named member of staff is designated to help advise families on benefits which may be available to help with travel costs. Where a family's financial situation is particularly difficult, parents should be made aware of any assistance the hospital social worker can provide …'

and recommended the agreement of service specifications which:

> '… recognise that parents and members of the immediate family are not visitors, encourage and assist them to be with their child at all times (especially those that are most stressful, i.e. during anaesthesia, treatments, investigations and during post-operative recovery) and enable them to give continuous love, care, comfort and support for their child.'[416]

337 In respect of 'life-threatening illness', the guidance:

> '… encourages health authorities and hospitals to establish links with voluntary organisations active in their areas to achieve maximum co-operation in the planning and organisation of services like social work support. It also recommends that those involved in agreeing contracts should ensure that:
>
> 'all staff are sensitive to the needs of children and their families … and are able to draw upon staff specifically trained in care and counselling;
>
> 'parents are informed in an appropriate manner, as soon as possible of their child's condition and given every opportunity to talk through their feelings;
>
> 'care is taken not to "avoid" parents whose child is dying, while at the same time recognising the need for privacy;
>
> 'where children are taken home, advice is available to parents on the help available from statutory or voluntary agencies to ensure ongoing support and counselling for as long as necessary;
>
> 'parents have the opportunity to return to the hospital to find out anything further they wish to know about any aspect of their child's illness, care or treatment.'[417]

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[416] INQ 0025 0013; Dr Humphrey's paper

[417] INQ 0025 0014; Dr Humphrey's paper

338 In relation to the death of a child, the guidance:

> '… states that it is essential that parents/carers are helped to cope with the sense of loss and grief and also given practical assistance to help them make necessary decisions. Health authorities and hospitals are advised to ensure that:
>
> 'a member of staff trained in care and counselling is designated to give families, including siblings, all the necessary support including help with the arrangement of bereavement counselling and practical issues like burial arrangements;
>
> 'the results of any post mortem investigation are conveyed in a sympathetic manner to the family…;
>
> 'the family's GP is informed as soon as possible so that, as necessary, the GP can help them cope with the medical effects of bereavement.'[418]

Non-governmental guidance

339 Dr Humphrey also commented on guidance and recommendations from non-governmental sources. She wrote:

> '… a number of professional and voluntary bodies have made recommendations in recent years concerning the care of children in hospital. Most of these endorse or reiterate the standards contained in the DoH guidance in relation to parental involvement and support.'[419]

340 She set out those that went into more detail or made additional recommendations. She noted that the British Paediatric Association's 1995 report *'Tertiary Services for Children and Young People'*:[420]

> '… points up the "vital role" of the specialist social worker … It observes that in some regions, specialist social worker posts have been reduced or discontinued because of new funding arrangements.'[421]

341 She also noted that Action for Sick Children published recommendations *'Setting Standards for Children Undergoing Surgery'* in 1994[422] which included guidance in relation to parents' needs, such as the need for information about wards and hospital facilities on admission, and support for parents. Recommendations included the provision of support for:

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[418] INQ 0025 0014 – 0015; Dr Humphrey's paper

[419] INQ 0025 0015; Dr Humphrey's paper

[420] British Paediatric Association. *'Tertiary Services for Children and Young People'*, 1995

[421] INQ 0025 0015; Dr Humphrey's paper

[422] Hogg C. *'Setting Standards for Children Undergoing Surgery'*, Action for Sick Children, 1994

> '… link workers to help prepare families from minority communities and help them to express their wishes and anxieties and to ask questions;
>
> 'for parents who may become distressed and anxious once the child is unconscious.'[423]

342 Dr Humphrey noted that:

> 'In 1988, a working party involving the British Paediatric Association, the King's Fund and the National Association of Health Authorities produced guidelines on the care of dying children and their families.[424] These go into considerable detail into the support needs of parents at all stages from diagnosis to bereavement including, for example, the need to …
>
> 'ensure good communication between parents and professionals;
>
> 'ensure that parents have adequate finance;
>
> 'ensure that parents are aware of the range of people (and self-help groups), both in hospital and in the community, who might help by listening and talking;
>
> 'give parents the opportunity to talk to other parents in a similar situation;
>
> 'offer continuity, friendship and sensitive support responding to individual needs.
>
> 'The guidelines also suggest mechanisms for ensuring that these principles are translated into practice through, for example, education and support of staff involved.'[425]

Expert evidence

343 In addition to the oral evidence of Mrs Vegoda, Miss Stratton, the Reverend Cermakova and Mrs Pratten, the Inquiry heard evidence from Mrs Mandelson, Manager and Senior Counsellor at the Alder Centre, a centre based at Alder Hey Children's Hospital, Liverpool to offer support and counselling to anyone affected by the death of a child.

344 Mrs Mandelson told the Inquiry that the Centre had been open for ten years and provided a range of services to parents who had suffered bereavement, from parents who have lost a child through miscarriage, to those who had experienced the death of an adult child. The Centre also offers training and consultation to other professionals and carers who may be supporting bereaved families.[426]

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[423] INQ 0025 0015 – 0016; Dr Humphrey's paper

[424] British Paediatric Association, King Edward's Hospital Fund for London, National Association of Health Authorities. *'The Care of Dying Children and their Families'*, 1988

[425] INQ 0025 0016 – 0017; Dr Humphrey's paper

[426] T44 p. 11 Mrs Mandelson

345 In her evidence to the Inquiry, Mrs Mandelson commented:

> 'I do feel however that when we are talking about loss and grief work we need to recognise that it does not only apply to families who have lost a child but families who, when their child is diagnosed as having a life threatening condition, can find themselves dealing with potential loss and certainly the loss of a future they might otherwise have expected.'[427]

346 Mrs Mandelson commented on the structures and systems in place at Bristol and the nature of the services provided, and compared them with those in place at other centres during the relevant period.

347 She expressed the view that the necessary 'joined up services' within the hospital seemed to be lacking. In terms of structure, she said:

> '… I think it is very important when we think of the need for line management, and line management not only so that there is accountability, but there is also support and supervision of people carrying out a very difficult job. In a sense, that reflects on the service that they are able to deliver to the users of that service, because anyone who is under a great deal of pressure and stress emotionally, obviously then it is very difficult for them to question the service that they are able to deliver …'[428]

348 Asked about the degree of isolation which came across in the evidence she said:

> 'I think the question of isolation is one that would be quite common in a sense, because I think in the late 1980s this was a fairly new area of work. I think bereavement services, bereavement support, counselling, was something that people certainly in the mid-1980s, they were doing as part of their work rather than being specifically employed in that position. It was an add-on; it was an extra. I think there were a lot of people working very hard to raise awareness around the issues and needs of bereaved families and bereaved parents, and I think with that push, we have seen the development of some of these dedicated posts, but very often, in a hospital you might just get one person doing that.'[429]

349 She stressed the need for peer support and peer co-operation and for the person in that role to fit into part of a team so that the support given to bereaved families is part of a continuum of care.[430]

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[427] INQ 0026 0007; Mrs Mandelson

[428] T47 p. 178 Mrs Mandelson

[429] T47 p. 178–9 Mrs Mandelson

[430] T47 p. 179 Mrs Mandelson

350 As to how the services at Bristol compared with those in the rest of the country at the time she said:

> '… I think certainly in the late 1980s, people were becoming very much more aware of the needs of families …
>
> 'The centre of which I am a part opened in 1988 and at the time was the first centre of its kind in the country … We have already heard Helen Vegoda say she paid a visit to the Alder Hey Centre. It seems a centre of excellence.'[431]

351 By the time Miss Stratton left in early 1994, Mrs Mandelson said that it was fairly common to find structures for support and counselling, of one kind or another, in most critical units:

> 'You may well find in some hospitals still it would be specialist social workers; in Leeds, certainly, there are structures that I am aware of through their Accident and Emergency Department doing a lot of work on bereavement support.'[432]

352 Mrs Mandelson stressed:

> 'One of the things that I feel is very important … is the need for protocols. I think it is so easy for people and families to fall through the gap, certainly when there are lots of families, lots of demands on services and resources are scarce. We need to ensure that there are protocols in place for referral, for management of referral systems, etc to try and make sure that happens as little as possible.'[433]

353 Mrs Mandelson noted the distinction drawn between the terms 'support' and 'counselling', but told the Inquiry that what was important was that there were proper protocols or other measures in place to ensure that those most in need were identified and offered care. They would not necessarily identify themselves.

354 She stated in her paper:

> 'What needs to be in place is a continuum of care that offers readily accessible and appropriate intervention at the time when it is needed by patients and families. Research has shown that often when people need help most that is the time they have the least personal resources to access such help. It falls to the professionals employed within an organisation such as the NHS to ensure that a system is in place that enables potential users of a support service to know what is available and how to access it. Whilst, for a number of reasons, not everyone would wish to use such a service, protocols and procedures should be in place which ensure equity of access to information and appropriate interventions.'[434]

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[431] T47 p. 182 Mrs Mandelson

[432] T47 p. 183 Mrs Mandelson

[433] T47 p. 183 Mrs Mandelson

[434] INQ 0026 0008; Mrs Mandelson

Chapter 17 – Communication Between Healthcare Professionals and Patients

Introduction

1 This chapter will focus on communication between healthcare professionals and parents (and patients).

2 One feature of the communication process was the process of obtaining consent to treatment and this is dealt with in detail.

3 Communication goes beyond language. Non-verbal interaction between the staff of the Bristol Unit and parents is also addressed here.

National, regional or local guidelines

4 General advice and guidance to healthcare professionals on communication with patients (and their parents in the case of children) and on obtaining consent before treatment can be found in a number of documents. These guidance documents were issued by (a) the Department of Health (DoH) and (b) professional and related bodies. Some of these documents have model consent forms.

5 In 1971 the Department of Health and Social Security (DHSS) discussed model consent forms with the British Medical Association (BMA), the Medical Defence Union (MDU), the Medical Protection Society (MPS) and the Medical and Dental Defence Union of Scotland (MDUS). As a result of this, agreement was reached on standard consent forms for use in the case of surgical operations: D.S. 30/71 *'Consent Forms for Operations'*,[1] dated 2 February 1971.

6 This guidance included the following:

> 'It is important that the question of obtaining a signature to a consent form should not be allowed to become an end in itself. The most important aspect of any consent procedure must always be the duty to explain to a patient or relative the nature and purpose of the proposed operation and to obtain a fully informed consent.'[2]

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[1] DOH 0014 0046; *'Consent Forms For Operations'*, D.S. 30.71

[2] DOH 0014 0046; *'Consent Forms For Operations'*, D.S. 30.71

7 In 1990 the DoH issued new guidance on consent:[3] HC(90) *'A Guide to Consent for Examination or Treatment'*.[4] In Chapter 1 it stated:

> 'A patient has the right under common law to give or withhold consent prior to examination or treatment … This is one of the basic principles of health care.'[5]

It went on:

> 'Patients are entitled to receive sufficient information in a way that they can understand about the proposed treatments, the possible alternatives and any substantial risks, so that they can make a balanced judgement. Patients must be allowed to decide whether they will agree to the treatment, and they may refuse treatment or withdraw consent to treatment at any time.'[6]

8 The 1990 Guidance stated further:

> 'Where a choice of treatment might reasonably be offered the health professional may always advise the patient of his/her recommendations together with reasons for selecting a particular course of action. Enough information must normally be given to ensure that they understand the nature, consequences and any substantial risks of the treatment proposed so that they are able to take a decision based on that information. Though it should be assumed that most patients will wish to be well informed, account should be taken of those who may find this distressing.'[7]

9 The Guidance also advised that the patient's ability to appreciate the significance of the information should be assessed,[8] in the case, for example, of patients who might be shocked, distressed or have difficulty in understanding English. It further stated that:

> 'A doctor will have to exercise his or her professional skill and judgement in deciding what risks the patient should be warned of and the terms in which the warning should be given. However, a doctor has a duty to warn patients of substantial or unusual risks inherent in any proposed treatment. This is especially so with surgery but may apply to other procedures including drug therapy and radiation treatment.'[9]

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[3] This appears to be the first guidance that addresses the position of the law on consent

[4] HOME 0004 0018 – 0034; *'A Guide to Consent or Treatment'*, HC(90)

[5] HOME 0004 0020; *'A Guide to Consent or Treatment'*, HC(90)

[6] HOME 0004 0020; *'A Guide to Consent or Treatment'*, HC(90)

[7] HOME 0004 0021; *'A Guide to Consent or Treatment'*, HC(90)

[8] HOME 0004 0021; *'A Guide to Consent or Treatment'*, HC(90)

[9] HOME 0004 0021; *'A Guide to Consent or Treatment'*, HC(90)

10 The 1990 Guidance stated that:[10]

> 'The standard of care required of the doctor concerned in all cases is laid down in Bolam v Friern Hospital Management Committee [1957] 1 WLR 582, namely, that he or she must act in accordance with a responsible body of relevant professional opinion.'[11]

11 It further stated:

> 'Guidance on the amount of information and warnings of risk to be given to patients can be found in the judgement of the House of Lords decision in Sidaway v Gov of Bethlem Royal Hospital [1985] AC 871.'[12]

12 The 1990 Guidance stated that consent may be implied or express. It then gave guidance on when written consent should be obtained:

> 'Written consent should be obtained for any procedure or treatment carrying any substantial risk or substantial side effect … written consent should always be obtained for general anaesthesia, surgery, certain forms of drug therapy …'[13]

It went on:

> 'Oral or written consent should be recorded in the patient's notes with relevant details of the health professional's explanation. Where written consent is obtained it should be incorporated into the notes.'[14]

13 As regards written consent, it stated:

> 'The main purpose of written consent is to provide documentary evidence that an explanation of the proposed procedure or treatment was given and that consent was sought and obtained.'[15]

14 The 1990 Guidance cautioned:

> 'Where a patient has not been given appropriate information then consent may not always have been obtained despite the signature on the form.'[16]

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[10] See further the analysis of the law on consent in the Interim Report: BRI Inquiry Interim Report, '*Removal and retention of human material'*, p. 20–34 and at Annex B of the Interim Report, particularly at p. 68–9

[11] HOME 0004 0028; *'A Guide to Consent or Treatment'*, HC(90)

[12] HOME 0004 0021; *'A Guide to Consent or Treatment'*, HC(90)

[13] HOME 0004 0022; *'A Guide to Consent or Treatment'*, HC(90)

[14] HOME 0004 0022; *'A Guide to Consent or Treatment'*, HC(90)

[15] HOME 0004 0022; *'A Guide to Consent or Treatment'*, HC(90)

[16] HOME 0004 0022; *'A Guide to Consent or Treatment'*, HC(90)

15 The Guidance emphasised the importance of discussing treatment with the multidisciplinary team and other doctors. These discussions, it stated, should also be documented in the clinical case notes.[17]

16 In 1991 the DoH issued guidance entitled, *'Welfare of Children and Young People in Hospital'*[18] which stated:

> 'Districts and provider hospitals should ensure that good practices are followed on seeking consent to the treatment of children. A guide to consent for examination and treatment published by the NHS Management Executive in August 1990[19] will be of assistance here.'[20]

17 The 1991 Guidance gave advice on 'Parental Attendance and Involvement':[21]

> 'District and provider hospitals are advised to agree service specifications which:
>
> - 'recognise that parents and members of the immediate family are not visitors and encourage and assist them to be with their child *at all times* unless the interests of the child preclude this
> - 'enable parents to give continuous *love, care, comfort, and support to their child* and, especially, be together with their child at the most stressful times – e.g. during and after treatment, anaesthesia, investigations and x-rays
> - *'help parents* themselves to undertake many familiar tasks helpful to the care of their child (e.g. dressing and undressing) and, where appropriate, learn any clinical procedures which will enable them to care for their child at home after discharge
> - 'provide maximum help and advice to parents to enable them to play a part in the care of their children and *to continue the care* following the child's discharge from hospital
> - 'ensure that, exceptionally, when consideration is given to advising a parent on medical grounds *not to visit* a particular child, the decision is taken by the consultant in charge only after *full consultation* with other professional staff (the reason for the decisions will need to be recorded in the child's medical records)…'[22]

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[17] HOME 0004 0028; *'A Guide to Consent or Treatment'*, HC(90)

[18] HOME 0002 0001; *'Welfare of Children and Young People in Hospital'*, DOH 1991

[19] HOME 0004 0018 – 0034; *'A Guide to Consent or Treatment'*, HC(90)

[20] HOME 0002 0013; *'Welfare of Children and Young People in Hospital'*, DOH 1991

[21] HOME 0002 0024; *'Welfare of Children and Young People in Hospital'*, DOH 1991

[22] HOME 0002 0024; *'Welfare of Children and Young People in Hospital'*, DOH 1991 (emphasis in original)

18 On 28 July 1992 the NHS Management Executive (NHSME) issued Guideline HSG(92)32, entitled *'Patient Consent to Examination or Treatment'*.[23] It superseded the 1990 Guidance:

> 'Following discussion with representatives of the medical profession, the Department has revised the model consent forms … This should remove some of the misunderstandings that have arisen since HC(90)22 was introduced.'[24]

Guidance from professional and related bodies

The Medical Defence Union

19 In November 1992 the MDU published its guidance on consent entitled *'Consent to Treatment'*.[25] On 'Informed Consent', the MDU stated:

> 'A doctor … or other healthcare professional has a duty to explain to the patient in non-technical language the nature, purpose and material risks (vide infra) ["see below"] of the proposed procedure. *The patient must be capable of understanding the explanation given*; if he is incapable, whether from unsound mind or any other cause, informed consent cannot be obtained. If the proposed treatment is difficult to understand, it may be helpful for clinicians to use, for example, drawings, diagrams and models to supplement the verbal explanations. If necessary an interpreter should be present to ensure that the explanation is given in a language which the patient comprehends. The full explanation given to the patient is of paramount importance. The signing of a consent form is of secondary significance. Where the patient has been given insufficient information, the clinician may be found to have been in breach of his duty of care to the patient.'[26]

20 The MDU guidance advised that, when obtaining consent:

> 'The task should not be delegated routinely to a junior doctor, especially if a complicated or specialised procedure is contemplated. It is not appropriate to ask a student to obtain consent. It is important that the person who discusses the procedure with the patient should whenever possible be the person who will carry out the procedure. If that is not possible then consent should be obtained by someone who is appropriately qualified and familiar with all the details and risks of the proposed procedure, and any alternatives.'[27]

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[23] DOH 0014 0037 – 0044; *'Patient Consent to Examination or Treatment'*, HSG(92)32

[24] DOH 0014 0037; *'Patient Consent to Examination or Treatment'*, HSG(92)32

[25] DOH 0014 0001 – 0036; *'Consent to Treatment'*, MDU

[26] DOH 0014 0002; *'Consent to Treatment'*, MDU (emphasis in original)

[27] DOH 0014 0004; *'Consent to Treatment'*, MDU

21 As to when consent should be obtained, the MDU stated that:

> 'Consent should be obtained preferably a short time before the proposed procedure … In the case of elective surgery, where no change in the basic condition requiring operative treatment is to be expected, there is no objection to obtaining the patient's signed consent during the out-patient clinic. If the patient's condition alters between the out-patient appointment and admission to hospital so there is some material change in the nature, purpose or risks of the procedure, then the patient's consent should be obtained again; a further explanation should be given and a fresh consent form should be signed. Similarly, if a considerable time has elapsed between the out-patient appointment and admission, consent should be obtained again.'[28]

The General Medical Council

22 Sir Donald Irvine, President of the General Medical Council (GMC) from September 1995 to present, outlined the focus of the GMC's guidance in the 1980s in his written evidence to the Inquiry:

> 'In the early 1980s, the GMC saw its standard-setting role primarily in terms of character and conduct and hence of the standing and reputation of the profession and the doctor. As a result the guidance focused on questions of honesty, improper relationships and abuses of trust. Those issues were – and remain – important. However they virtually excluded standards of clinical practice and relationships with patients, both seen as vital today.
>
> 'Until 1995, the guidance on standards was published as part of the description of the GMC's conduct procedures.'[29]

23 Sir Donald went on:

> 'The guidance was the product of the culture in which medical regulation was seen as a reactive means of coping with exceptional misconduct, rather than a means of promoting good practice across the whole profession.'[30]

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[28] DOH 0014 0003; *'Consent to Treatment'*, MDU

[29] WIT 0051 0007 Sir Donald Irvine

[30] WIT 0051 0008 Sir Donald Irvine

24 Sir Donald explained the GMC's role in the following exchange:

> 'Q. I was exploring with you the nature of the way in which inadequate practice might be regulated by the one branch or other of the regulatory bodies, taking as a given that the GMC is really the end of the road, the long-stop. I have it right, have I? That is essentially how the GMC sees itself?
>
> 'A. Yes, although I qualify that: within the statutory framework that I have described, we have been undergoing a considerable change of outlook ourselves which began, again, in the early 1990s, and that was effectively to see how far within the framework, the statutory framework as it was, we could be as effective as possible.
>
> 'That change of view was occasioned by our understanding that couching advice to the profession in fairly negative terms, in terms of what doctors could not or should not do, seemed to be unsatisfactory, that there had to be a better way of doing this because one effect of that policy was to leave doctors feeling that, "Well, since I am clearly not bad, none of this advice applies to me".
>
> 'This recognition was coupled also with our understanding that the culture of medicine needed to take far greater account of patients, what patients thought about doctoring, what they expected of their doctors, and there seemed to be a gap, as it were, a mismatch here between the public and its confidence in the kind of advice given and the advice that we were actually giving.
>
> 'Thirdly, it was triggered by the issues of advertising, which do not seem central to performance, but nevertheless, the examination that we made at the time and the questioning about doctors' advertising led us in, I think it was 1991, really to put as central the whole question, for instance of information to patients, to discard much of the conventional thinking which was restrictive, and it was that kind of way of thinking which then encouraged us and led us to think that we ought to address our remarks more positively and more explicitly to the whole profession about their duties and responsibilities.
>
> 'The last point – it is very fundamental to the notion of self-regulation, but that is not an end in itself, only a means to getting the best care for the patient – was to make explicit that which had always been implicit in medicine, and that there is a contract between doctor and patient and that a registered practitioner, in accepting the privileges of being registered, which includes the ability to earn one's livelihood as a doctor, enters into certain obligations to the patient, to the public, as a result.
>
> 'It is that kind of thinking, Mr Langstaff, which was a million miles away from the very restrictive interpretation that we had traditionally placed on matters earlier.

> 'It was in tune, lastly, with the more general move in medicine towards being explicit about good standards of practice wherever possible. The whole guidelines movement as you know was developing at that time, and I have given some background to that in Annex B to my evidence.'[31]

25 Sir Donald stated in his written evidence to the Inquiry:

> 'The policy began to change in the mid 1980s, as The Blue Book[32] was expanded to include new advice on standards of patient care … This process of change culminated in the publication of *"Good Medical Practice"* (1995)[33] where, for the first time, the GMC defined systematically the principles of good practice expected of all doctors.'[34]

26 *'Good Medical Practice'* (1995) advised doctors:

> 'In providing care you must:
>
> - 'recognise the limits of your professional competence;
> - 'be willing to consult colleagues;
> - 'be competent when making diagnoses and when giving or arranging treatment;
> - 'keep clear, accurate, and contemporaneous patient records which report the relevant clinical findings, the decisions made, information given to patients and any drugs or other treatment prescribed;
> - 'keep colleagues well informed when sharing the care of patients …'[35]

27 Sir Donald stated:

> 'Throughout the 1980s and early 1990s the Council saw a clear distinction between areas governed by law – both common law and legislation – and questions of conduct and ethics. The GMC gave no guidance on matters which it believed were covered principally by law and would be dealt with in the courts. This is still the policy, but not every subject falls neatly into one category or the other.
>
> 'This became increasingly clear in relation to consent. No advice on the issue was included in The Blue Book since consent was regarded as a complex legal issue falling outside the area in which the GMC was competent to give advice. However,

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[31] T48 p. 31–3 Sir Donald Irvine

[32] *'General Medical Council's Professional Conduct and Discipline: Fitness to Practise'* (published by the GMC)

[33] WIT 0051 0122 – 0132; *'Good Medical Practice'*, GMC 1995

[34] WIT 0051 0008 Sir Donald Irvine

[35] WIT 0051 0124; *'Good Medical Practice'*, GMC 1995

> neither The Blue Book nor *"Good Medical Practice"* attempted to provide a comprehensive guide to all matters which could raise a question of serious professional misconduct, and it therefore remained possible for the PCC [Professional Conduct Committee] to hear cases based on, or involving consent.
>
> 'During the late 1980s and 1990s the Professional Conduct Committee considered a number of such cases … in which the PCC emphasised the importance of doctors providing information about procedures and options open to their patients, obtaining consent and respecting patients' decisions.'[36]

28 The then Secretary of the British Medical Association (BMA), Dr Ernest Armstrong, stated in his written evidence to the Inquiry:

> 'In 1984, the BMA published a revised edition of its ethics handbook[37] which aimed to provide guidance for doctors on a range of issues. The issue of patient consent, including consent of minors is briefly covered, with little mention of parental consent. There was a clear expectation that doctors would not proceed without valid consent but the steps entailed in seeking that consent were not explored. The equivalent publication in 1993, *"Medical Ethics Today"* [38] featured over 30 pages of advice on the topic of consent generally and a separate chapter on aspects of treatment of children. In the interim period between these two publications, BMA ethical guidance tried pro-actively to encourage much greater recognition of the importance of patient/parent informed consent to treatment.'[39]

29 He went on:

> 'The BMA's ethical publications address the type of questions which doctors routinely raise with the Association at any given time. The absence of debate about some issues does not imply that they were regarded as unimportant but indicates that doctors are likely to have felt that they were part of a professional consensus, precluding the need for questions. … The relatively low level of emphasis given to issues of consent in the 1984 ethics handbook indicates that this was not an area viewed by doctors as ethically problematic …
>
> 'By 1993, it is very clear from the BMA's published advice that professional guidance was already moving distinctly in a rights-based direction.'[40]

30 As regards the discussion of risks associated with surgery, Dr Armstrong stated:

> 'The 1984 BMA advice typified much thinking at the beginning of the period in that the guidance contained next to no detail and left a great deal to clinical discretion.

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[36] WIT 0051 0076 Sir Donald Irvine

[37] WIT 0037 0143; *'The Handbook of Medical Ethics'*, BMA 1984

[38] WIT 0037 0149; *'Medical Ethics Today: Its Practice and Philosophy'*, BMA 1993

[39] WIT 0037 0018 Dr Armstrong

[40] WIT 0037 0019 Dr Armstrong

> It was generally assumed that doctors would come to their own decisions in each case about the manner in which consent was sought and the degree of information provided. The core statement in the extract from the 1984 handbook is that "the onus is always on the doctor carrying out the procedure to see that an *adequate* explanation is given" [emphasis added].[41] No indication is given in the guidance, however, about what would constitute adequacy or by whose standard (doctor's or patient's) adequacy should be judged, although it would normally be assumed that the medical standard would be the benchmark. There is a brief paragraph on the importance of clear communication and avoidance of misunderstanding but the necessity of discussing risks associated with treatment is entirely absent.'[42]

31 Dr Armstrong went on:

> '… the 1984 guidance makes clear that doctors should answer questions unambiguously but again leaves open how much information doctors should volunteer if no question is posed.'[43]

32 He stated that:

> 'The graver the decision and the riskier the procedure, the greater the need for well informed consent to be provided.'[44]

33 He added:

> 'The BMA expects doctors to base their recommendations for treatment on the most reliable evidence available about benefit and there is a clear expectation in the BMA's 1993 advice that doctors should not conceal any piece of information materially relevant to the patient's decision.'[45]

34 Dr Armstrong stated that the idea that a surgeon had an obligation to refer to specific factors such as outcome data 'was not an issue for discussion in 1984'.[46]

> 'A not uncommon argument during the period (although not one endorsed by the BMA) was that doctors had moral obligations to promote hope of recovery. In the 1993 version of its advice, the BMA noted that a past concern of doctors had been to avoid worrying patients and that historically this had led to a reluctance to tell them the full implications of an illness or the different options for treatment. While the Association assumed that this approach was increasingly being seen as outdated by 1993, it noted a continuing reluctance on the part of some doctors to discuss uncertainties in medicine. It is very likely that this idea about the duty for beneficence was interpreted by some members of the profession as a justification

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[41] WIT 0037 0144; *'The Handbook of Medical Ethics'*, BMA 1984
[42] WIT 0037 0020 Dr Armstrong
[43] WIT 0037 0021 Dr Armstrong
[44] WIT 0037 0021 Dr Armstrong
[45] WIT 0037 0021 Dr Armstrong
[46] WIT 0037 0021 Dr Armstrong

> for not discussing risk, despite the ever-increasing emphasis placed by courts and by professional guidance on informed consent. In addition at the beginning of the period in question [1984], it is possible that some doctors were discouraged from drawing comparisons with outcomes from other colleagues or other facilities because of a perception that this could potentially undermine patient confidence or risk improper disparagement of colleagues.'[47]

35 The BMA's *'Handbook of Medical Ethics'* (1984), referred to by Dr Armstrong, stated that:

> 'Consent is only valid when freely given by a patient who understands the nature and consequences of what is proposed.
>
> 'Assumed consent or consent obtained by undue influence is valueless … It is particularly important that consent should be free of any form of pressure or coercion … No influence should be exerted through any special relationship between a doctor and the person whose consent is sought.
>
> 'Doctors offer advice but it is the patient who decides whether or not to accept the advice. The necessary degree of understanding of what is proposed depends on the patient's education and intelligence and the seriousness and urgency of the condition being investigated or treated. The onus is always on the doctor carrying out the procedure to see that an adequate explanation is given.'[48]

36 The 1993 BMA guidance *'Medical Ethics Today: Its Practice and Philosophy'* gave the prerequisites for valid consent under the heading 'Consent to examination and treatment':

> 'In order for the consent of any person to be valid it must be based on competence, information and voluntariness. In our view, this can be broken down into several fundamental points:
>
> 'a) the ability to understand that there is a choice and that choices have consequences;
>
> 'b) a willingness to make a choice (including the choice that someone else choose the treatment);
>
> 'c) an understanding of the nature and purpose of the proposed procedure;
>
> 'd) an understanding of the proposed procedure's risks and side effects;

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[47] WIT 0037 0021 – 0022 Dr Armstrong

[48] WIT 0037 0144; *'The Handbook of Medical Ethics'*, BMA 1984

> ‘e) an understanding of the alternatives to the proposed procedure and the risks attached to them, and the consequences of no treatment;
>
> ‘f) freedom from pressure.’[49]

The Royal College of Surgeons of England

37 Sir Barry Jackson, the President of the Royal College of Surgeons of England (RCSE), gave the Inquiry his views on discussions with patients in the following exchange:

> ‘Q. If I can just turn then to another aspect of this particular document,[50] … the subject of how doctors explain risk to patients. It sets out the relationship between the consultant and the patient, the fact that areas of uncertainty and significant risk must be explored, the use of information leaflets and tapes, and then, at the bottom of that it says:
>
> ‘”The Colleges and specialist associations have an important role in the production of suitable information on a national basis but the surgeon must know and divulge local and personal figures.”[51] For the success or otherwise of an operative procedure, presumably.
>
> ‘That is clear guidance from the College published in 1998. What would have been the standard in this area throughout the period of our Terms of Reference?
>
> ‘A. I do not think it would be so explicitly stated as it is stated here for surgery in general. I cannot speak for particular branches of surgery and specifically for cardiac surgery because I do not know, but it would certainly have not been in any way firm College guidelines that on a national basis surgeons should divulge local and personal figures relating to outcomes such as has been recommended in this document.
>
> ‘Q. Our understanding is certainly that there was no guidance to that effect because we are looking at a 1998 document that I think is clearer than any other on that subject, but are you able to help us on the practice that would nevertheless have been adopted at a local level?
>
> ‘A. I think it would have been uncommon, unless the patient had asked for that information. I imagine that that might differ from specialty to specialty within surgery because my understanding is that in the field of cardiac surgery, very high risk surgery, this information was not infrequently asked by relatives or by patients of the surgeon in question, whereas in other branches of surgery, it would have been extremely uncommon to have been asked that question.

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[49] WIT 0037 0158; *‘Medical Ethics Today: Its Practice and Philosophy’*, BMA 1993

[50] RCSE 0001 0009; *‘Response to the General Medical Council Determination on the Bristol Case’*, The Senate of Surgery of Great Britain and Ireland, Senate Paper 5, October 1998

[51] RCSE 0001 0009; *‘Response to the General Medical Council Determination on the Bristol Case’*, The Senate of Surgery of Great Britain and Ireland, Senate Paper 5, October 1998

'Certainly, from personal experience, not as a cardiac surgeon, I think I would have been asked specific questions regarding risks in general and certainly the risks in my own hands exceedingly – exceedingly – infrequently over my entire professional practice.

'Q. The Inquiry will, of course, hear from parents and also from the doctors concerned as to what their practice was, but it might be suggested that it would be unusual for a patient to be able to have the knowledge, as it were, to ask not merely about what the outcome or likely outcome was in broad terms, but to be able, to make a distinction to go behind a 30 per cent risk of mortality, to ask such further questions as, "Well, is that a national figure, is that a local figure, is that your personal figure?"

'That would accord with your experience, that patients did not really do that?

'A. Absolutely. I think it would have been most unusual for any patient to do that, and I would imagine, but others will be able to verify or refute my belief, that that would have been unusual in cardiac surgery, and specifically in paediatric cardiac surgery.

'Q. So this is an area where practice must have changed very recently and very rapidly?

'A. Well, I think that it does not happen now. I do not think patients by and large ask that information, other than, perhaps, in the field of cardiac surgery, largely, I suspect, as a result of the publicity that the circumstances in Bristol obtained.

'Q. What is being suggested in that guidance is that it is not merely surely a matter for the patient to ask, but for the doctor to volunteer this information?

'A. That is what is stated, correct.

'Q. But so far, does it follow from your earlier answer that that is not necessarily the practice, or is not common practice on the ground?

'A. I think that is probably not common practice, and as I have – I think I have not said specifically, but if I have, I am sorry to repeat it; if I have not, perhaps I could say that any College guideline that comes out, such as the one you have on the screen at the present moment, is a recommendation by the College to its fellows and others, but it is not mandatory upon our fellows and others to follow those guidelines or those recommendations.'[52]

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[52] T28 p. 117–120 Sir Barry Jackson

The United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC)

38 The *'Code of Professional Conduct for the Nurse, Midwife and Health Visitor'*[53] issued by the UKCC in 1984 contained no guidance on obtaining consent or communication with patients.

39 In 1989, the UKCC published guidance entitled *'EXERCISING ACCOUNTABILITY – A framework to assist nurses, midwives and health visitors to consider ethical aspects of professional practice'*.[54] Under 'Consent and Truth', the guidance stated:

> 'For the purposes of this document "informed consent" means that the practitioner involved explains the intended test or procedure to the patient without bias and in as much detail (including detail of possible reactions, complications, side effects and social or personal ramifications) as the patient requires. In the case of an unquestioning patient the practitioner assesses and determines what information the patient needs so that the patient may make an informed decision. The practitioner should impart the information in a sensitive manner, recognising that it might cause distress. The patient must be given time to consider the information before being required to give the consent unless it is an emergency situation.'[55]

40 It continued:

> 'If the nurse, midwife or health visitor does not feel that sufficient information has been given in terms readily understandable to the patient so as to enable him to make a truly informed decision, it is for her to state this opinion and seek to have the situation remedied … Discussion of such matters between the health professionals concerned should not take place in the presence of patients.'[56]

41 It further stated that there will be occasions where a patient's:

> '… subsequent statements and questions to a nurse, midwife or health visitor indicate a failure to understand what is to be done, its risks and its ramifications. Where this proves to be the case it is necessary for that practitioner, in the patient's interest, to recall the relevant medical practitioner so that the deficiencies can be remedied without delay.'[57]

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[53] UBHT 0221 0013 – 0017; *'Code of Professional Conduct for the Nurse, Midwife and Health Visitor'*, UKCC 1984

[54] UBHT 0221 0001; '*EXERCISING ACCOUNTABILITY – A framework to assist nurses, midwives and health visitors to consider ethical aspects of professional practice*', UKCC 1989

[55] UBHT 0221 0007; '*EXERCISING ACCOUNTABILITY –A framework to assist nurses, midwives and health visitors to consider ethical aspects of professional practice*', UKCC 1989

[56] UBHT 0221 0007; '*EXERCISING ACCOUNTABILITY – A framework to assist nurses, midwives and health visitors to consider ethical aspects of professional practice*', UKCC 1989

[57] UBHT 0221 0007; '*EXERCISING ACCOUNTABILITY – A framework to assist nurses, midwives and health visitors to consider ethical aspects of professional practice*', UKCC 1989

The *'Patient's Charter'*

42 The *'Patient's Charter'* was introduced in 1992. The fifth right under the Charter entitled a patient to be given a clear explanation of any proposed treatment and any associated risk, and any alternative methods of treatment, before agreement on treatment is reached. To comply with this right the UBHT stated:

> 'Clinicians take great care to give explanations in all circumstances to the patient or a person having responsibility for the patient such as a parent. Furthermore some nursing "standards" include a requirement that a nurse also gives explanations. An example is in the Cardiac Surgery Unit where a trained nurse carries out a pre-operation talk to the patient and family and a visit is made to the Intensive Therapy Unit.'[58]

43 In the note of a meeting of the Patient Care Advisory Group of the UBHT, held on Monday 13 January 1992, it was recorded that:

> 'Dr Roylance explained that it was not always appropriate or possible to give patients a clear explanation of proposed treatment. It was agreed that the advice of the Medical Director would be sought on the most suitable method of obtaining patients'consent to treatment.'[59]

Expert evidence

44 Mr Leslie Hamilton, a consultant paediatric cardiac surgeon at Freeman Hospital, Newcastle, and one of the Inquiry's group of Experts, told the Inquiry:

> 'I think the move towards being much more explicit has been a more recent phenomenon and I would have put it in the 1990s. I have only been a consultant since 1991, so I can only speak from my own practice since then. It is only my perception that we felt we were protecting parents by not exposing them to all the worrying factors of what might happen, and that would have been the practice, I would have thought, in the 1980s.
>
> 'I think it is very important to state that every set of parents is different, and different parents will want different levels of information and different parents will take in different ideas during the consultation. I think there has been some work done, I think a figure of about 30 to 40 per cent of the information you give in a consultation is retained, because it is a very difficult and very traumatic time. So my

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[58] UBHT 0018 0345; the *'Patient's Charter'*, Patients Standard Care Committee Mar 1992–Sept 1993

[59] UBHT 0022 0343; note of meeting of Patient Care Advisory Group, UBHT, 13 January 1992

> own feeling is that the consent is a process; it is an ongoing process. I see that starting when I see the family in outpatients and I try in my practice to see them in outpatients in advance of the operation, when they were actually going on the waiting list. I see that as the actual point of consent.
>
> 'I think when they come into hospital the night before, I then do not go over all the details I have discussed in outpatients, because I think that is the last thing parents want to hear at a time of great anxiety.
>
> 'I would go even further. I think for me the final point of the consent process is actually after the operation. I like to see them again and make sure they have understood what I have actually done, how things have gone and what I would predict for the future, because, again, that is the last point at which I would see them because they would then go back to the care of the cardiologist. I do not think that is necessarily standard practice and I do not know if that is ideal practice.
>
> 'I think one of the difficulties we have in describing risks to parents is that we do not have a system of risk stratification for children's operations … It is a very individualised thing. The idea of going back to results and quoting a specific figure I think is not possible. I try and give the parents a ball-park figure of whether it is a high, medium or low risk operation. Most parents will want you to put a figure on it so I will try and do that, but as I have said, I emphasise statistics do not apply to individuals, they apply to populations.'[60]

45 Mr Hamilton went on:

> 'I certainly will give what I feel are the important parts of the consultation initially, depending on the diagnosis, and I think it is important to say that "Your child may die", because unless you say "die" or "death", parents do not want to hear that, so they will try and push that aside, so I think it is important to say that but then to try to quantify it and give some idea of the level of risk.
>
> 'But then I will mention the fact … that complications are relatively infrequent; it depends on the operation, but they can affect any part of the body. I will then give them the chance to ask questions and some parents will want to know every detail. They will ask specifically about brain damage, but I must admit, I do not go into specific detail unless they want me to. I try and be guided by them in their reaction to my conversation, as to how much they want.
>
> 'So this is a very difficult area. I do not think there is a clear answer, but I think things have changed dramatically since the 1980s and we are now much more explicit with parents.'[61]

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[60] T51 p. 128–130 Mr Hamilton

[61] T51 p. 131–2 Mr Hamilton

46 Professor de Leval and Mr Jaroslav Stark (former consultant in paediatric cardiothoracic surgery), both of Great Ormond Street Hospital for Sick Children, gave expert evidence to the Inquiry in a joint session. Professor de Leval said '... I do not think that in the 1980s we were giving the parents the information you expect today.'[62] On the issue of information to be given to parents and discussion with parents about the fact that a surgical procedure like the Arterial Switch was new, Mr Stark told the Inquiry:

> '… when you [Counsel to the Inquiry] say "when you discuss it with the parents", you actually are not asking the parents to make the decision, because I think, to some extent, the way you see the benefits, you are willingly or unwillingly influencing the parents. But the other way round, the parents sometimes influence you.
>
> 'I would like to give you an example. One of the very difficult conditions is pulmonary atresia, with major collaterals coming from the aorta.
>
> 'For this condition, although the outlook has improved, the usual scenario in the 1970s/80s was that we would do two, three, four palliations in the first three years. Eventually there was nothing to offer. So on those occasions when we told the parents this scenario and suggested, because the outlook is so bad, that perhaps we should not treat the child, of course very often the parents feel anything that could be done should be tried, and we did, and then the scenario was followed.
>
> 'Then, a few years later, the parents would write to me and say, "We are sorry we did not take your advice because the misery we have suffered during those three or four years was immense."
>
> 'So I think that there is always both sides that influence each other.'[63]

47 Speaking of the extent to which parents during the 1980s and 1990s would understand or be informed that their child was amongst the first to have a new (Switch) procedure, Professor de Leval told the Inquiry that:

> 'I think that the parents were informed that the procedure was new or that there was an alternative, but we were implying or proposing a new procedure, but I think all this was done in the context of a relationship of confidence between the families, the cardiologist first and the nursing staff, the surgeon, and I do not think that parents ever considered that they were probably the "victims" or "guinea pigs" or whatever you would call that. I think that they were, you know, as fully informed as we thought they should be, and we were totally open in what we were doing. The fact that we were telling them that it was a new procedure implied, without being necessarily specific in spelling it [out], that there was probably a higher risk in those days than now, because we have done more.

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[62] T50 p. 18 Professor de Leval

[63] T50 p. 21–2 Mr Stark

> ‘But I think the relationship and the ambience where all those things were taking place was such that there was full confidence between parents and the institution.’[64]

48 Mr Stark, agreeing with Professor de Leval, said:

> ‘I think this is a very important point, because I could give you an example of one operation which I thought could be done and it has not been done before, and when I talked to that family, I put it to them in those simple terms: “It has not been done before. I think it could work.” The parents, and many other parents, in those days usually did not comprehend fully the anatomy of physiology, because … it is quite complex. Very often the answer was, “We know that you will do your best and we trust you”. So we went ahead with the operation. That particular operation went well, but the feeling that the nurses, cardiologists, surgeons had the full trust of the parents probably made the explanation, even under such difficult conditions when we started new operations or where we knew the risk was still high, somewhat easier.’[65]

49 As for quoting risks, Mr Stark said:

> ‘I think very often we would quote the parents actually [a] very broad idea, like saying the risk is less than 50:50. Only when the parents insisted, we put together our own experience, we put together the data from the literature, but it was not scientific; I completely agree. Unfortunately, we did not have the basis for that.’[66]

50 Professor de Leval indicated that:

> ‘Nowadays, obviously, we are careful what we say, what we write and we try to choose our words, but I think that, frankly, when I was talking to parents in 1985 about risks, I did not know exactly what my results were and certainly not what the confidence interval was, so it was a clinical impression of what I had done; also a knowledge of what had been published and what I had heard at meetings. Some of the conditions, the number of cases I had done, we had done, was very small, rare conditions, and the risk quoted was the best I thought I could do in terms of assessing what the risk was, plus taking into consideration my own performance from previous cases … You tell the parents that three of the last four patients have died while all the others before had survived? We did not, but I am sure that when I was quoting a risk of an operation, having lost one or two patients from the same condition, I was more pessimistic. But this is no science. There was no confidence interval quoted.’[67]

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[64] T50 p. 26–7 Professor de Leval

[65] T50 p. 27–8 Mr Stark

[66] T50 p. 33 Mr Stark

[67] T50 p. 34 Professor de Leval

51 Mr Stark told the Inquiry that he tried to avoid quoting percentages because he thought they were meaningless to a number of parents. He said he tried to explain what the alternatives of not operating were to the parents and mentioned that 'even if the risk was 1 per cent … if that 1 per cent was their child, therefore it was 100 per cent.' He said: 'We did not have a better way to do it.'[68]

52 Dr Eric Silove, consultant paediatric cardiologist at Birmingham Children's Hospital and Senior Clinical Lecturer at the University of Birmingham and Dr Alan Houston, paediatric cardiologist at the Royal Hospital for Sick Children, Glasgow and Honorary Senior Lecturer at Glasgow University jointly gave expert evidence to the Inquiry.

53 They referred to the practice of holding 'joint meetings' between surgeons and cardiologists. Dr Houston told the Inquiry:

> 'But of course the surgeon will have looked at the angiogram with you [the cardiologist]. The surgeon is not going in to see if the coronaries are all right; he will have looked at the pictures and probably agreed with the physicians and the surgeons that they are all right. So he would be involved in that decision to operate as well, yes.'[69]

54 In relation to the collaboration between cardiologists and surgeons, the following exchange took place:

> 'Q. You talked of the determination being made as it were by the cardiologist in isolation or by the surgeon, that they would collaborate and look at these things together. Is that an essential prerequisite for the proper treatment of a patient, that the two of them collaborate and discuss?
>
> 'A. (Dr Houston): I would have said so, for all but the most relatively minor conditions, and I think in all centres, there are joint meetings of the cardiologist and cardiac surgeons. Perhaps for some simple things like tying a duct, you would not necessarily sit down and look at the information, or even an Atrial Septal Defect, but anything like this would be expected to be discussed at a combined meeting.
>
> 'A. (Dr Silove): I agree with that.'[70]

55 Dr Silove and Dr Houston told the Inquiry about prevailing practice (in their experience) during the period covered by the Inquiry's Terms of Reference regarding information given to and communication with parents about old, new and emerging surgical procedures. In the following exchange, they discussed general practice at the time concerning quoting risks:

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[68] T50 p. 36 Mr Stark

[69] T49 p. 64 Dr Houston

[70] T49 p. 66–7 Dr Houston and Dr Silove. See Chapter 3 for an explanation of clinical terms

‘A. (Dr Silove): I think it is very unlikely that cardiologists and surgeons at that time, sort of in the late 1980s, early 1990s, would have discussed the pros and cons in such depth with the parents. I think that today they would. In 1999 we know that there is a demand for a great deal of information, and some of that is good and some of it has major problems. But at that time – I cannot quite remember, but I suspect that one would have said to the parents, “We used to do an operation called the Atrial Switch”, say, “and our results for that were good but we know that children who had that operation, over a period of years, sometimes as early as the age of –”, I mean, I have talked about 20s and 30s, sometimes as early as 12 or 15, would die suddenly, would certainly get into big trouble as they got into their 20s, and would not have a normal life.

‘“We are now adopting the Arterial Switch operation; we have not done enough of these operations to be able to tell you just what the outlook is going to be; we expect that the long-term outlook will be very much better; we have a much better chance of having a live child when he or she is an adult, and we are not quite certain what the mortality rate is that we can expect at this stage, but we would expect it to be probably a little bit higher than the mortality rate for the Atrial Switch.”

‘That is what I think, I cannot remember, I think is the way we would probably have approached it. I do not know whether Dr Houston might recall how he would have approached it?

‘A. (Dr Houston): I think it perhaps would be very similar to that, but perhaps if you clearly believe what you are doing is the correct thing, you may put it a little more strongly than that … I think it is difficult to say exactly what words you would use, but you would clearly get over the concept that you thought the chances were much better by going for the Switch rather than the inflow correction, but briefly mention that that had been done in the past.

‘Q. (Mr Langstaff): Suppose that the parent says, or said to you at the time, “Well, what are the chances of my child coming through the operation, coming through this operation? How does that compare with the chances of my child coming through that operation?”

‘Q. (The Chairman): And we are talking about two kinds of chances. The chances immediately and the chances long-term, so perhaps in addition to Mr Langstaff’s question, you can address that as well, because Dr Houston, you used the word “chances”and of course it refers to two distinct time periods.

‘A. (Dr Houston): I cannot recollect anyone about that time asking me that directly. Perhaps it is different nowadays, but people often do not push for the exact details. I am very wary about giving percentage figures, because everyone is different. But I think at that time you would have said the risk of the Switch was up to 20 per cent mortality. The risk with inflow would probably be five or less. That would have been the sort of figures I would have thought of at the time, I think.

‘A. (Dr Silove): I think at the time that we moved over to the Arterial Switch, we would probably also have said that the experience of centres that are doing a lot of Arterial Switches is that the mortality is somewhere in the region of 10 per cent, whereas the mortality for the Atrial Switch operation is about half of that. But we feel that there are so many advantages to going for the Arterial Switch in the longer term, that is what we are advising.

‘Q. (Mr Langstaff): If I can just ask you both really to comment on this … we are here dealing with the risks and chances of survival or not, and using figures such as 10 per cent or 5 per cent.

‘To what extent would they be meaningful to a parent or patient when the reality is that the parent has no choice but to have a child with a congenital heart defect, the child has no choice, it is born that way and when the reality is, it is either death or survival, and percentages can be very false and take one away from the fact that in each case there is a real child?

‘A. (Dr Silove): Yes. I mean, the point you have made is a very real point. I think that what we are really saying is that if the mortality rate is less than 10 per cent, it is a reasonable risk, whereas if the mortality rate is 30 per cent, it is a very high risk. We really need to think twice about whether we would go in for an operation with a mortality rate of 30 per cent. ...

‘A. (Dr Houston): All I can think of is myself when we started, I had a figure of 20 per cent from general results that people are talking about for the procedure. It is less now, but that was the figure, 1 in 5, I tend to prefer that to percentage, somehow, and then less than 1 in 20 for an inflow correction ...

‘Q. (The Chairman): … would it have been part … of the habit or behaviour of cardiologists to say, “Well, we only do X, but if you go elsewhere, they do Y and as it happens, Y does have a greater chance of survival, albeit that there are problems later on down the road, as we understand them”, so that the parent can weigh that in the balance as well. Would that have been a habit?

‘A. (Dr Houston): I would have thought not, because you can talk about people not only in this country but elsewhere.

‘A. (Dr Silove): I agree with Dr Houston there. When you are dealing with a large population of patients, you have to be practical in the sense that you cannot really think of transferring everybody, if they wish to be transferred, to some other place, because you have to go through the logistics of organising that, and the place that you might want to transfer them to might not be able to take them.

> ‘Once you start trying to make those judgements in your own centre, it really becomes very difficult. You cannot just single out one or two conditions; you have to deal with every single condition that you see in the same way.
>
> ‘A. (Dr Houston): I do not know when we are talking about … We generally know who has good results now; would we have known them in the late 1980s?
>
> ‘A. (Dr Silove): You probably would only have known by sort of word of mouth at the meetings of our professional associations. ...
>
> ‘Q. (Mr Langstaff): We may not be talking here about good results, but alternative operations. That is certainly going to be known, is it not: who is still doing Mustards, who is still doing Sennings?
>
> ‘A. (Dr Houston): I think if parents had said, “I want a Mustard” or “I want a Senning done”, I think in most places it would have been discussed. No-one would refuse to do that for them but I think one might try to dissuade them and suggest the other alternative was the better, but if they wanted it, no-one would say “You are not getting this operation, you would have to go elsewhere.” I do not think so. Would that be correct?
>
> ‘A. (Dr Silove): I do not remember anyone saying that. ...
>
> ‘Q. (The Chairman): … One is really asking you as experts whether, in the late 1980s and early 1990s, it would have been perceived as part of your duty to tell the patient about other procedures elsewhere and the option of choosing X rather than Y.
>
> ‘A. (Dr Houston): I would have thought not. Not in detail. Again, to mention that previously there was an operation which had better immediate results but poorer long-term ones.
>
> ‘A. (Dr Silove): Let us take an extreme example. If I was in a centre where I knew that the mortality rate for a particular operation was, say, 50 per cent, and I knew that the same operation could be done with a mortality rate of, say, 10 per cent in one or two other centres in the country, I think I would tell the parents that. Supposing the mortality in my centre is 40 per cent, I would tell them that. If it is 30 per cent, I think I would still tell them that. But if it is 20 per cent, I am not so sure, because I do not know whether the mortality rate is going to stay at 20 per cent or come down to 10 per cent.’[71]

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[71] T49 p. 104–11 Dr Silove and Dr Houston. See Chapter 3 for an explanation of clinical terms

56 Dr Silove and Dr Houston discussed the practice of informing parents about the risk of morbidity and of quoting risks in the following exchange:

> ‘A. (Dr Silove): … it is very interesting how surgeons and cardiologists over the years have always talked in terms of mortality rates, and any papers that you look at in the literature refer to mortality rates. There is very little actually written about the incidence of brain damage and kidney damage and liver damage and all sorts of other problems that occur.
>
> ‘I think that for every percentage mortality rate that one gives, one has to give a percentage of perhaps a half a per cent for a risk of neurological damage. That is something which many of us, as cardiologists and cardiac surgeons, have tended not to do in discussing operations or proposed operations with parents.
>
> ‘Q. (Mrs Howard): If that question, however, was asked specifically of you, how, in your practice, would you have answered that?
>
> ‘A. (Dr Silove): I would say, with any operation, not only is there a risk of death, but there is a risk of other problems. I mean, that is something I always have said, but I have never gone on to specify the problems.
>
> ‘If they are asking me, “Is there a risk of brain damage?” I would have said, “Yes, there is a risk of brain damage. I cannot quantify precisely what the risk is”, largely because I do not think I knew what the risk was at that stage. I think it is only in the last five years or so that people have been writing a little bit more about the incidence of brain damage following cardiac surgery, at least, in the papers I read. I do not know what Dr Houston feels?
>
> ‘A. (Dr Houston): For a long time, in fact for as long as I can remember as a consultant we have been writing down, “Parents interviewed, warned of risks”, no matter how minor the thing is, risk of death, brain or kidney damage, but it certainly has not been my practice to quote a sort of figure for risk of brain or kidney damage. If they asked me, what would I say, it would depend on what the condition was they [the surgeons] were operating on, clearly.’[72]

57 Professor de Leval and Dr Silove in their expert evidence told the Inquiry that cardiologists and cardiac surgeons (and others) worked as a team when proposing the Switch procedure to parents:

> ‘A. (Dr Silove): … the cardiologist would see the parents first, but the cardiologists and the surgeons will have discussed all of the ramifications in quite some detail before the cardiologist ever puts something to the parents.

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[72] T49 p. 146–7 Dr Silove and Dr Houston

> ‘I am sure it is the cardiologist who would be the first to suggest to the parents, “We have discussed this problem and we feel that the right way to go forward is to go for the Arterial Switch operation”. It then becomes a question of how it is dealt with in an individual institution, whether the parents see the surgeon or whether the cardiologist and the surgeon see the parents together, but the communication is terribly important …
>
> ‘It is a team consultation, it is a team decision and it is a team responsibility. I do not think the surgeon should take the flack for everything that goes wrong. I think the whole team is responsible for things going right or wrong.’
>
> ‘A. (Professor de Leval): I fully agree with that … every single patient operated on has been discussed once, twice or three times in great detail by at least two consultants, a surgeon and a cardiologist, but most of them by the junior staff, other consultants. If it is a difficult problem, we would repeat investigations. In the beginning we used to go back with the echocardiograms, repeat an angiogram, to find out where the coronary arteries were. Because the coronary artery was so crucial, sometimes we went ahead with a Switch and found different coronary arteries than expected and we had to back up to a Senning.
>
> ‘So all these decisions were team decisions in which we all took responsibilities. I think this is that type of attitude, corporate attitude that was communicated to the parents, which I think, allowed us to work in an atmosphere of trust and confidence. I think it is absolutely vital. I do not think the parents have ever seen me, as a surgeon, as a single individual within the hospital. I have been always part of a team, and they knew when I talked to them that it was after discussing with others, it was the decision, which had been taking place at the conference.’[73]

58 Dr Michael Scallan (consultant anaesthetist at the Royal Brompton Hospital) gave expert evidence to the Inquiry. Dr Scallan, commenting on Dr Stephen Pryn’s evidence, indicated that:

> ‘A. It is not normally the practice for an anaesthetist to give a specific risk figure for paediatric heart surgery. The surgeon will quote a figure and, as he said, that covers the whole procedure which anaesthesia is upon.
>
> ‘Q. Because the relative risk associated with anaesthesia is very small?
>
> ‘A. That is true, but like so many things, this is evolving and it is becoming increasingly obvious that the details of the anaesthetic and the risk will probably have to be explained to parents and patients in far more detail in the future. It is not inconceivable that at some future date there may be a separate anaesthetic consent form as distinct from the surgical consent form. We are not yet at that point.’[74]

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[73] T50 p. 28–30 Dr Silove and Professor de Leval. See Chapter 3 for an explanation of clinical terms

[74] T72 p. 177–8 Dr Scallan

UBH/T clinicians' evidence

59 Mr Janardan Dhasmana in his written evidence to the Inquiry stated:

> '… in the 70s and 80s, there was no concept of "Informed Consent". The "consent taking", as [it] was called at that time, ranged over a wide spectrum. At one end were the surgeons, who spent minimum time in explanations, recommended the operation and expected the patient/guardian to sign the consent form while at the other end considerable time and effort was devoted in explanations. Similarly the patients also ranged in two categories, one who did not wish to know too much and wanted to leave the details to surgeons, and others who did wish to enquire about details of the procedure.'[75]

60 Mr Dhasmana went on:

> 'The decision to operate on children was taken jointly with the attending paediatric cardiologists in all cases. In fact the child was initially admitted, investigated and treated by the paediatric team and then referred to surgery … All routine and most of the urgent cases were discussed in the joint meeting[76] attended by clinicians involved with the investigations and management of these children. The child's clinical condition, haemodynamic data and angiogram would be discussed at this meeting, which would also include risk assessment and their suitability for surgery. Clinician's opinion on the child's condition used to help in prioritising the admission for surgery and conveyed as such to the parents during our meeting.'[77]

61 Mr Dhasmana stated that he believed parents were informed of the risks of proposed surgery on at least three occasions in routine cases:

> 'a. By the cardiologist — after the diagnosis was established following the investigations ... when surgery was considered as the choice of treatment … Usually the cardiologist would have talked in detail about the pathology and pros and cons of the choice of treatment. I believe risk of surgery was mentioned during this discussion;[78]
>
> 'b. First meeting[79] with the surgeon — This used to take place in the outpatient department in most of the cases but on some occasions in the medical ward after the investigation and discussion in the joint meeting. …;[80]

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[75] WIT 0084 0116 Mr Dhasmana

[76] For a typical example of Joint Cardiac Meeting minutes, see UBHT 0188 0001

[77] WIT 0084 0121 Mr Dhasmana

[78] WIT 0084 0116 – 0117 Mr Dhasmana

[79] See below for details of what transpired at a 'first meeting'

[80] WIT 0084 0117 Mr Dhasmana

> ‘c. On admission to the surgical ward — In routine cases children were admitted about 48 hours before operation and I used to see parents again before surgery and invite [them] for another discussion if they so wished. Since it was now our second meeting, it would have been run on the lines of a question and answer session and I would try to clarify if there was some doubt or misunderstanding in their mind. However I tended to be a bit more reassuring during this second meeting as I did not wish to increase their anxiety any more than was naturally present on the day before their child’s operation.’[81]

62 As for emergency operations, Mr Dhasmana stated that the first contact with parents would be treated as a ‘first meeting’:

> ‘… the meeting would take place in the ward, usually introduced by the referring cardiologist or the accompanying ward nurse… I would stress the gravity of [the] situation and the reasons for recommending an emergency surgery. On a number of occasions I would have emphasised that even though the risk was high, i.e. 50:50 or even higher, their child may not survive without surgery. Examples are when babies were suffering from TAPVD, Truncus and some with complex and multiple problems, especially if they were already on ventilator and haemodynamically unstable.’[82]

63 Mr Dhasmana described what happened at a ‘first meeting’, with parents, which mostly took place in the outpatient department but on some occasions took place in the medical ward:

> ‘(i) I would introduce myself as a surgeon to whom the child was referred, examine the patient and start my preoperative discussion. The abnormality in the child’s heart would be explained with the help of a diagram or sketches. These would come from either the cardiologist’s notes/catheter report, or from my file of collection of various diagrams and sometimes in the form of hand drawn rough sketches. The surgical techniques would be explained in the same way with the help of sketches. It would have always been mentioned whether the procedure was open-heart surgery or a closed procedure and where it would be performed …
>
> ‘(ii) The risks, in particular the mortality, was mentioned in the form of percentage i.e. 20% or to simplify 2 out of 10 would not survive the operation. The morbidity or the possibility of postoperative complications would be mentioned during this discussion but figures would not have been mentioned, as these were not available at the time locally or from any other centre in the country. I have always mentioned that there was [the] possibility of injury to other organs of [the] body like lungs, kidneys and brain following the use of heart lung machine but these are becoming rarer with the continuing improvement in perfusion and surgical techniques. I would have also mentioned that these injuries would not be noticed until a few

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[81] WIT 0084 0119 Mr Dhasmana

[82] WIT 0084 0119 Mr Dhasmana. See Chapter 3 for an explanation of clinical terms

days after the surgery … Similarly the possibility of incidence of paraplegia after the surgery for Coarctation of Aorta was mentioned to parents of these children. The discussion on morbidity could go in more detail if parents asked further questions.

'(iii) I would have mentioned if there were possibilities of any further surgery in the future. For example, if the intended operation was a palliative procedure, i.e. shunt or PA banding, I would have mentioned the possible time frame for the definitive repair along with a brief description of that operation. Similarly, in cases of Tetralogy of Fallot, AV Canal and some other conditions where a VSD was also present, a possibility for repeat operation for residual VSD or further surgery on affected valve or scar related narrowing of Aorta and/or Pulmonary artery would also be mentioned.

'(iv) I would also state at this meeting that most children after surgery would require some form of medication for some time. This would be supervised by the cardiologists in the follow-up clinics and withdrawn, once the child has made full recovery from the operation. I also used to state that their children would be followed by the cardiologists for some time, maybe years. They would monitor the child's progress clinically and with investigations, such as a 2-D Echo examination, and refer the child back to me if any further intervention was required.

'(v) I tried to be as open and frank as possible during this meeting and as a result, on [a] number of occasions parents used to get upset especially with the mention of mortality and at times the accompanying nurse or counsellor would spend some time in trying to reassure the parent. I have also tried to reassure them on occasions with the statement, like, hopefully their child would come through this operation without too much trouble.

'(vi) I believe that this meeting was the best opportunity to discuss the risks associated with surgery. This gave them the time to ponder on various aspect[s] of the discussion and raise some further questions, which was not clear to them, with their GP and/or referring cardiologist. They could seek further clarification with me when the child was admitted for surgery. However, since it was our first meeting, the parents used to be very anxious and at times certain part[s] of the discussion could have been misunderstood as I found out on few occasions through their GP or the referring cardiologist's phone calls or letters. Similarly, there were [a] few occasions when parents had stormed off from the clinic or the ward after our first meeting, to return later after due consideration on their part.'[83]

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[83] WIT 0084 0117 – 0119 Mr Dhasmana. See Chapter 3 for an explanation of clinical terms

64 Mr Dhasmana told the Inquiry further that:

> ‘Whenever I have mentioned, I think if I was seeing a child, then talking to the parents, I would in a way draw diagrams and I would really say what was wrong, and of course, then I would mention that there are two ways of dealing with it: one is if I am seeing the child at 7 or 8 months of age, and no VSD, then there is no use talking about the Switch there; that is a straightforward Senning.
>
> ‘But of course in a child where both operations could be advised, there, especially a neonate, I would be talking of two ways of dealing: one is Senning, but that means waiting for 6 to 8 months from now, when this would be carried out. Unfortunately, the long-term outlook of Senning is not certain. Secondly, the Arterial Switch which I can repair right now, of course, it carries a high mortality, as compared to Senning, but with Senning, low mortality and long-term uncertainty, I think higher mortality at this time is quite acceptable, and I would strongly recommend that Arterial Switch is the better operation. That is how I put it.’[84]

65 On the role of non-clinicians, such as specialist nurses, family support services staff and junior staff, Mr Dhasmana stated that:

> ‘There was no organised set up where these groups could routinely express their opinion. However the “Joint meeting” used to be attended by few nurses, cardiac technicians and the cardiac counsellor, but mostly as observer.’[85]

66 Mr James Wisheart, consultant cardiac surgeon, stated in his written evidence to the Inquiry:

> ‘For decision-making about elective patients there were two meetings each week for virtually the whole of the period between 1984 and 1995. These were essentially meetings between the cardiologists, the cardiac surgeons and the cardiac radiologists but which frequently included the paediatric counsellor together with nurses and radiographers who worked in the catheterisation laboratory. From time to time an anaesthetist attended but this was not common. Where consultants were present, as far as possible, their juniors would attend also … Within these meetings patients were referred to Mr Dhasmana or me. The format of the meeting was that the paediatric cardiologist responsible for any given child would indicate to which surgeon the referral was being made. He would then present the case giving an account of the clinical history, the findings on examination, the ECG and chest X-ray, what the echocardiogram showed and what were the findings at cardiac catheterisation, angiography and any other special tests which had been done, such as a CT or an MRI scan. It would be normal for the echo to be shown to the whole meeting, as would the angiograms, plain X-rays, CT or MRI scan.’[86]

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[84] T87 p. 86–7 Mr Dhasmana. See Chapter 3 for an explanation of clinical terms

[85] WIT 0084 0121 Mr Dhasmana

[86] WIT 0120 0128 – 0129 Mr Wisheart

67 Dr Pryn stated:

> 'As an anaesthetist, I was not involved in pre-operative planning. This was no different from my experience in Oxford, although when I was in Southampton I would be involved in such discussions when cases planned for the next week were presented at a multi-disciplinary case conference.'[87]

68 Mr Wisheart stated that the nature of the discussion which followed would be determined by whether:

> - '... the patient in question was quite straight forward and there was a broad body of accepted knowledge and practice concerning what should be done.
> - 'the child had a straight forward condition about which there would be little disagreement as to what was appropriate, but in whom there were significant additional features of one sort or another. These additional features might require a discussion, modification of the usual strategy or even a more radical change in strategy.
> - 'the patient had a condition and needed treatment which was more complex; there would then need to be a detailed discussion of the criteria on which selection for any given procedure was made.
> - 'the child was one of a very small group with a rare condition needing uncommon and complex procedures; in some of these we might feel it wise that the patient should be discussed with colleagues at another centre, usually Great Ormond Street.
>
> 'In order to reach a decision there would then be a discussion which might primarily be between the referring cardiologist and the surgeon to whom the patient is referred but which would actively include all the others attending the meeting. The discussion was always open and contributions were always welcome from whatever source.'[88]

69 Mr Wisheart then set out the four possibilities arising from the meeting and discussion:

> - '... that advice should be given to the parents that an operation should be undertaken and the parents would then be seen, either in the ward or in the outpatients.
> - 'that further investigations should be carried out and the findings reviewed subsequently.

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[87] WIT 0341 0018 Dr Pryn

[88] WIT 0120 0129 Mr Wisheart

- 'that a decision not to operate should be taken which might actually be one in principle for the long term or one to be reviewed after an interval.

- 'advice might be sought from elsewhere.'[89]

70 As regards the involvement of other members of the team, Mr Wisheart stated:

> 'While the cardiologist may well have suggested what type of surgical procedure would be appropriate for the child, at the end of the discussion the surgeon has to make a recommendation.'[90]

The role of junior staff

71 Mr Dhasmana stated that:

> 'Traditionally the junior doctors used to get parents to sign the consent form soon after admission in the ward as a part of their clerking procedure in routine cases. I used to talk to junior doctors on the pathology and reparative techniques along with the risks involved during the ward rounds. Therefore most of junior doctors would have been aware of common routine conditions like ASD, VSD and Tetralogy, after they have spent few weeks in the cardiac unit. They also knew that parents have already talked to me in the clinic and have agreed for their child to have surgery. The new SHOs [senior house officers] were not supposed to get consent signed on their own. There were always few experienced doctors available in the unit to help the new SHO. In addition I always advised junior doctors in the unit, not to get consent signed if for some reason, I had not seen and talked to parents before or if they had questions regarding any aspect of surgery… I used to see parents in the ward before surgery and then have another discussion later on. I would get the consent signed at the end of this meeting, if it was not signed before. There was some change in the ward policy, around 1993 or 1994 when SHOs were asked not to get consent signed, but to leave it to the experienced Registrars or Consultants. In emergency situations I would get the consent signed after my meeting with parents in the ward.'[91]

72 In July 1993 Professor John Vann Jones wrote a letter to Mr Wisheart with a copy to Mr Dhasmana, stating:

> 'My junior colleagues have complained to me today that they feel unhappy about consenting people for cardiac surgery and for writing up their pre-med. The reason

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[89] WIT 0120 0130 Mr Wisheart

[90] WIT 0120 0132 Mr Wisheart

[91] WIT 0084 0123 – 0124 Mr Dhasmana

> for this is they are distinctly unfamiliar with cardiac surgery and when it comes to consenting the patient they do not really know the procedures they are prescribing … they do feel that someone who is familiar with what the patient is about to undertake should be doing the consenting …'[92]

Calculating risks and informing parents about them

The approach of the clinicians in Bristol

Mr Dhasmana

73 Mr Dhasmana stated that:

> 'The national data, as received from the UK Cardiac Surgical Register (UKCSR) certainly influenced me in my discussions with parents. I believed that this data was an average for all centres in the country, some of which were lesser volume units like ourselves and may have been new to the procedure, and therefore should be achievable. As the data from the individual units were not available, this was the best guide I could have, during the early part of my career in mid to late eighties, when I had [a] smaller number of cases, where figures could not be predicted with any confidence. But the register was not helpful in … operation[s] like Arterial Switch, as the UKCSR categorises paediatric patients according to the pathology and not the type of operations. The Arterial Switch was performed in different group of patients and similarly the patients with Transposition of Great Arteries were treated by more than one technique in the country. Therefore the true mortality figures of the Arterial Switch procedures for a particular group of patients could not be known from the register.'[93]

74 Mr Dhasmana said he used the data relating to the BRI as a basis for discussion with parents for most procedures, with the exception of Arterial Switches, which only he carried out.[94]

75 Mr Dhasmana stated:

> 'I did take account of my record after 1990 when I had enough patients on my list to speak with any confidence on most of procedures. But this did not help me with Arterial Switches, which was started late (1988 in older children and the neonatal programme in 1992). In addition I was operating on average on 2 – 4 patients per year, not enough to speak with any confidence on my own figures, except in the

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[92] UBHT 0344 0013; letter from Professor Vann Jones to Mr Wisheart dated 5 July 1993

[93] WIT 0084 0119 – 0120 Mr Dhasmana. See Chapter 3 for an explanation of clinical terms

[94] WIT 0084 0120 Mr Dhasmana

> group of older children, where I developed enough experience by the end of 1992, to quote with confidence my own figure.'[95]

76 Mr Dhasmana told the Inquiry that he did not inform parents of the figures relating to his success or failure figures in a particular procedure unless he was asked:

> 'A. The first few patients I always quoted 50:50 may or may not make it. I even quoted 60 per cent, but my record is very good in Truncus after 1989; I had done 6, 7 or 8 without any deaths. I think in 1993/94 when I was talking to a parent about truncus, I would be giving a risk of about 30 per cent.
>
> 'Q. From that last answer, it appears you modify your assessment of risk given your own personal experience?
>
> 'A. That is right. If you have a series you will quote with confidence, you can quote. If you have no series, you have nothing else to fall back on except published literature, which you believe in.
>
> 'Q. I want to contrast the fact that your good experience causes you to reduce an estimate of risk made to a parent, as in, you say, your Truncus Arteriosus after 1989, but your bad experience, as in the neonatal Switch, did not cause you to increase your risk estimate to a parent, rather it made you go back to published literature and rely on the general medical risk in any particular centre.
>
> 'Why take a different approach depending on whether your results were good or bad?
>
> 'A. It was not a different approach. I find it difficult to explain nowadays with whatever information we have in the post-1995 era, what we should be talking to parents and what we should not be. I do believe that one has to put [in context], especially as a surgeon, in the era you were talking to parents, and what was happening. I did not think I was doing anything different than what was being done elsewhere. If any of those parents would really have asked me what was happening before, I would definitely have told them that had happened.
>
> 'Q. That relies on them asking you. You are the expert?
>
> 'A. Well, I am afraid at that time, that is what the practice was, and I was just following the practice.

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[95] WIT 0084 0121 Mr Dhasmana

> ‘Q. You did not have to follow anyone else’s practice; you had your own relationships with parents, did you not?
>
> ‘A. Well, you do not develop a relationship on the first day you are seeing them, really, do you?
>
> ‘Q. What, if anything, prevented you from saying, for instance, “Well, the risk in this operation is 25 per cent but what you ought to know is that the last five such cases that I have dealt with have been entirely successful.” That is one way of putting it, if that has been the case. One would have no problem with that, if 25 per cent reflected a general risk.
>
> ‘The converse: “The risk is 25 per cent but what you need to know is that sadly, for I think particular reasons, but sadly the last five I have operated on have all died.” Did you ever think of putting it that way?
>
> ‘A. Not at that time, no. I did not tell them my successes or failures, unless I was asked about it.
>
> ‘Q. Do you think you ought to have told them, rather than wait to be asked?
>
> ‘A. Now, I think what has happened after 1995, I think, yes, we should be now doing that, but thinking always changes with the passage of time. We have become wiser now.’[96]

77 Mr Dhasmana stated that:

> ‘My quotations for mortality figures changed over years keeping in pace with improvement nationally. To quote an example, in Tetralogy of Fallot a figure of 15% mentioned over mid to late eighties changed to under 10% after the year 1992–93. Similarly in cases of Complete AV canal, quotes for the mortality figures came down from 25–30% in late 80s to 20% in 90s.’[97]

78 As regards referral to another centre, particularly when the proposed surgical procedure was new, Mr Dhasmana stated that he followed what he understood to be the standard practice prevalent amongst his colleagues, together with knowledge from his training. He stated that his practice was to inform parents when new procedures or modifications to existing procedures were being proposed.[98]

> ‘In 1988 when I started the Arterial Switch programme, the parents of the first patient were informed and asked whether they would like to take their child to another centre like Birmingham … Similarly in 1992 when I started the neonatal

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[96] T87 p. 90–2 Mr Dhasmana. See Chapter 3 for an explanation of clinical terms

[97] WIT 0084 0123 Mr Dhasmana. See Chapter 3 for an explanation of clinical terms

[98] WIT 0084 0122 Mr Dhasmana

> Switch programme, the parents were informed that this was a new operation in the neonatal period and that I had performed this procedure in older children.'[99]

79 Mr Dhasmana further stated:

> 'I was not aware of any obligation that I should have quoted any comparative figure from other centres to parents during the preoperative discussion. During my training I had not witnessed this in any of the centres … I was aware that in most cardiac operations I was within UK figures or catching up … For Arterial switches no comparative data was available from other UK centres except from Birmingham until 1992 …'[100]

> '… I would have provided some information to parents if asked.'[101]

80 He referred in his written evidence to the Inquiry to a meeting with parents of a baby with Truncus who did ask about comparative information. He stated that he could only give figures from the UKCSR:

> 'I mentioned centres like GOS [Great Ormond Street Hospital] and Birmingham without any real data, as no figures were available from these or any other centres in the country.'[102]

81 As regards informing parents, during pre-operative discussions, about the current record relating to mortality and outcome in the Unit, Mr Dhasmana told the Inquiry:

> 'I used to tell them, in a way, that we were not doing this type of thing before; now we have started doing it. But I do not think I have really mentioned, except for the first few cases in the beginning, that this is what has happened in the past and I am not – you know, this is my results, no, not that way.'[103]

82 Discussing guidance on informed consent and on quoting risks, Mr Dhasmana said:

> 'There was no guidance at that time, and I did not know we were supposed to be saying that, because I had worked in a number of places and I heard nobody saying those things.'[104]

Mr Wisheart

83 Mr Wisheart described his approach in his written evidence to the Inquiry:

> 'My training, reading and personal views led me to explain to parents in detail what was involved in an operation and what estimate of risks were attached, and

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[99] WIT 0084 0122 Mr Dhasmana
[100] WIT 0084 0122 Mr Dhasmana
[101] WIT 0084 0123 Mr Dhasmana
[102] WIT 0084 0123 Mr Dhasmana
[103] T87 p. 84 Mr Dhasmana
[104] T87 p. 85 Mr Dhasmana

> I devoted a substantial amount of time to this part of my work. This was the case throughout my time in Bristol from 1975 and initially I understood that my practices in this respect, were new in Bristol.'[105]

84 Mr Wisheart stated that he understood:

> '... that the first written advice from the GMC on consent was published in 1999. Their booklet *"Good Medical Practice"* published in October, 1995, contained general advice only. The Senate of Surgery of Great Britain and Ireland gave advice on consent in October, 1997 in *"The Surgeon's Duty of Care"*.
>
> 'I believe that there was a booklet prepared by the Medical Protection Society on the subject of Consent, but it was only sent out on request or in relation to a relevant enquiry.'[106]

85 Mr Wisheart stated that as regards informing patients of the risks involved in surgery:

> 'During the period 1984–1995 I provided information on the risks associated with surgery in the following manner, in outline:
>
> - 'I provided an explanation of the abnormality that was present in the heart.
> - 'I explained what would be the consequences of that abnormality if left untreated.
> - 'I indicated what treatment was available for this abnormality.
> - 'I indicated what I believed was the treatment of choice, and gave that as my advice. I would have indicated what I hoped would be achieved by following that course and whether there were any major predictable limitation. I would then have given them an indication of what risk of mortality was associated with this advised operation. I would normally do this by saying either:
>
> '(i) that the risk of this operation is X%, by which I mean that if 100 children had the operation 100–X would come through but X might die at or following the operation.
>
> 'Or
>
> '(ii) I might simply say that if 100 children had this operation I would expect so many to come through (quoting a number) but that the remainder (quoting the residual number) would not come through, or would die at, or following the operation.

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[105] WIT 0120 0368 Mr Wisheart
[106] WIT 0120 0368 Mr Wisheart

> ‘Occasionally, I would have discussed alternative methods of treatment.
>
> ‘Save for coarctation surgery … it was not part of my routine to indicate the risk of surviving with a permanent complication or injury, which for practical purposes means a central nervous system injury. It is my belief that such explanations were not generally given until recent years …
>
> - ‘This explanation, in nearly all cases was given by myself and in many cases would have been in the presence of a nurse, a counsellor or a junior doctor.
> - ‘I always invited parents to ask questions and discuss the issues.
>
> ‘For completeness, consent for cardiac catheterisation was obtained by the cardiologist and consent for general anaesthesia by the anaesthetist.’[107]

86 Mr Wisheart told the Inquiry that he took account of data relating to his own practice, in so far as they were relevant to the patient whom he was treating at the time.[108] In his written evidence to the Inquiry he stated:

> ‘The risk involved in a procedure, is the risk in the here and now; that is to say in this Institution, by this surgeon, in the present era. It is not sufficient to quote the results of another surgeon or an eminent centre elsewhere, such as the Mayo Clinic. There will normally be figures for the Institution and for the surgeon which can be the basis of information provided to the patient or to the patient’s parents. However, the difficulty is that for many operations, the numbers involved in the Institution’s own experience will be so small as to make those figures unreliable, or unhelpful. Reference must then be made to larger registers and other sources of information.
>
> ‘It is also important to note that the risk given for any given child is not just the risk for a set procedure, taken from some list or document, it is the risk of that procedure taking account of all the relevant details and circumstances of that child. Thus for example;
>
> ‘1) If the child has additional abnormalities, or
>
> ‘2) If the child’s condition is unstable at the time of the operation, or
>
> ‘3) If the operation is of an emergency nature,
>
> ‘any of these factors will add to the risk of the operation. Therefore the risk to be given has to be tailored to the needs and the circumstances of the individual child.

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[107] WIT 0120 0357 – 0358 Mr Wisheart. See Chapter 3 for an explanation of clinical terms

[108] T92 p. 57 Mr Wisheart

> 'Finally it would be quite wrong to depict a surgeon as a doctor who simply carries out procedures, the results of which can be measured, or that the understanding between a surgeon and his patient is simply that the surgeon will carry out a tightly defined procedure.'[109]

87 Mr Wisheart told the Inquiry further:

> 'The indication of the level of risk that I would give to parents about a particular child would be based on the information I had about that child and would be tailored for that individual child. So in this context if the child under consideration to the best of our knowledge had an AVSD with either nothing more or only something that would have changed things relatively marginally, then that would have been quite different from a situation where a child had an atrioventricular Septal Defect and let us say I knew that the child had left ventricular outflow tract obstruction or if I knew the child had severe but not inoperable pulmonary vascular disease. So you cannot just say AVSD, press a button and get a number. The individual child has his own characteristics or her own characteristics and one therefore does one's best to tailor what one says to those individual characteristics because I think it would clearly be inappropriate to ignore those differences that I have just indicated to you if you knew them.
>
> 'So when I looked back on my experience, I think you said at this point I have operated on 13 patients in this particular series from 1990,[110] and that would be correct, so I can say to you that just 9 of those 13 were free of a significant abnormality. Therefore if the child in front of me now appears to be free of any significant additional abnormality or risk factor, then the immediate relevance of the previous 13 patients has to be carefully considered, and it is not just a matter of transferring the number or whatever it may be from that experience to this child.'[111]

88 Mr Wisheart stated in his written evidence to the Inquiry that information on the child's condition was:

> '… the essential and the fundamentally most important information in assessing the risk of that child having any particular procedure. The risk can be predicted to be influenced by such factors as –
>
> 'i. Additional abnormalities.
>
> 'ii. The child's condition at the time of the operation; eg. is he or she ventilator dependent?
>
> 'iii. Is it an emergency operation?

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[109] WIT 0120 0360 – 0361 Mr Wisheart

[110] AVSD series. See Chapter 3 for an explanation of clinical terms

[111] T92 p. 58–9 Mr Wisheart

> ‘iv. The presence of Pulmonary Vascular Disease, which has not achieved a level of severity that would contra-indicate the operation altogether.
>
> ‘v. In the early part of the era mainly young age and low weight would have been considered important incremental risk factors.
>
> ‘This group of factors, without doubt influences the risk. Some factors will do so to a marginal extent and others to a highly significant extent. The difficulty is that there is no general accepted basis for assessing in a precise or quantitative manner, the degree to which any of these factors would increase the risk. It is only possible therefore to do so in a qualitative or, even possibly, an arbitrary manner. Once a risk factor is identified then one can begin the work of attempting to neutralise or minimise the effect of a risk factor and thus reducing the risk of the operation.
>
> ‘It was my practice always to consider factors such as these when making an estimate of the risk, even though there was no basis for doing so in a precise manner.’[112]

89 Mr Wisheart stated that, as a consequence, the BRI’s and his own personal record were the basis for any quotation of risks to parents:

> ‘These should be taken together as they are the real foundation for advice to parents about the risks of any particular procedure. In 1999 it might be thought that such data would have been constantly updated and freely available to surgeons throughout the period under review by the Inquiry. However, this should probably not always be assumed to be correct. I depended on my own log and on the material in the annual statistical summaries. In my experience the main limitation of local data was that for many of the procedures, the numbers locally may be very small. Indeed these numbers may be too small to be considered in isolation.’[113]

90 Asked by Leading Counsel to the Inquiry about the extent to which risk stratification could affect the way he described the degree of risk to a parent, Mr Wisheart replied:

> ‘… risk stratification are the factors that may exist within each of those categories altering the risk above or below the figure given and that is the core of the problem in all of this issue.
>
> ‘Because I can describe the presence of the abnormalities, I can give a qualitative indication of their severity but I cannot put a figure on it and therefore I cannot do a calculation and say “In this group of patients the risk is half normal, double normal, treble normal”, I cannot do that. All I can say is that the effect of all of these observed additional factors put together seems to be important and may double or whatever the risk. But there is no basis for being precise about it. That really is the

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[112] WIT 0120 0363 – 0364 Mr Wisheart. See Chapter 3 for an explanation of clinical terms

[113] WIT 0120 0362 – 0363 Mr Wisheart

> central difficulty. Otherwise I think one would be able to communicate it much more clearly.'[114]

91 Referring to the figures and the quoting of risks at other centres, Mr Wisheart stated:

- 'In general, this information about individual centres was not known, therefore it would not have been possible to refer to risks at other institutions.
- 'There may have been some procedures, for which there may have been information (although not necessarily precise information) about higher or lower risks at some other institutions.
- 'I am not aware of any professional or ethics guidance or requirement to refer to risks at other institutions during the period under review by the Inquiry.'[115]

92 Mr Wisheart described the use of national and international data and published papers. As for national data, he stated:

> 'Throughout the period 1984–1995 there has been national data in the form of the United Kingdom Cardiac Surgical Register (UKCSR). It has strengths and weaknesses, which have been outlined elsewhere in the evidence provided to this Inquiry. For the surgery of any condition, it provides an aggregated figure for the whole country or a national average. It does not provide the range of results from the Institutions or surgeons across the country, nor does it provide risk-stratified data. Nevertheless, where the unit's or my own surgical figures for the procedure in question are very small, I would also consider and give appropriate weight to the reported experience across the UK.'[116]

93 Regarding international data, Mr Wisheart stated:

> 'During the period 1984–1995 data from registers in other countries or from international registers was very limited. The only data which I can recall came from two groupings of surgeons in North America, namely the Congenital Heart Surgeons of North America and the Paediatric Cardiac Care Consortium. The information they made available up to 1995 was very limited. The latter group has published the results of their work for 1984–1995.'[117]

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[114] T92 p. 109–110 Mr Wisheart
[115] WIT 0120 0367 Mr Wisheart
[116] WIT 0120 0361 Mr Wisheart
[117] WIT 0120 0362 Mr Wisheart

94 As for published papers, Mr Wisheart stated:

> 'Often these papers came from centres of excellence and usually only papers are published which give the best results. They are therefore not representative, and are of limited use, and do not often contribute to the assessment of the risk in a particular operation. Over the years I can only remember a very few occasions when I relied on reports in published papers, to make an estimate of the risks of an operation.'[118]

95 Commenting on the views of other members of the team, inclusive of specialist nurses and family support services, Mr Wisheart stated:

> 'In general the opinion being expressed to the parents by me as a surgeon, was indeed the opinion which had previously been reached by the team. That is to say the cardiologists, the radiologists, the surgeon and any others who may have been in attendance at the clinical meeting. In the case of an emergency operation, generally it is the opinion of the cardiologist on call and myself as the surgeon on call, who will have conferred together. The advice being offered is virtually never the unilateral advice of the surgeon.'[119]

96 Mr Wisheart concluded:

> 'I always sought to make my estimate of risk as accurate as possible, but also sought to avoid optimism. I believe that my estimates of risk were adequate in that they were as precise and accurate as possible.
>
> 'However, I wish to make two points:-
>
> 'i) The accuracy, precision or statistical reliability of any figure given to a patient or a patient's family, will always be questionable. Such a figure is at best an approximation and its validity would virtually always be open to debate. The importance of this consideration is underlined by the very large number of different procedures which are carried out in paediatric cardiac surgery, each type of procedure being carried out in very small numbers.
>
> 'ii) For the patient or parent such a statement is always inadequate, because in the event for that patient, the risk will either be zero per cent or 100 per cent.'[120]

97 Mr Wisheart described where and when discussions with the parents took place:

> 'For elective operations I believe that the explanation should be given at a reasonable time interval before the operations so that the parents would have time to absorb and come to terms with, whatever has been said in the explanation. They

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[118] WIT 0120 0362 Mr Wisheart

[119] WIT 0120 0364 Mr Wisheart

[120] WIT 0120 0370 – 0371 Mr Wisheart

> also would have an opportunity on mature reflection, to think of any other questions that they might wish to ask. I usually met with the child and the family in the outpatient clinic. In a minority of instances, usually where the decision was a difficult one, more than one consultation would be needed to reach a conclusion.
>
> 'It would be my practice to see the parents again on the ward when the patient is admitted for surgery. On that occasion I would offer to repeat the explanation or to answer any questions which they would ask.
>
> 'Inevitably in the course of complex medical treatment, such as paediatric cardiac surgery, unforeseen findings may be encountered. It is not practical to obtain further consent from the parents during the course of the operation. In these circumstances the surgeon has no alternative but to take whatever action he believes protects the best interest of the patient.'[121]

98 As regards the use of written information or leaflets to inform parents, Mr Wisheart stated:

> 'These were rarely used in my practice beyond occasionally using a pre-existing diagram to explain the abnormality in the heart.'[122]

99 Mr Wisheart stated further that:

- 'I am not aware of any guidance as to how one should quote for risk, in the sense of the process of … making the best estimation of risk. I believe I did understand how to quote for risk, in the sense of how to talk with a patient or parents.
- 'In quoting for risk I took into account the procedure being advised, the detailed circumstances of the patient, the experience of the surgeon and the institution, and where appropriate, the national or internationally available data.'[123]

100 In his written evidence to the Inquiry, Mr Wisheart described his practice relating to the discussion of morbidity:

> 'From the early 80s the risk of paraplegia following Coarctation surgery in children was something which I explicitly stated to parents. This risk was of the order of 1 in 200 to 1 in 300. Indication of the risk undoubtedly caused distress and anxiety until the operation was over.'[124]

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[121] WIT 0120 0359 Mr Wisheart

[122] WIT 0120 0365 Mr Wisheart

[123] WIT 0120 0369 Mr Wisheart

[124] WIT 0120 0373 Mr Wisheart. See Chapter 3 for an explanation of clinical terms

101 Mr Wisheart also said:

> ‘It was not part of my routine to mention the possibility of Central Nervous System injury as a risk of other operations.
>
> - ‘If I were asked about this, I would have responded by indicating that there was a risk, but that it was very small.
> - ‘My view was that the risk of *surviving* with *severe* neurological damage was very small.
>
> ‘In the latter part of the period there was discussion in the field of cardiac surgery generally, including paediatric cardiac surgery, about the need to indicate the possibility of Central Nervous System Injury. I do not believe that it ever became common practice in the UK to do so during or before 1995.’[125]

102 Mr Wisheart stated further that:

> ‘Recoverable complications would only be discussed if I was asked about them.’[126]

103 Mr Wisheart described his practice relating to discussing with parents the likelihood of future surgery or continuing care being needed:

> ‘Where the risk of future surgery was predictable I told the parents about it in the discussion. For example, I would say that:
>
> ‘a) A patient having a palliative procedure would normally require a corrective procedure later.
>
> ‘b) If Coarctation surgery was carried out very early in life (the first 3 months), then the possibility of a recurrence of the Coarctation was greater than if carried out later. This might lead to the need for further surgery (or in the latter part of the period under review, to the need for non-surgical intervention).
>
> ‘c) The use of any prosthetic or bio-prosthetic material (other than a simple patch), early in life, meant that as the child grew that prosthesis or bio-prosthesis would be inadequate in size and therefore would need to be surgically replaced.
>
> ‘d) In some operations, of which Atrio-Ventricular Septal Defect (AVSD) corrections are an example, the surgery was complex and the risks of needing some later surgical treatment were greater than after most other procedures. Following AVSD correction further repair or replacement of the mitral valve might be needed or a permanent pacemaker might be required in the event of complete heart-block.

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[125] WIT 0120 0373 Mr Wisheart (emphasis in original)

[126] WIT 0120 0375 Mr Wisheart

‘e) The likelihood of protracted drug regimes being needed was relatively uncommon, but might be predictable as a possibility in a small number of cases. I doubt that this would have been routinely discussed before surgery.’[127]

104 As regards any discussion with parents as to alternative methods of treatment, Mr Wisheart stated:

- ‘Sometimes there would be a choice between correction or initial palliation and part of our advice would be to indicate which was more appropriate for the child. The advice would be determined by consideration of the details of the abnormality and the operations involved.
- ‘Sometimes it would be agreed that an operation was needed but that there would be no urgency as to this procedure and therefore there could be a discussion about its timing.
- ‘The view would have been held with increasing conviction throughout the period under review, that usually, and for most conditions, anatomical correction relatively early in life gave the best chances for future length and quality of life. Therefore alternatives to anatomical correction were in principle undesirable.
- ‘With increasing importance as time progressed through the period under review, for some abnormalities there was a choice between surgical and non-surgical intervention. Usually these two options would have been discussed by the cardiologists, surgeons and radiologists at the clinical meeting and if the patient was referred for surgery, it was because the clinicians had agreed that surgery offered the better prospect for the patient. If non-surgical intervention were mentioned in that discussion, it would usually have been indicated that we regarded it as a less favourable course of action.
- ‘If at a clinical meeting the clinicians had decided that non-surgical intervention was the course of choice, then the cardiologists would have explained that to the parents and the patient would not have been referred to the surgeon.’[128]

105 As regards non-intervention, Mr Wisheart stated:

- ‘If the conclusion reached at the clinical meeting by the clinicians was that surgical intervention was not appropriate, then that patient or that patient’s parents would not normally see the surgeon. The advice would have been conveyed to them by the cardiologist.
- ‘The possibility of non-intervention is referred to in the discussion with every patient, when the outcome of the condition if it is left untreated is discussed.

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[127] WIT 0120 0374 Mr Wisheart. See Chapter 3 for an explanation of clinical terms

[128] WIT 0120 0375 – 0376 Mr Wisheart

- 'If the decision to advise surgery was genuinely borderline (ie there was a fine balance between the risks and benefits), and the patient was referred to the surgeon, then the real option would have been discussed. This was an uncommon situation and the patients would have been in two groups:

'a) those with a trivial abnormality, in whom the prospects of a long and fit life untreated were good, but the prospects following surgery would have been better in our opinion. Such benefits are relatively marginal and a long way into the future. The two options would have been discussed and surgery could only be considered if its risks were very low. The patient or the patient's parents then decide.

'b) Those in whom the condition was extremely complex, and a proposal to operate may have been on the borderlines of what was possible. Again that would have been discussed, with a rehearsal of the main factors on either side of the decisions.'[129]

Dr Martin

106 Dr Robin Martin discussed reference to data from other centres, its uses when referring to other centres and the relevant considerations for referring to Bristol, in the following exchange:

'Q. … if you had said to the parent, who perhaps is the best judge of the child's interests "You may stay here in Bristol where it is good and it is local and where we have only done three operations of this sort on children at this age and they have all died, or we can, if you wish, send you to Birmingham where there is a risk, we cannot deny the risk but there appears on what we know about the figures to be a better chance of survival"; how do you suppose a parent would react from your experience to a choice put in those terms?

'A. That predisposes I had that information. As I have already said, I did not have information from other units. The only crude data I would have would be that from the Surgeons' Registry, the Society of Cardiothoracic Surgeons' Registry which gave very broad data for different groups, but it was not operation specific. We had really no comparable data to be sure about based on that. So whether I should refer patients to another hospital because Joe Bloggs had said their results when I met him at a meeting were good, I do not think that is a basis for making the referral. I would really have liked to see more data than that.

'Q. I think you jumped the question.

'A. Have I? Right.

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[129] WIT 0120 0376 – 0377 Mr Wisheart

‘Q. You have answered the question which I had not yet asked, which is: why did you not? The question I was asking: suppose the parent were presented with the option in something like those terms, what would you, from your experience, expect the parent to do? We will come in a moment to whether you could have put it in those terms because you may not have had the information. Suppose you had put it in those terms to a parent, what would the parent do you think have said?

‘A. It is very hypothetical. As I already said, that presumes you have the knowledge to put it in those terms.

‘Q. If you had the knowledge to put it in those terms and you said it, what would you expect most parents would say to you?

‘A. I think if you put it in those terms without any riders, I would expect probably the parents to say “I will go to a different centre”, most likely.

‘Q. You suspect that because, if those terms are appropriate on that hypothesis, I appreciate, there is really no answer, is there, to the suggestion that the child is probably better cared for in a centre which has an apparently better track record and has a much greater experience of the operation?

‘A. That predisposes you know that information.

‘Q. But on that hypothesis, that must be right, must it not?

‘A. If you tell me so. I think it is very difficult to judge, but there are many reasons why you might favour a referral to your own centre, which is the sort of line you are taking. There is the geographical ideas we have already discussed. The patients you are talking about may be only a relatively small proportion of your overall work so you build up a working relationship with your surgical colleagues. You certainly come to rely on their experience and expertise and listen to their advice. Any patient that is being assessed for surgery, it is not something I am saying this is what has to be done, it is something you discuss as a group and — I am not sure whether you have seen yet, but the joint conference data notes that would be done for most patients mean that opinions are canvassed from different areas, so my cardiological colleagues, my surgical colleagues all would have input into that decision-making process.

‘So deciding what treatment is right for that particular patient is a complex one; it is a complex interaction between many individuals of a team.

> ‘Q. As part of that answer you have said to me that the building up of a relationship with the surgeon in your centre is a matter of importance?
>
> ‘A. You inevitably build up a working relationship with colleagues and to an important degree you do listen to other people’s advice, you know, within your unit. So building up a relationship per se is not the “be all and end all”, but it is an important part of how cardiologists, cardiac surgeons work, they work as a team.
>
> ‘Q. Do you think it would prejudice the relationship of any cardiologist at Bristol with the surgeons at Bristol to have said “In this case we are going to refer this child to another surgeon for an operation which can be done here, but we think it can be done better there”?
>
> ‘A. It is very difficult to say. I think you would have to ask other colleagues, you know, particularly the surgical colleagues, whether they would have done.
>
> ‘I think there would have been a danger it could do so.’[130]

Dr Joffe

107 Dr Hyam Joffe discussed the role of the cardiologists, in informing parents, particularly as regards new procedures, in the following exchange:

> ‘Q. You said a moment ago that once the decision [to operate] had been taken, that the cardiologists – I forget your phrase –
>
> ‘A. Supported the service.
>
> ‘Q. — fully, I think, was the impression you were giving?
>
> ‘A. Yes.
>
> ‘Q. Does that mean that the cardiologists, in talking to parents about the operation, gave perhaps a more enthusiastic description of the operation and what it might achieve than they individually would have given had the decision as it were been theirs alone and had they not been part of the collective that decided to conduct the Arterial Switch?
>
> ‘A. I do not believe so. I think, with any new procedure, one has to be as open as possible, with parents. I do not believe actually we mentioned to anybody that this operation had never been done in this unit before, but the view would certainly have been given that this is a new operation, generally; that the results are not quite as good or not as good as the results of immediate post-operative surgery using the Senning procedure, but that the belief is, among the cardiac fraternity, paediatric,

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[130] T76 p. 136–9 Dr Martin

around the world and in this country, that the long-term benefits would be better. So, of the two operations available, we would recommend the Arterial Switch.

‘Q. Why was it, do you think, that it was not mentioned by anyone that this was the first or the second such operation being done in the unit?

‘A. I think at the time I do not believe that any unit would have taken a different approach, personally.

‘Q. That is not quite the same – that is not quite an answer.

‘A. I was going to come on to say that either one started a new procedure or one did not. I believe that it is a very difficult question to deal with, but I do not believe we would have necessarily started that operation if the advice had been given to parents in such a way that they knew we had no experience at all in neonates and would most likely not have wanted to do the operation.

‘At the same time, we would have told them that the surgeons had a fair amount of experience with the non-neonatal Switch, and that in that procedure the surgeon doing the operation has been achieving results that are more or less equivalent to those in other units in the country. And that that same surgeon would be tackling the neonatal Switch.

‘Q. So what you are saying in effect is that if you told the parents the whole truth, the whole facts about the operation, they probably would have said “No, I will not have the operation”, and to avoid that as a result, you did not volunteer all the facts?

‘A. Not all the facts, no, but I think we would have indicated, certainly, that this was a new operation and that if asked, I think we would have informed the parents that in fact, at that point for case number 1, we had not done one previously. There always has to be a case number 1.

‘Q. How many parents, in your experience, say to you, “Doctor, this is the operation you are recommending; tell me, have you ever done one before?”

‘A. I agree with you entirely, today that is exactly what I would say, that we have not done one before. In the current climate of 1992, which was more defensive, that was the view of, I believe, most of my colleagues around the country and that was the one we followed. I think it is inappropriate today, in retrospect, I would agree with you.’[131]

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[131] T90 p. 135–7 Dr Joffe. See Chapter 3 for an explanation of clinical terms

108 As regards informing parents generally, Dr Joffe told the Inquiry:

> '… I think the understanding of the lay public (and that includes parents as well as other patients) has evolved, has changed, has opened up, has become more desirous of knowing the full facts and I believe now (and I am using my usual kind of non-direct approach, if you like) [it is] probably best to give the full facts but put them in perspective as far as one can and somehow retain the sense of hope in the patient.
>
> 'But I still believe there is an element of judgement and selectivity involved and that there are some patients or parents … where I think I might have been a little tardy about telling them absolutely everything in a stark fashion because of my judgement, not that they would not want their child to be operated upon, but because it might – destroy is too strong a word, but might be too tough for them to cope with at that time.
>
> 'I would rather, under those circumstances, perhaps break up the information into what I believed at the time they would cope with, with a view to seeing them again once or twice before an operation and try and convey additional risks thereafter; it is a very difficult subject. I believe it comes with experience of being with people and unfortunately I have had to be part of the process, not only of informing people of the total picture but also of being present at bereavement situations and inevitably there will be a difference of opinion about how that should be handled. But I think one does one's best in one's own perception of the requirement.'[132]

109 Asked by the Chairman whether seeking to retain 'some sense of hope'[133] in the patient was misleading or unhelpful, Dr Joffe replied:

> 'It is a balance. I think the primary or the overriding risks I think should be stated and I do not think that under any circumstances one should shy away from that.
>
> 'By that I mean that if an operation has a risk of 1 in 3 or 1 in 4, and quite frankly at that time I do not think there is a difference in a parent's mind about what 33 mortality rate is versus 35 mortality rate, it is a real mortality rate, their child could die is the point and I think that is as far as one needs to go, frankly, at that stage but one cannot hold back on that, that is reality.
>
> 'But in terms of some of the less common complications, I believe that can be introduced in a gentler way in the case of cerebral haemorrhage or as Dr Houston mentioned, renal failure and other sorts of complications that would be far rarer.'[134]

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[132] T91 p. 35–6 Dr Joffe

[133] T91 p. 36 Dr Joffe

[134] T91 p. 36–7 Dr Joffe

110 Dr Joffe was asked about training in communication skills, in the following exchange:

> 'Q. Did you have any training in communication skills?
>
> 'A. No, not at all.
>
> 'Q. You have picked up the skills that you have by practice?
>
> 'A. Yes, correct.'[135]

Dr Jordan

111 Dr Stephen Jordan discussed the issue of giving estimates of the risks involved in an operation to parents, in the following exchange:

> 'A. … from my own point of view I find this whole business of emphasis on giving parents an exact figure for the mortality for an operation rather strange and it did not seem to relate to the real world in which I worked at the time. It may well be the situation in 1999 is entirely different, but I was much more prone to use terms like "This is a major operation, there are going to be considerable risks, but on the other hand ... " and you know, describe what the advantages are.
>
> 'In other words it was not my practice unasked to say to the parents "I am going to tell you what the statistics are with regard to the chance of your child surviving this operation".
>
> 'Q. In terms of statistics from other centres, I think we have already discussed this a couple of times, there was not any reliable published comparative data showing the comparison between Bristol or any other centre and other individual centres?
>
> 'A. The statistics on this occasion would consist of what either we heard formally at meetings of people presenting results or what was discussed over coffee at the same sort of meetings with clinicians there.
>
> 'Q. There might be papers published by centres who were anxious to broadcast to the relevant professional community?
>
> 'A. Papers usually are sort of given as presentations first. You would probably hear of it more quickly by going to something like a British Cardiac meeting or surgeons going to one of the Cardiac Surgical meetings.
>
> 'Q. Typically centres would be more anxious to write papers and give lectures and presentations on their successes as opposed to their failures?
>
> 'A. That is true, yes.'[136]

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[135] T91 p. 38 Dr Joffe

[136] T79 p. 173–4 Dr Jordan

112 The issue of informing the parents before a neonatal Switch procedure was discussed by Dr Jordan in the following exchange:

> 'A. My best recollection of what I said in effect was that, rather similar to starting off what I would have said about a normal neonatal Arterial Switch operation, the severity of the condition and obviously it is important that the parents realise once you are starting to talk about an operation with important risks that you are also talking about an operation on a child who otherwise is not going to survive. That is the first thing that is said.
>
> 'The second thing is to say that there are actually two ways of dealing with this condition. We will be discussing with the surgeon, this is if I had not already discussed it with the surgeon, that "There is one operation which can be left for some time and in our hands has very good immediate results, but the operation which would actually correct the condition is a much more major operation and it would have to be done fairly soon while your baby is still very small."
>
> 'Q. What would be said about the relative risks of mortality in that Arterial Switch procedure?
>
> 'A. As I have said before, I was not one to write figures on a piece of paper, I know the surgeons did on occasions, but I would have used terms like "major risk"and so on.
>
> 'Again, had I been pushed I would have said at that time "I think that the risks of doing a neonatal Arterial Switch operation in our hospital with this surgeon with his previous experience in a relatively uncomplicated transposition are going to be similar to the risks that would have occurred in the older patients with the more complicated form of anatomy".'[137]

Dr Masey

113 Dr Sally Masey stated:

> 'It has always been my practice to see patients prior to surgery, as far as is possible. Consequently I would visit a child having cardiac surgery the evening before surgery and discuss with the parents, and child if old enough, the anaesthetic plan. I would give them the opportunity to ask questions although I was not involved in obtaining consent for surgery.'[138]

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[137] T79 p. 181–2 Dr Jordan. See Chapter 3 for an explanation of clinical terms

[138] WIT 0270 0005 Dr Masey

Dr Pryn

114 As regards discussing risks associated with surgery with parents, Dr Pryn stated:

> ‘I always visited the patients on the afternoon or evening prior to surgery. I attempted to coincide my visit with the child’s parents or guardians, although this was not always possible. I did not see it as my role, nor did I have the experience, to re-assess the patient’s cardiac condition, with a view to determining whether the proposed operation was still indicated, nor whether this was the optimum time for the surgical intervention. This I assumed to be performed by the cardiac surgeons in conjunction with the paediatric cardiologists … I developed an anaesthetic care plan in my mind and explained to the parents the basics of my plan for pre-operative starvation, pre-medication, anaesthetic induction, invasive monitoring and intensive care. I always invited questions from parents or guardians. I did not specifically cover issues of operative risk, although if asked directly I covered it in general terms and referred the parents to their surgical consultant for further discussion. The approach I have always taken to pre-operative visits is encompassed by the standards subsequently published by the Royal College of Anaesthetists (RCA Guidance for Purchasers 1994). There were no information booklets on anaesthesia for parents, similar to that produced by AAGBI (Anaesthesia and Anaesthetists – Information for Patients and their Relatives), available within the BRI. Consequently no literature was provided for the parents concerning anaesthesia.’[139]

115 Dr Pryn stated in his written evidence to the Inquiry that he would explain operative risks to parents in ‘general terms’. He discussed this further in the following exchange:

> ‘A. I would say: “Your child is extremely unwell. His is a high-risk procedure. You are aware of that”, or “Your child is relatively well at the moment. We do lots of these procedures. It is relatively low risk”, that sort of general terms, but I would not put figures on it.
>
> ‘Q. What about risks associated with anaesthetics? Is there any necessity to explain any of those?
>
> ‘A. I thought that that was all incorporated within the overall surgical risk, because the risk associated with an anaesthetic is relatively small in most patients compared with the operative risk.
>
> ‘Q. So there was no need to treat that separately at further length?
>
> ‘A. I did not feel at the time.

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[139] WIT 0341 0016 – 0017 Dr Pryn

‘Q. At the time?

‘A. I did not feel so, so I did not.

‘Q. Presumably one of the reasons why you might refer a patient, or parent rather, back to the surgeon for further surgical discussion of risk would be if you picked up the fact that they did not appear to be adequately informed about the dangers of the operation that lay ahead.

‘Would that be correct?

‘A. That is true, but Mr Wisheart and Mr Dhasmana were extremely conscientious of documenting in the notes, in their clinic appointment that they had spoken to the parents about risk, and they often would write down the risk that they quoted to the parents. So I knew pretty much what had been told to the parents already.

‘Q. And, knowing what had been told to the parents, were there any occasions when you felt concerned about the adequacy of that explanation that had been apparently offered by the surgeons?

‘A. No.

‘Q. What about parents’ perception of the advice that had been given to them? Were there times when, having looked at the notes, you thought an adequate, proper, reasonable explanation of risk had been given, but it did not appear to have filtered through on to the consciousness of the parents?

‘A. I cannot remember any instances when I thought that the parents were not adequately prepared for a very risky procedure.

‘Q. So overall this was an area that did not cause either concern or a need to refer back patients or parents to the surgeons for further discussion?

‘A. Not often, no, and, in fact, the night before surgery is not a good time to have detailed discussions of risks anyway, so I probably did not court those discussions.’[140]

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[140] T72 p. 73–5 Dr Pryn

116 Dr Pryn expanded on the incorporation of any risk from anaesthesia into the risks of surgery in the following exchange:

> 'A. I assumed that when parents are told about the risk of the procedure, that risk incorporates all the risks: anaesthesia, surgery, intensive care.
>
> 'Q. Is that integration of risk a normal assumption for you, or do [you] separate the risk in any other situation, and therefore discuss with parents risk of anaesthesia as a separate issue?
>
> 'A. I think it is normal to group them together. I think the one time you would not group it would be, say, for a cardiac catheter study, where the risk of the procedure is relatively small, the main risk is that of anaesthesia, but for a complex surgical operation, the main risk will be surgery.'[141]

Nurses

Sister Woodcraft

117 Joyce Woodcraft, Senior Sister, BRHSC ICU 1985–1994, indicated in her written evidence to the Inquiry that, whilst nurses did not generally play an active role in obtaining consent from parents, they were present during discussions between the clinicians and parents.

118 She stated:

> 'In relation to Mr Dhasmana and Mr Wisheart, I have sat in with them many times whilst they explained to parents and family members the operation required. In my professional opinion they explained carefully and showed a great deal of empathy with the family. They drew diagrams to explain the surgery to the families. They were always careful to fully explain the risks involved.'[142]

Sister Disley

119 On the role of nurses in the discussions about consent and the risks of surgery, Sister Disley, Ward Sister, BRI, told the Inquiry:

> 'Q. You say that you had no role in discussing with families what the risks and benefits of the operation were. Whose role was it?
>
> 'A. The surgeon's.
>
> 'Q. Anyone else?
>
> 'A. Possibly the cardiologists must have been involved.

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[141] T72 p. 175 Dr Pryn

[142] WIT 0121 0009 Ms Woodcraft

‘Q. The cardiologist, would he normally be involved?

‘A. Yes, they would. They would see the children in the initial stages.

‘Q. For adults, the cardiologist would be in the same building as the surgeons?

‘A. Yes.

‘Q. Was there any difficulty in having these discussions in the case of children when the cardiologists were based elsewhere? Did the cardiologists come down to the BRI to take part in this discussion?

‘A. This particular discussion, I would have imagined would have taken place at the Children’s Hospital before the children were admitted for surgery.

‘Q. Do you remember witnessing the risk discussion, if I can put it like that, between the surgeon and the cardiologist and parents of a child at the BRI?

‘A. No. No.

‘Q. So when you say that you attended discussions in supporting role —

‘A. I think what I am referring to is discussions that probably happened maybe one or two days pre-operatively. I think they were discussions to just clarify issues that had been discussed several times before with the parents about the risks and benefits.

‘Clearly, the day before surgery is not the day to be identifying those risks and benefits. That is the stage to which I am referring.

‘Q. Would your role at this stage have been to provide essentially reassurance to the parents, to the patients?

‘A. I think so. I think parents were probably very anxious and had questions to ask afterwards. It was useful if you had been there to explain.

‘Q. Let us take parents of a child. The child is going to have surgery tomorrow or the next day. What kind of questions would the parent ask of you, as the Sister, as opposed to the cardiologist or the consultant surgeon?

‘A. I think they would be asking things about the pattern of the post-operative recovery, how long the child might be on a ventilator, how long they might have chest drains, where they could eat, at what stage they might be expected to wake up, that sort of thing.

‘Q. Would they ever ask you about the surgeon himself? Would they ever say, “Is X good?”

‘A. I do not recall anybody asking me that.

‘Q. Would you provide reassurance by saying things like, “Your child is in good hands with Mr X”?

‘A. I might have done. It is very difficult to remember.

‘Q. Is that the sort of reassurance that you might well have provided?

‘A. I think the reassurance that I am talking about refers to their post-operative recovery in the intensive care, explaining that route that the child would go down.

‘Q. Do you ever remember attending one of these discussions and hearing a risk or a benefit quoted to a patient, or a parent of a patient, that you disagreed with?

‘A. I do recall such an occasion, but it was actually after the child had had surgery.

‘Q. What was the occasion?

‘A. It was an occasion where the child was — I cannot even recall the surgery he had. He had made slower than expected progress, and was beginning to fit, if I can recall.

‘Q. What was said that you disagreed with?

‘A. I cannot recall the details of the discussion, but I felt that it seemed optimistic.

‘Q. The chances of survival being quoted? What was being quoted that was optimistic?

‘A. The recovery that the child would make.

‘Q. What did you do when you heard this being quoted that you thought was optimistic? How did you react?

‘A. At the time, I did not do anything — at the time, no, I did not do anything.

‘Q. When was this incident that you recall?

‘A. It must have been 1995.

‘Q. Who was the clinician who was giving what you thought was an optimistic prognosis?

‘A. Mr Wisheart.

‘Q. If you had a similar experience tomorrow at work with a patient and a clinician, would you react differently now?

‘A. Yes, I think there are occasions perhaps when we are discussing the care of long-term patients, and — yes, I would.

‘Q. Who would you go and talk to? Would you go to Fiona Thomas or Rachel Ferris or a clinician?

‘A. I would probably talk about it with a clinician.

‘Q. The one who had given the advice?

‘A. Yes.

‘Q. Can we go to WIT 85/35, please? This is again Dr Bolsin’s comments on your statement. He has given a comment on this particular paragraph. He said he would be surprised if a senior ward manager of long-standing, which I think is a reference to you, did not enquire of the surgeons whether the figures being quoted to relatives were correct or not.

‘First of all, is that something that you did before 1995, to enquire of the surgeons in that way?

‘A. As I have said earlier, these discussions, talking about figures being quoted, were undertaken pre-operatively, and not commonly undertaken in the ward for the first time.

‘I did not question them.

‘Q. As far as you were aware, were you alone in not questioning them, or was that common practice among ward sisters?

‘A. I do not know.

‘Q. Do you know of anyone who did enquire of the surgeons whether the figures quoted were correct or incorrect?

‘A. No, I do not.’[143]

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[143] T32 p. 118–123 Ms Disley

Counsellors

Reverend Robert Yeomans

120 In his written evidence to the Inquiry, the Reverend Robert Yeomans, advisor to the UBHT in spiritual and religious matters from 1993, stated that:

> 'I felt on those few occasions when I sat in with surgeons' discussions with parents that they stressed the seriousness of what was happening and did not gloss over it. I recall risks being discussed. They were discussed in the form of percentages. I cannot recall anything about the figures. The information was given with sensitivity. I recall the use of diagrams and sometimes parents would show me these. I usually felt that parents were told as much as they could know and understand. Some parents were unable to cope with the explanations because of other practical pressures, being emotionally drained, or a deep wish to have things "put right" without needing to understand. Some people took in every word and talked it over. Some people seemed to understand but could seemingly recall nothing. None of this is particular to cardiac parents but these are aspects of human nature. Sometimes the parents wanted clarification, or perhaps wanted something repeated, and I would try to give them the courage to go back to ask for further information, which they usually did.'[144]

Mrs Vegoda and Miss Stratton

121 In his written evidence to the Inquiry, Dr Joffe stated:

> 'During the early 1980s, it became apparent that, after the detailed initial discussion with parents at the time of diagnosis about the implications of the child's condition, and the plan of action to be followed, Dr Jordan and I found it increasingly difficult to spend sufficient time with parents to allay their anxieties. This was aggravated by the paucity of junior medical support in the BCH and the demands of the many peripheral clinics. Consequently, I approached Mrs Jean Pratten, Secretary of the Bristol and South West Children's Heart Circle, to seek financial support for a post of Counsellor in Paediatric Cardiology, who could act as a liaison between the cardiologists and parents. The Heart Circle decided to back this initiative and Mrs Helen Vegoda was appointed in late 1987 to one of the first such posts in the UK. She commenced duties in January 1988. A few years later because of parents' concerns about surgery and the split site, there was a need in the BRI ITU for a similar post but with a medical background. The Heart Circle also supported this post and Ms Helen Stratton was appointed in about 1991.'[145]

122 Dr Joffe stated further that both Helen Vegoda and Helen Stratton were involved in providing bereavement support. Bereavement support was developed in the BRHSC by Helen Vegoda who established a regular monthly meeting for those parents who wished to receive ongoing support.[146]

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[144] WIT 0274 0016 Reverend Yeomans

[145] WIT 0097 0014 Dr Joffe

[146] WIT 0097 0014 – 0015 Dr Joffe

123 Mrs Helen Vegoda described her role:

> ‘I understood it was quite a complex role, because it involved the emotional and psychological support and counselling to families. It involved giving information – … not medical information but other supportive information. It involved being there as a very general support at times of stress. It involved what I would have called “orientation”, helping parents to know what facilities were around in the Children’s Hospital in Bristol. It had a liaison element to it in terms of the community, and there were certainly other aspects, but I think at that time those were probably, possibly, the main ones.’[147]

124 Mrs Vegoda explained what she did by way of counselling and providing support:

> ‘… I think there is a continuum from counselling through to support, and it does not stop at a particular point.
>
> ‘What I was very careful not to do was to, what I would say, counsel in terms of medical information because I did not have that background. The counselling that I gave, the emotional support I would give, was, for example, there were certain particularly key points for parents that were emotionally extremely stressful and, for example, the diagnosis or a child going for a catheterisation or surgery, or at other points like that, and quite a bit of my counselling and support would be to try and be around at those key points and to give parents space to allow them, or maybe facilitate their emotional response at those times, to be there to listen to them.’[148]

125 In her written evidence to the Inquiry, she stated:

> ‘I became involved with the children and their families when they were admitted to the hospitals … I provided emotional and other support at key times during the child’s admission, for example, being available to parents accompanying the child to theatre or the catheter lab and supporting them whilst they awaited the child’s return. Some of my support was to liaise with parents’ employers to obtain leave of absence, give information about voluntary organisations such as the Heart Circle and the Downs [*sic*] Heart Group, and help make preparations for discharge by contacting other agencies, e.g. Social Services, GPs and Health Visitors. Having attempted to establish a working relationship with the families, my involvement with them varied from very intense to minimal, depending on the needs of the family.’[149]

126 Mrs Vegoda stated that occasionally she sat in with cardiologists and surgeons when a diagnosis was made or when details of surgery were given to parents.[150]

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[147] T47 p. 85–6 Mrs Vegoda

[148] T47 p. 92–3 Mrs Vegoda

[149] WIT 0192 0002 – 0003 Mrs Vegoda

[150] WIT 0192 0003 Mrs Vegoda

127 She told the Inquiry how she decided which occasions it was appropriate for her to sit in with parents at the discussions with clinicians:

> 'What I did was, I made a point of going down to the outpatients clinics at the BCH, and I think they were on Wednesdays. That would be when the pre-operative discussion took place with the parents.
>
> 'The nursing staff knew that I went down, and what would happen was that either I met there parents whom I had met previously, who I knew were going to be there … and I knew that they were going to talk to the surgeons, so that I might have prearranged to accompany them, if that is what they wanted. So that was one set of parents.
>
> 'Others, the nursing staff might have involved me and actually said to me, "There is a family in this afternoon who are going to be talking to one of the surgeons; it is quite a complex operation, I am just telling you that." If I did not know that family, I might go and introduce myself and offer to be around. But it was the parents' choice. If they did not wish me to be there, and obviously I cleared this with the surgeons and the cardiologists, then I would not sit in.'[151]

128 Mrs Vegoda stated that:

> '… I would usually try to ascertain whether a parent understood what any treatment or surgery entailed following the meeting with the cardiologists or surgeons. If it was apparent that a parent needed clarification of the information, I would ask the consultant/Registrar or one of the nurses to meet with the parents again to explain the procedures. I would never explain the medical aspect of any procedure to a parent, as I was not qualified to do so. I could provide the details of the process and place of treatment only… If parents were still concerned about procedures I would encourage them to go back to the cardiologist or arrange a meeting for them.'[152]

129 Mrs Vegoda told the Inquiry how she was able to judge whether parents had properly understood the details of what the clinicians had told them:

> '… it is a combination of what I heard myself, and as time went on, I became more familiar with some of the language that was used, and also, very much checking out with parents. I mean, if, for example, I was ever there when there was a diagnosis or surgery was explained or a procedure was explained, I did always ask the parents, or I hope I always asked the parents, you know, "Did you understand what was being said? Is there anything you are confused about or you want to go back over, or you want repeated?"

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[151] T47 p. 149–150 Mrs Vegoda

[152] WIT 0192 0003 Mrs Vegoda

> 'To an extent, because I did not have the background of everything myself, I suppose there might have been instances where the parents said they did understand and possibly they did not. But I think with time, possibly I was getting more information as well.'[153]

130 Mrs Vegoda described her role in bereavement counselling:

> 'Part of my role included emotional support, counselling and practical help to parents at the time of, or following a child's death. My contact with bereaved parents was open ended, and in some instances continued for several years.
>
> 'At the time of death my support could include staying with the parents until they were ready to go home, accompanying the parents to register the child's death, meeting them if they returned to the hospital to see their child in the Chapel, and liaise with and be present at meetings with the Surgeon or Cardiologist …
>
> 'I sent out regular cards to parents on the anniversary of their child's death and birth and instigated and organised an annual Remembrance Service for Cardiac families for three years …'[154]

131 Miss Stratton described her role in her written evidence to the Inquiry:

> 'My understanding of the role was to bring together the BCH paediatric/cardiac activities with those of the BRI. The aim was to ensure the smooth transition for parents and children from the BCH to the BRI. This would include corresponding with the child's health visitor and/or GP. I also had to ensure that parents had accommodation and had practical information on the child's admission to the BRI and their forthcoming stay. This would include advice on transport and the envisaged length of stay… I would work in a very practical way with the parents … My understanding was that I was there to support the parents so that when the child was in surgery or in intensive care the liaison nurse could spend time explaining for example why the child was on a ventilator and what the lines were for, and the reason for sedation. The nurses caring for the child often did not have the time to spend with the parents and explain at length what was happening.'[155]

132 Miss Stratton explained how she approached parents:

> 'At the beginning of every month I would get a theatre list with all the adult and children's names on it along with the referring GP. I would write to the parents and introduce myself and say that they may have met Helen Vegoda at the BCH and that my role was to provide support and care while they were at the BRI, in conjunction with Helen Vegoda … I also rang the Health Visitor to notify her of the admission

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[153] T47 p. 94 Mrs Vegoda
[154] WIT 0192 0005 – 0006 Mrs Vegoda
[155] WIT 0256 0002 Miss Stratton

> and to let her have my number. Sometimes the Health Visitor would inform me of any social aspects of the family that I would relay to Sarah Appleton the social worker.'[156]

133 Miss Stratton stated:

> 'I had come across a book at GOS called *"Heart Children"*… which had concise and easy to understand explanations of the commonest cardiac conditions with diagrams. It was written for parents and it was very good. They were not cheap so I had a master copy to show to the parents and if they wanted to buy a copy I would sell them one and give the money back to the Heart Circle.'[157]

134 As regards bereavement, she stated:

> 'Where a child died, I would notify the health visitor and would tell them how the parents had reacted and their plans for returning home. This then allowed the Health Visitor to go and see them. I would tell the Health Visitor as much as I was able to so that the Health Visitor could meet the parents and already have an idea of what had happened while the parents and the baby were at the BRI.'[158]

135 She told the Inquiry that:

> '… I kept a red book with patients' names and addresses, the name of the health visitor, how often I had spoken to the health visitor, the name of the GP and other information like whether I had referred the family to the Social Worker. It was really a record that I could see: had I contacted the health visitor, when did I last contact them, had the parents received any support from the social worker and had they received any financial support from the Heart Circle …
>
> 'It had the date of the operation, the date the child was extubated and taken off the ventilator, the date they were moved through to the nursery, the date that they went home and the date they died …'[159]

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[156] WIT 0256 0008 Miss Stratton
[157] WIT 0256 0007 Miss Stratton
[158] WIT 0256 0008 Miss Stratton
[159] T46 p. 161 Miss Stratton

Parents' evidence on communication with clinicians and the process of obtaining their consent to surgery

The Inquiry's Experts

136 Dr Houston told the Inquiry about the difficulty that parents under stress have in remembering information and the fact that any information given to them could be perceived differently from what was meant:

> '… there are two people in any communication situation, there is not just the doctor, there is also the parent and usually we are talking to them when they are very emotionally upset. Sometimes when you speak to them subsequently their perception of what was said is not what was said, and I think there is no doubt about that.
>
> 'I can certainly recollect a parent coming back and asking her "What were you told about this?", and I said, "Who on earth told you that?", looked up the notes and it was myself and I have a pretty standard way of putting things, so people do perceive things differently. I was very interested in this ... people come back and say "Yes, I was told that this would be done when the child was 7, 6, 8" and I do not believe anyone actually said that. Sometimes they may say "When would it be?" and we might say, "We have to wait and see", and whether they might have said at that time "About 8?", and someone might have said "It might be the case I am not even sure of that", but people do come with this idea of set times when things would be done …
>
> 'They have this perception, and again how things are put by different people are taken up differently.
>
> 'I am sure we all offer to see them again and go over it again if they want, but patients do not very often come back and ask, I think they do not like perhaps to ask us and it is only when we say "Do you want me to go over it again?" some will say, "No it is all right"and some will say "Yes, could you".'[160]

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[160] T91 p. 40–2 Dr Houston

Parents

137 Justine Eastwood, mother of Oliver, told the Inquiry of her experience of communicating with clinicians in the following exchange:

> 'A. ... I had got to know Mr Dhasmana over a long period of time. I knew that I understood the way he spoke and things he was saying. Mr Moore and Dr Mather,[161] perhaps it is because I did not know them so well, I do not know. They perhaps used more technical terms with me. I did have a particularly difficult conversation with them, which I think is what we are talking about.
>
> 'Perhaps they were not quite so approachable. Maybe that is the word I am looking for. Maybe I did not feel confident enough to ask the right questions with them, whereas I always felt very confident asking Mr Dhasmana.
>
> 'Q. There were occasions, were there, when some staff appeared to show a lack of sensitivity in their relationships with you? There was one doctor who made a comment that you took exception to, asking if Oliver was Down's syndrome?
>
> 'A. Yes. We were actually in the ward for a very short period of time. Dr Hayes had actually asked the therapist to speak to me, because Oliver was unable to suck, because we were trying to introduce the bottle to him. She felt a speech therapist would be useful. It was actually the speech therapist who made this comment, because she had been given a few notes on Oliver, and I believe it was a Junior Registrar who had actually told her that Oliver was a Down's syndrome child, so she did say to me, "When did you realise that Oliver was a Down's child?"and I said "Just now". It was a little bit of a shock. So it was a mistake by somebody which, you know —
>
> 'Q. It was upsetting?
>
> 'A. Very upsetting. I do have to say, he did come and apologise profusely later in the evening, but very upsetting, yes.
>
> 'Q. From what you are describing, the communication skills varied from doctor to doctor?
>
> 'A. Exactly, yes. We dealt with so many people, this is the trouble. I would not say there was probably one person in that hospital who did not know Oliver or his case, so we were dealing with an awful lot of people down the line, really.
>
> 'Q. You make the point in your statement of the honesty of Mr Dhasmana in the sense that he refused to exaggerate the chances of Oliver's survival.
>
> 'A. Right.

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[161] Cardiologist at the BRHSC

> ‘Q. Did you find that unsettling, or helpful, or helpful only in retrospect, or what?
>
> ‘A. We just felt he was being honest. He was not putting us under any false illusions. We knew that Oliver was extremely unique with his problems, he had heart problems and also problems with his trachea, and unfortunately — I mean, there was hope, but nobody ever, particularly Mr Dhasmana, never built our hopes up, which is how we wanted it. There was no getting away from the fact that we were dealing with a very difficult situation.
>
> ‘Q. We have heard Mr Dhasmana described to us as “brusque” or “abrupt” at telling someone bad news. From your dealings with him over some time, do you think he might be perceived in that way?
>
> ‘A. Might be. In the very first pages of my diary, I did actually write he came across as a negative man. Maybe that could be looked at as brusque. I would not say so, though. It was perhaps his manner. I never thought of him in that way. Everyone comes across in a different way. We had the opportunity to get to know him over a year, and I certainly would not put him down as a brusque uncaring man.
>
> ‘Q. What made him seem negative?
>
> ‘A. Because he never built our hopes up. If anything, he went the other way. I would say he was just honest. He did not build our hopes up, perhaps, in the way we wanted him to, because things were looking so grim, but he was just that way.’[162]

138 Justine Eastwood told the Inquiry her views on whether parents who had just been told that their child had a heart defect were given sufficient information:

> ‘I think everybody initially is bemused and confused by it all. My experience is, there were many books around. There were plenty of people to try to explain things to you if you did not understand it, but again, from what I saw, if you did not understand it, people came back and told you again and again, until you perhaps did understand. You were not left with one conversation and then they walk away and let you get on and hopefully muddle it through. It was not like that.
>
> ‘If my memory serves me correctly, I vaguely remember there was actually a little booklet that had been made by parents and professionals for parents, and I believe it was something like that that we actually first read. So it was very basic, but it just gave us some sort of insight into heart problems.’[163]

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[162] T95 p. 75–7 Justine Eastwood

[163] T95 p. 69–70 Justine Eastwood

139 Karen Welby, mother of Jade, described the approach of Mr Wisheart in 1984:

> ‘Because I was very, very upset, taking Jade off to theatre and I wanted to have — I wanted to think she was going to come out and everything was going to be fine, but he was not going to let me believe that for one minute. He wanted me to understand she was possibly going to die on the operating table. I did not want to accept it, so I thought he was very cruel to tell somebody who was almost hysterical that their daughter was probably going to die. Obviously later on I realised that that is what he should have said to me, that is what I needed to know; I did not need to be given any false hope, and I appreciated that from then on, that he was very, very honest and that whenever he said to me that things were looking good, then I could breathe a sigh of relief, and think “Mr Wisheart says she is going to be okay”.’[164]

140 Karen Welby described the difficulties of understanding what was happening:

> ‘… I found it very difficult to understand everything that was going on anyway. I was only young myself [20 years old] and I was in such a state of shock …’[165]

141 She continued:

> ‘Probably after her operation I started to get a better understanding of what was going on. I remember that she was shaking and in quite a state before her operation, and nobody seemed to be telling me the truth about what was happening then. They were making excuses of her being upset because she had had X-rays done. When I went back later, she was still that way and I thought, “This is not right. Nobody is telling me quite what is going on here.” I did actually demand to see a doctor, to have that explained to me. They explained that the drug they had her on to keep the valve open, they were not quite sure of the amount they were giving her, they thought might be upsetting her, but they thought if they reduced it again, her valve might shut off.’[166]

142 Sheila Forsythe, mother of Andrew, told the Inquiry of her experience in 1986:

> ‘I asked the questions and I found that everybody answered them to the depth that in fact I was asking the question to. If the staff could not actually answer the question because they had not the time to explain it, they would actually come back and answer the question to my level of understanding later, and I used to tell parents, when they came into the BRI, that they must ask the questions and keep asking the questions until they were satisfied to the level of information that they required. There was never any problem so far as we were concerned.’[167]

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[164] T95 p. 78 Karen Welby

[165] T95 p. 73 Karen Welby

[166] T95 p. 73 Karen Welby

[167] T95 p. 74 Sheila Forsythe

143 Michelle Cummings, mother of Charlotte, referred to the factors that can affect parents' perceptions of any information that they are given:

> 'I think the difficulty as well is that it has to be recognised that there are some people, and perhaps all of us at different times, during the time our children were in hospital, you reach the point where you actually cannot take the news that you are being given. You physically and mentally cannot take any more and you shut off. That is a problem, because that, then, opens the opportunity for later down the road to actually come back and say, "Actually, I was not told that", when in fact you were told it; it was just that you have mentally, for preservation purposes, shut off. I think that is a very real problem.'[168]

144 Diana Hill, mother of Jessica and James, told the Inquiry of the conflicting information she was given in 1989 by Dr Joffe on the one hand and Mr Dhasmana on the other. Diana Hill first saw Dr Joffe when Jessica's heart condition was diagnosed:

> '… he explained to me she had a VSD. He said what it was, he said basically it was a hole in the heart but it seemed to be that there was no concern from him about this.'[169]

> 'The one thing I do remember is that he did not relay any concern, it just seemed that it was a VSD, a hole he hoped would close up and that is all it seemed like. I mean I cannot remember him saying anything about pulmonary hypertension to me.'[170]

145 Diana Hill said that nothing was said to her at all about Jessica's attendance for echocardiography and the appearance of the pulmonary artery and turbulent flow:[171]

> 'Nothing was said to me at all. The only thing I can remember was Dr Joffe saying to me that he wanted to wait for the hole to close.'[172]

146 She continued:

> 'He said he wanted to do a catheter just to see how bad I think the VSD was. I remember him going over the catheter procedure because he said to me "There is always a chance that a baby can die having this procedure". That is what put me off having the whole thing done because I thought "Gosh, I am going to lose my baby having this done". It seemed quite a big thing compared to the reasons. I thought there was nothing wrong with her, it seemed like there was nothing wrong with her and they were doing this catheter and she could die having this catheter. That is what he explained.'[173]

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[168] T95 p. 80–1 Michelle Cummings

[169] T83 p. 5 Diana Hill

[170] T83 p. 6 Diana Hill

[171] MR 1761 0053; letter from Dr Joffe to Dr Vulliamy (Paediatric Registrar)

[172] T83 p. 9 Diana Hill

[173] T83 p. 9–10 Diana Hill

> ‘I was worried that she was going to die having that catheter because he did tell me sometimes that can happen, yes, it made me worried.’[174]

147 Diana Hill then described her initial meeting and communication with Helen Vegoda:

> ‘I think she was trying to help me but I am surprised she did not feel that I did not want her there because I did — I was saying it in a way, I did not just tell her to go away because I thought that was not the nice thing to do, but she must have known I just did not want her there, I did not. She would say things that were helpful that were making me worse. I just remember at the time in the hospital I really wished she had not been there. After the hospital, when I saw her after she was helpful.’[175]

148 Diana Hill told the Inquiry of her recollection of a meeting after the catheterisation:

> ‘… I remember them putting on some X-rays on a screen in the room. Nobody ever said to me she had a bad condition of pulmonary hypertension, nobody ever explained to me because if they had I would have then been prepared for it, they had not, it was just still the same as what I knew before, she had a VSD and that seemed to be what she had and that was it.
>
> ‘… I just assumed from what Dr Joffe had said that he was waiting for her hole to close and was waiting for her lungs to develop. If this did not happen, he said possibly she may need an operation in the future. The future — I came to the conclusion she would probably have an operation when she was 1, 2, but he did not say anything was really wrong with her, he never said she was going to die or anything. I actually thought I had a well baby, although she might need an operation later.’[176]

149 Diana Hill then described her meeting with Mr Dhasmana:

> ‘He introduced himself, said “Hello”, we sat down, I sat down with my mother and he just said to us, he said “There is nothing I can do for her” and he said it quite matter-of-fact and it just was something I was not expecting to hear at all. I thought I was going there to hear him say she would have an operation in a year’s time but he just said “There is nothing I can do for her”, he said she was inoperable.’[177]

150 She continued:

> ‘When I saw Mr Dhasmana, after he said there was nothing he could do for her, she is inoperable … he just saw how shocked we were. He was shocked at the fact we did not know. It was written all over his face.

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[174] T83 p. 11 Diana Hill

[175] T83 p. 12–13 Diana Hill

[176] T83 p. 13–14 Diana Hill

[177] T83 p. 15 Diana Hill

> 'He then said "Because of her age, 7 months" – which at this time she was not 7 months, she was about 8 and a half months, but he kept saying she was 7 months – he felt he had to give her the chance of operating. He said as time was going on her pulmonary hypertension — he was the first person to tell me about her pulmonary hypertension, I had never heard about it before. He drew diagrams and he explained to me what was happening and as time was going on he would not be able to perform the surgery. He said to me if another month elapsed he would not be able to do the surgery. So he told me to come in on 16th August and he would perform the operation on the 18th.
>
> 'There was no choice. He then proceeded to say that he was going on holiday that day and [Mr] Wisheart would be doing the post-operative care. As soon as he said this I thought, "No, she is not going to have proper continuity of care". I told him this. I said, "I do not want Mr Wisheart doing the post-operative care, I want to have the same surgeon". Everything was telling me, signs were telling me I did not want her to have it done now here. All of a sudden I had this well baby and then suddenly she was going to die, it was like she was just going to die.'[178]
>
> '… he said, and I remember these words like yesterday: "The surgeons get the worst job of telling the patients".'[179]

151 Diana Hill stated that she (and her mother) did not like Mr Dhasmana's bedside manner, which they both thought was 'extremely arrogant'.[180]

152 In his notes Mr Dhasmana recorded that 'High risk explained. Mother broke down.'[181]

153 Diana Hill told the Inquiry of her feelings:

> 'It was a shock. I just wanted the floor to open and take me away. I had a well baby crawling around on the floor at this time.
>
> 'He then had to test her heart, he had to check her chest, check her heart and do all those things. I could not cope. I was in a terrible state, my mother was in a terrible state, we were all in a terrible state, none of us knew, none of us knew that she was this bad.'[182]

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[178] T83 p. 16–17 Diana Hill

[179] T83 p. 17 Diana Hill

[180] WIT 0263 0007 Diana Hill

[181] MR 1761 0020; medical records of Jessica Hill

[182] T83 p. 17–18 Diana Hill

154 Diana Hill's mother had a meeting with Mr Dhasmana the next day. Diana Hill told the Inquiry that the reason was:

> '… because Mr Dhasmana wanted us to make a decision there and then to have the operation. I felt I could not make that decision because part of me was telling me I wanted to take her to America to have this operation because she was the most precious thing, I would have done anything for her. It just did not feel right for her to be having it done there. I cannot explain what it was, I think it was just the shock that I had not been told before, that is what made me feel like that and I thought "No, I am not going to decide today, I want to think about what else I can do".
>
> 'So my mother rang him the next day because she was quite upset how Dhasmana — he was quite arrogant and blunt, his whole manner, his body language you know was quite blunt and arrogant. So she rang him up the next day asking if there was anywhere else we could take her. He said "No, Bristol is the best place"and then he said "I do not have to operate, you know".
>
> 'He was very matter-of-fact with everything. He did not relay any sort of compassion. I mean I was in shock, my mother was in shock. It is like, there was no sort of compassion from him at all, it was just very matter-of-fact, "This is what I am doing" — it almost felt you were lucky to be having this operation, I was lucky to be having this operation on that day.'[183]

155 Diana Hill recalled the discussion she had with Dr Joffe after the meeting with Mr Dhasmana:

> 'I had a discussion with Joffe about two days later and I remember it because I remember feeling really, really anxious about the whole thing and he then gave me 70/80[184] per cent chance that Jessica would be okay. This was a different statistic to what I had from Mr Dhasmana. Mr Dhasmana had given me 50/50 per cent that she would live so I knew it was like she could die. But Dr Joffe was giving me a 70/80 per cent chance she would live. Even then when I spoke to him it was as if she was going to live with this operation. It seemed like he was not concerned at all.'[185]

She continued:

> '… I remember him painting a picture to me that it was going to be quite — that it was like she was not going to die. I remember him saying to me there was a 70/80 per cent chance she was going to be okay because automatically I thought — it made me feel better actually when he said that because I thought perhaps she is going to be alive. I wanted somebody to tell me she was going to live and he was doing that.'[186]

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[183] T83 p. 18–19 Diana Hill

[184] MR 1761 0037; this figure is quoted in a letter from Dr Joffe

[185] T83 p. 19–20 Diana Hill

[186] T83 p. 20–1 Diana Hill

156 Diana Hill described her anxiety at the passage of time:

> 'Things worried me like, I know she was getting older, it was getting worse and I just remember fixing this month in my head, Dhasmana saying she was 7 months and in actual fact she was not 7 months, she was 8 and a half, so by that time she was getting older anyway and then it was another month later she had the operation, so by the time she had the operation she was 9 and a half months. Surely if she is inoperable she is not going to live because "inoperable" means she cannot live.'[187]

157 She indicated that:

> '… I did not want her to have it done here but the fact is I did not have much time to take her anywhere else although I wanted to.'[188]

She added:

> 'People were explaining to me what was going to happen, you know, there is no doubt about that. But you could just tell from some people, some of the medical staff[189] were telling me "You could pull out if you want to". It almost felt as if she was not going to live.'[190]

Further:

> 'It was very difficult because I had a baby who was very well. She was by this time — well, she was standing up, she was babbling, she was crawling. I did not have an ill baby on my hands so it was very hard to watch this well baby that they were saying was inoperable who was going to die, who was ill. I could not believe it.'[191]

158 In her written evidence to the Inquiry Diana Hill expressed the view that:

> 'I think that Dr Joffe did not tell me how serious Jessica's condition was, and that Mr Dhasmana covered up for him.'[192]

159 Helen Rickard, mother of Samantha, told the Inquiry of her and her husband's experience after Samantha's catheterisation:

> 'Andy and I obviously waited at the hospital for Samantha to come back out of the theatre … Dr Jordan came back up to the ward with Samantha, where we were waiting. We both looked at him expecting him to be forthcoming with some kind of information about what they had done, what they had found. That did not happen.

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[187] T83 p. 21–2 Diana Hill

[188] T83 p. 22 Diana Hill

[189] WIT 0263 0009 – 0010; Diana Hill mentions a House Officer, Helen Vegoda, a nurse she believes is called L Syonng and Dr Bolsin

[190] T83 p. 23 Diana Hill

[191] T83 p. 24 Diana Hill

[192] WIT 0263 0014 Diana Hill

> Dr Jordan was not willing to talk to us. He said that he would need to discuss the findings with his colleagues and we would be contacted after that.
>
> 'I asked to see Samantha's medical records at that point and I was told no, that would not be possible. We were basically just left there with no information again.'[193]

160 Kathleen Tilley's daughter, Lauren, underwent a Switch operation performed by Mr Dhasmana in February 1988. Lauren died on the operating table.

161 The problem with Lauren's heart was discovered within hours of her birth. In her written evidence to the Inquiry, Kathleen Tilley described meeting Dr Jordan in the ICU at the BRHSC:

> 'He told us that they were unsure what the problem was but she was having difficulty breathing and there was obviously a heart condition. He told us that they would need to take her down to do a cardiac catheter and a scan. He explained exactly what they would do and that was to cut Lauren and then feed a tube through so that they could actually find out exactly what the position was.
>
> 'I had no complaints about the way we were treated at Bristol nor have I any complaints about the procedures or the explanations that we were given.'[194]

162 As regards being told about the diagnosis of Lauren's problem, she stated that Dr Jordan:

> '... told us that Lauren had a condition which was known as the Transposition of the Greater [*sic*] Arteries and also had a hole in her heart. He said that they would operate immediately. He explained to Glyn [her husband] and myself exactly what the condition was and what they were going to do … I was devastated and although I accept that Dr Jordan did his utmost to explain the operation in detail to us so that we knew what was going on, it was not until I returned home a week later and I spoke to a family friend who was a nurse, that I fully understood the implications of the condition that Lauren had. I place no blame on Dr Jordan for my lack of understanding and can only put it down to my emotional distress.'[195]

163 As regards the timing of Lauren's operation, Kathleen Tilley stated:

> '… at one of the regular monthly check ups at Dr Jordan's clinic at the Royal Gwent Hospital in Newport he told me that he thought that it was time she needed the operation. Both at the time and in hindsight I was surprised at the decision that was taken. I had no idea why the decision was taken to operate at that meeting. No explanation was given. It is true that Dr Jordan said that she had not put on any

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[193] T52 p. 122 Helen Rickard

[194] WIT 0230 0003 Kathleen Tilley

[195] WIT 0230 0004 Kathleen Tilley. See Chapter 3 for an explanation of clinical terms

> significant amount of weight since she was born. However, that was nothing new. She was not distressed, and her breathing was as good as it had been throughout the period and I am therefore at a loss to understand the reason for the sudden rush. I use the word "rush" because almost immediately after being told that she should have the operation we received a letter from the Bristol Children's Hospital giving us a date for the operation for 29th February 1988.'[196]

164 Kathleen Tilley met Mr Dhasmana two days before Lauren's Switch operation. She stated that:

> 'He introduced himself and confirmed that he would be operating on Lauren. He then went on to explain what procedure he was going to undertake.
>
> 'Mr Dhasmana said that this was an operation which had not been performed for very long and that he himself had not done it many times. He said the chances of success were 75%. I must admit that when he said that he had not done it very often both Glyn and I were very perturbed. Glyn then asked him about the operation and questioned him about what he had said. Mr Dhasmana replied that it was not a common operation but that despite that and despite the fact that he himself had not done this particular operation very often, it was in his opinion the best thing for Lauren.
>
> 'As a result of that answer neither of us questioned him any further about his ability to undertake the operation or the chances of Lauren's survival. The conversation took at least half an hour but at no time during the conversation was it made known to us that there was any other choice. We were not offered any other explanation nor were we told at this or any other time that there were other centres and other surgeons with far higher success rates. So far as Glyn and I were concerned, at the time, we trusted the surgeon in front of us and we accepted the information which he gave as we had no reason, at that time, to doubt it.'[197]

165 She said later in her statement:

> 'Lauren was operated on in 1988 and I accept that she was one of the very first to be dealt with by Mr Dhasmana. I therefore accept that there may have been no trend at that stage and that insofar as Lauren is concerned it might not be appropriate to complain about the failure to disclose the actual morbidity rate. However, as a mother and a member of the public, I do have serious concerns about the management of the hospital, from at least 1990 onwards because they should have made sure that the significant losses of childrens lives was investigated. The fact that they did not do so means that they failed both in their duty to the individual children as well as their duty to the general public which the hospital served.'[198]

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[196] WIT 0230 0007 – 0008 Kathleen Tilley

[197] WIT 0230 0008 – 0009 Kathleen Tilley; Mr Dhasmana's response to this is at WIT 0230 0036 – 0037

[198] WIT 0230 0014 Kathleen Tilley

166 John Williams' daughter, Melanie, had a successful Switch operation in September 1988. A few weeks after her birth in September 1983, Dr Jordan had diagnosed that Melanie had TGA, amongst other cardiac problems, and, according to Mr Williams, he had 'explained that due to her age and all of her complications, it would be impossible to correct all the problems with one operation …'[199]

167 Mr Wisheart performed the first operation on Melanie. John Williams stated that:

> 'We were very impressed by Mr Wisheart, whose conduct towards us had given us every confidence in him. His advice had been very positive but at the same time realistic. We also fully understood that this was only a temporary solution and that further surgery would be needed at a later age.'[200]

168 He stated that when he saw Mr Wisheart in April 1987:

> '… he [Mr Wisheart] went through Melanie's problems with us and talked about the possible surgical options. He explained that he felt the best option was the Switch operation, because he felt that this would give Melanie the best long-term chance.'[201]

169 According to John Williams:

> '… there was never the least suggestion that we might have considered going elsewhere other than to the Bristol hospitals, partly because of the adverse publicity surrounding other centres, but more importantly because we were very happy with what had been achieved so far and the way in which it had all been done.'[202]

170 He described the advice and information given to him:

> 'We met with Mr Wisheart on the 3rd September, and he reiterated to us that the operation was by no means straightforward. Nevertheless he said that her overall prospects would be good if she came through the operation. He also said that it was going to be a long difficult operation, and that he intended to undertake it jointly with Mr Dhasmana. We met with Mr Dhasmana and his way of expressing things came over as a little more pessimistic, not so as to suggest that he viewed the situation differently from Mr Wisheart but reflecting the different temperaments of the two Surgeons. Also he had not seen Melanie before, and he also mentioned that scar tissue from the previous operations could possibly give rise to problems.
> We also met with the Anaesthetist prior to the operation.

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[199] WIT 0140 0002 John Williams

[200] WIT 0140 0002 John Williams

[201] WIT 0140 0003 John Williams

[202] WIT 0140 0004 John Williams

> 'The operation that was to be undertaken was a "Switch" as the main arteries were the wrong way round. We were told that this was a new and relatively difficult technique, and we understood that the Surgeons had not done many of these operations before. Mr Wisheart had set out to us three possible courses of action, of which the Switch operation gave the best long-term prospects, and he gave quite a clear recommendation that this was the best option to take. The other options would have meant, in layman's terms, that the "wrong" side of the heart would still have been carrying out the wrong function, but the hope would be that the heart would redevelop to cope. These might be safer on a short-term view, but in the longer term, the Switch, if successful, would be a better solution. I understood that there was a relatively high degree of risk, and as far as I can recall I think it was put to us as a 25% risk, but we accepted that as a risk worth taking in the circumstances. This was certainly the choice that Mr Wisheart encouraged us to take, and I was glad that he gave us a firm and positive lead in taking the decision.
>
> 'We were happy as to the procedure for giving our formal consent to the operation. We had been given a great deal of medical detail, and that we had been given a proper and balanced assessment of the very real risks involved in the operation, and of which we had been made aware long before it came to the point of signing the Consent Forms.'[203]

171 Christine Ellis' son, Richard, had a non-neonatal Switch operation in June 1991. It was performed successfully by Mr Dhasmana. Mrs Ellis described meeting Dr Jordan and being given the diagnosis:

> '… I saw a female doctor in Doctor Jordan's team along with my husband. She told us that Richard required a balloon catheter operation to enlarge a hole in his heart in order to allow better mixture of his blood. She told us that a balloon catheter procedure was the prelude to a Switch operation. When the Switch operation took place would depend upon the progress that Richard made following the balloon catheter procedure. She indicated that Richard was seriously ill. She may have discussed the risk factor of a balloon catheter procedure, but I cannot remember that happening.
>
> 'The balloon catheter operation took place without incident …
>
> 'I do not think anyone gave a prognosis or discussed the risk factor of this particular procedure.
>
> 'There were no discussions on standards of care or success rate, but the procedure was discussed in detail.
>
> 'There was no discussion about whether a referral to another centre was required.'[204]

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[203] WIT 0140 0005 – 0006 John Williams

[204] WIT 0023 0003 – 0004 Christine Ellis

172 Christine Ellis stated that she met Mr Dhasmana on the day before Richard's operation and that Mr Dhasmana 'dealt with the detail of the planned surgery.'[205] As regards the information and quotation of risks which she was given before consenting to the operation, she stated that:

> 'Mr Dhasmana came over as friendly caring and concerned. That particularly struck me about him. I was left in no doubt that he wanted to do his best for my husband and I and Richard.
>
> 'Mr Dhasmana explained the surgery that was going to be carried out the following day. He drew diagrams for us to illustrate what was going to happen. He drew a diagram showing a normal heart. He drew a diagram showing the current problem with Richard's heart. He drew a diagram showing us what he was going to do to put that right. He could see that we had not taken on board exactly what was to happen the first time and he went through that all again until he was sure we understood what was to happen.
>
> 'Mr Dhasmana told my husband and I that the operation would take about eight hours and it is my recollection that he gave a sixty-forty chance of success.
>
> 'Mr Dhasmana said that if the operation did not take place then the balloon catheter would not last forever and as Richard got bigger he would be at risk. It was better for surgery to take place earlier rather than later.
>
> 'I was in no doubt that the operation had to take place whatever the risk.
>
> 'I remember the whole discussion as being unhurried, kind and friendly and I felt very comfortable.
>
> 'I was quite aware that any surgery would have risks under general anaesthetic.
>
> 'I had no discussions with the anaesthetist Doctor Masey prior to the operation as far as I can recall.
>
> 'There was no suggestion that either this operation or the balloon catheter operation should have been done elsewhere than at the Children's Hospital in the first instance and the BRI in the second instance.
>
> 'I do not recall whether the percentage success rate explained by Mr Dhasmana was the hospital's success rate, his success rate or the general success rate.
>
> 'I and my husband had no difficulty in giving consent to the operation and we did.

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[205] WIT 0023 0006 Christine Ellis

> 'I cannot recall the likelihood of future surgery or protracted drug regimes being discussed or side effects or other complications or alternative treatment methods.'[206]

173 Julie Johnson's son, Max, underwent a Switch operation in June 1994 which was performed by Mr Dhasmana. Max died a few days later.

174 Julie Johnson stated in her written evidence to the Inquiry that she remembered meeting Dr Alison Hayes in December 1993 who performed a cardiac catheterisation and an echocardiogram on Max so as to obtain a clearer picture of his heart. Mrs Johnson stated:

> 'Dr Hayes told us that Max's main arteries were switched round from their normal position. Both outlets came from the right ventricle of his heart. Dr Hayes told us that he also had a Coarctation of the Aorta, and that the aortic arch was severely underdeveloped. In addition, there was a hole between the bottom two chambers of Max's heart. Dr Hayes stated that, normally, this was a serious defect in itself but, since Max had no blood supply into the bottom left chamber, the hole was helping to keep him alive at this stage.'[207]

175 Julie Johnson stated that Dr Hayes then introduced her and her husband to Mr Dhasmana who informed them that:

> '… Max needed open-heart surgery, but that, due to his size and age, it would be better to give him closed-heart surgery first, as soon as possible. He would then need one more operation, which would take place around his first birthday, when he would be older and stronger. This would increase his chances of surviving open-heart surgery. Mr Dhasmana told us that the closed-heart surgery would involve reconstructing Max's aortic arch, resection of his coarctation, and putting banding on his pulmonary artery. These procedures would, basically, "patch him up" until he was older.'[208]

176 Julie Johnson described what she was told about the risks involved in the surgery:

> 'Dr Hayes said that there was about a 33% risk to Max's life from the closed-heart surgery. She then stated that the risks of open-heart surgery would be a bit higher — I did not ask her to quantify this latter risk as a percentage, as I did not really want to know at this stage. I then asked Mr Dhasmana if there was any possibility of brain damage occurring as a result of this surgery. He said, "No, he will either live or die on the operating table". I did not realise or believe that there was a risk to Max's life post-operatively, in the Intensive Care Unit (ICU). I was not offered a choice of different types of surgery, or of another hospital or consultant surgeon.

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[206] WIT 0023 0006 – 0008 Christine Ellis

[207] WIT 0178 0004 Julie Johnson. See Chapter 3 for an explanation of clinical terms

[208] WIT 0178 0005 Julie Johnson

> I asked if I had any alternative, but they said that Max would die without surgery. We agreed to allow surgery to take place.'[209]

177 Following tests in March 1994, Julie Johnson stated that she and her husband were informed by Dr Hayes that Max was suitable for the Arterial Switch operation.[210]

178 In April 1994 Steve and Julie Johnson met both Dr Hayes and Mr Dhasmana to discuss the Switch operation. Julie Johnson stated that:

> '… we initially saw Dr Hayes. She said that the surgery held serious risks for Max's heart, due to the fact that he had never used the left side of it. She said that it might take Max up to a fortnight to recover from surgery. I asked Dr Hayes if there was any alternative course of action, but she said that Max was getting sluggish, and needed surgery. We then spoke to Mr Dhasmana, and again asked him if Max would sustain any other injury, such as brain damage. He replied that the risk was all in the surgery, and that Max would either "live or die on the operating table". He also said that brain damage was "virtually unheard of". Mr Dhasmana did not quantify any risks as a percentage.'[211]

179 The day before Max's Switch operation, Julie Johnson met Mr Dhasmana to discuss the operation. Her recollection of events is that:

> 'He drew me a rough sketch of what he intended to do the following day, and said that, if the surgery was successful, Max would lead a near-normal life afterwards. I mentioned that Dr Hayes had said that it could be up to two weeks before we would know if the surgery had been successful, since Max's left side was turning to muscle. He said that she was being quite pessimistic; they had seen far more of this type of case in the BRI than in the BCH. He also said that he was quietly confident, and would be able to know if the surgery had worked in just three to four days. He added that Max had done well these past months despite his heart problems, that he was a strong baby, and that I owed it to him to give him a chance of a normal life. I felt more confident than before after this meeting.'[212]

180 Timothy Davies' son, Richard, underwent a neonatal Switch operation performed by Mr Dhasmana on 28 May 1992. Richard died on 8 June.

181 Dr Jordan diagnosed that Richard had cardiac problems within hours of his birth. Timothy Davies stated that he remembered rushing back to the hospital to meet Dr Jordan:

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[209] WIT 0178 0005 Julie Johnson; Mr Dhasmana's response to this is at WIT 0178 0026 – 0027

[210] WIT 0178 0008 Julie Johnson

[211] WIT 0178 0008 Julie Johnson; Mr Dhasmana's reponse to this is at WIT 0178 0027

[212] WIT 0178 0010 Julie Johnson

> ‘He told me that they had already performed one operation on Richard. He said that they had put a balloon in to keep the airways open. While I was trying to take this in, Dr Jordan made it clear that this operation had to be performed, and that is why it was carried out so quickly. Dr Jordan then went on to say that Richard’s arteries were the wrong way round in the heart. He produced a diagram[213]… on a piece of paper headed “Transposition of the Great Arteries”. I did not take any notice of the writing on this piece of paper and Dr Jordan did not draw my attention to any of it. What he did do was point to the picture of the heart on the left, showing the normal position, and explained that Richard’s heart was like the one on the right. He said that, basically, the blood was being pumped the wrong way, and that Richard needed a further operation.’[214]

182 As regards any information and advice and the process of consent, Timothy Davies stated that:

> ‘Dr Jordan stated that, normally, they could leave babies in Richard’s condition for between 6 months to a year. However, he then said something like, “We have decided that due to the severity of his condition we need to operate within the next 4 days.” Having said that there had to [be] the operation within the next four days Dr Jordan said that he had a Consent form with him for the operation to go ahead.
>
> ‘Having received no advice as to why I was at the hospital until Dr Jordan came in to see me, I found myself taken aback by what he was saying. I felt numb. I wanted to ask questions, but I thought “He is a Surgeon[215] and you can trust your child’s life into his hands”. I therefore just signed the Consent form. I had not read any of the information given on the sheet describing Transposition of the Great Arteries or taken in anything from the Consent form. I was too numb to take it all in. All I thought was that it had to be dealt with quickly. I was not given any time to think about matters, but just did what I thought was the right thing and signed the form. I cannot think that Dr Jordan was with us for longer than 10 minutes. As soon as I had signed the form, Dr Jordan left the room and Julie and I were left alone again.’[216]

183 Timothy Davies stated in his written evidence to the Inquiry that he did not meet with Mr Dhasmana or any other doctor before the operation to discuss what was going to happen:

> ‘The only persons we saw were the nursing staff. At no point can I recall any Doctor or Consultant coming to see me to explain what was going to happen.’[217]

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[213] WIT 0160 0016 – 0017 Timothy Davies

[214] WIT 0160 0006 Timothy Davies. See Chapter 3 for an explanation of clinical terms

[215] Dr Jordan was in fact a consultant cardiologist and not a surgeon

[216] WIT 0160 0006 – 0007 Timothy Davies

[217] WIT 0160 0009 Timothy Davies

184 On the day of the operation, Timothy Davies accompanied Richard to the BRI by ambulance:

> ‘On the way to the Bristol Royal Infirmary, the nurse said to me that we were very lucky; Mr Dhasmana was one of the best. She said that he had done a 36-hour operation a few days ago. I asked if the person had lived, and she said yes. I remember thinking that he must be a brilliant surgeon. This was the first time I had heard Mr Dhasmana’s name.
>
> ‘I met with an anaesthetist at the Bristol Royal Infirmary. I believe she was Su Underwood. She told me that it was time for Richard to have his first batch of injections. She said “he’ll see you later”. I remember feeling very distressed at this point, and said something to the effect that “he isn’t going to come back”. The anaesthetist said “yes he will — he’ll be fine”.’[218]

185 Timothy Davies stated that he met Mr Dhasmana for the first time two days after the operation, while he was in the ICU:

> ‘Later that morning, at about 5.30 am, a man came in. He came up and said good morning. He said the operation had gone well, and then went off into what seemed to be the nursery section of the room. I followed him in there, and asked him who he was. He said he had performed the operation. I asked him if he was Mr Dhasmana. He said that he was.’[219]

186 As regards his feelings about signing the consent form for the operation, Timothy Davies stated:

> ‘… I blame myself for killing Richard, because I signed the consent form. I keep asking whether I did the right thing; I just cannot get this out of my mind. I know that, had I not consented to the operation, Richard would not have lived anyway, but did I do the right thing in signing that form? I keep asking if I should have asked questions and found out more. What would have been the position if I had done so?’.[220]

187 Douglas Bwye’s son, Jason, underwent a neonatal Switch operation performed by Mr Dhasmana in July 1992 but died during the operation. In his written evidence to the Inquiry, Douglas Bwye recalled the events immediately preceding his signing the consent form:

> ‘… Mr Dhasmana explained once again the operation that he was to perform. He said the success rate was 80% and not the 70% from the previous doctor. In addition, however, he did not make it sound as straightforward. He informed us that not only did he have to deal with the greater arteries but that there were also

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[218] WIT 0160 0009 Timothy Davies

[219] WIT 0160 0011 Timothy Davies; Mr Dhasmana’s response to this is at WIT 0160 0019 – 0020

[220] WIT 0160 0015 Timothy Davies

> other smaller ones which had to be swapped which he said were more complicated. Although he was giving us a higher percentage of success rate I did not feel that he was as confident of the outcome of the operation as the previous doctor. Mr Dhasmana was not with us very long although I accept that may well have been because of what he told us and there were few questions which I had to ask. I confirm that I signed the consent form although I cannot recall whether I read it or not. Mr Dhasmana said that Jason would need further surgery when he was older because of the growing process and although I was disappointed at that at least I had the consolation of thinking that Jason would be stronger and more able to cope with any further procedure.'[221]

188 About seven days previously Douglas Bwye stated that had met another doctor in the hospital whose name he did not know:

> '… a doctor sat down with us and drew a diagram for us of the condition which Jason had. He explained that it was not a condition that they were unused to and that although there was a risk which he placed at 30%, there was an operation that they could do. I then asked him what happened in the 30% of cases where they were unsuccessful. He did not reply to that question but told me to focus on the fact that other than the heart defect which Jason had, he was well. I left that and did not pursue it again.'[222]

189 As regards the process of being informed, Douglas Bwye stated that everything happened 'so quickly that it was almost like a blur.'[223] He added:

> '… such was the confidence that both Janine and I had in the surgeons, that we felt it was wrong to interfere with them by asking [too] many questions. I am not saying that they refused to answer questions I am just saying that we did not feel that it was our place to ask questions which we may have thought of.'[224]

190 Douglas Bwye told the Inquiry in the following exchange that he could not remember events happening even though they were recorded in Jason's medical records:

> 'Q. When did anyone next speak to you about Jason?
>
> 'A. It is a difficult question to answer, that, because it was not necessarily one person coming back and telling me what the situation was. It was sort of on-going all the time. I was asking questions all the time. At the end of the day, I just realised that he was not right and that he was in an incubator, and I was just sort of thinking, "Well, they know what they are doing, so ..."

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[221] WIT 0002 0005 Douglas Bwye
[222] WIT 0002 0003 Douglas Bwye
[223] WIT 0002 0006 Douglas Bwye
[224] WIT 0002 0006 Douglas Bwye

‘Q. Would you like to have a look …[at MR 0403 0035] This is a note … from the Special Care Baby Unit. It reads: “Parents visited and seen by Dr Bradford who explained that baby possibly had pneumonia and that oxygen and antibiotics were necessary at present.”[225]

‘Do you remember seeing a Dr Bradford?

‘A. No.

‘Q. Do you remember an explanation being given to you as to what might be wrong with Jason?

‘A. I cannot remember the explanation that was given to me of what they thought was wrong at that time, but shortly after, I was told that it was not what they thought it was and that the oxygen was not in fact helping. They kept upping the level of oxygen up to 100 per cent, I think, and it still was not really having any effect.’[226]

191 Douglas Bwye was asked:

‘Q. There is a drawing which is in the medical records. I am going to ask you to look at it. It is [MR] 0403 0101… What I do not know … is whether the diagram we see here is one which you saw and if so, whether it was done at this earlier occasion, just after the septostomy, or whether it was done later on when you spoke to Mr Dhasmana in respect of getting consent for the bigger operation later on.

‘Can you help?

‘A. That drawing on there I do not think was done immediately after the septostomy, because in the room at the time I can remember the doctor grabbing a piece of paper to do it on, and as far as I could see, it was scrap paper. I do not remember seeing any of the writing on it, no.

‘Q. So that was probably something which was done later on?

‘A. Yes.’[227]

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[225] MR 0403 0035; medical records of Jason Bwye

[226] T6 p. 3–4 Douglas Bwye

[227] T6 p. 13 Douglas Bwye

192 Douglas Bwye returned to the diagram in the following exchange:

> ‘Q. Can we go back to the little picture that was drawn which I said I would come back to at a later stage?
>
> ‘This picture: was that one drawn by Mr Dhasmana?
>
> ‘A. I do not remember that being drawn.
>
> ‘Q. You do not?
>
> ‘A. I do not even recognise it, only because I have seen another picture drawn by someone else that was similar, but I do not actually recognise that.
>
> ‘Q. It is obviously not a picture drawn for Mr Dhasmana’s or any doctor’s benefit, because they would know the anatomy, so it must have been done for you or your wife at some stage?
>
> ‘A. Yes.
>
> ‘Q. It is in Jason’s records so we assume – we may be wrong – that is to do with Jason and something that one of the doctors, whoever it was, may have said to you?
>
> ‘A. Yes.
>
> ‘Q. Did more than one person, so far as you can remember, draw diagrams to explain to you what was involved?
>
> ‘A. I can only remember one person drawing a diagram.
>
> ‘Q. You cannot recall this diagram as being the one that was then drawn, because that was done on a piece of paper which was pulled across towards you?
>
> ‘A. That is right.
>
> ‘Q. So whoever it was who drew this, if it had anything to do with Jason – I appreciate it is in his records, it may be a mistake – but if it is anything to do with Jason, you cannot recall it being done?
>
> ‘A. No.’[228]

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[228] T6 p. 30–2 Douglas Bwye

193 As regards quoting risks, Douglas Bwye told the Inquiry:

> ‘He [Mr Dhasmana] volunteered the 80 per cent success without me asking, because I had already asked previously, when the balloon septostomy was done, and I had been told 70 per cent, so I was not asking him, because as far as I was concerned, I already knew. He volunteered that to me. ...
>
> ‘The reason I remember that so well is because as soon as he said a 30 per cent chance of failure, I said, “Well, can you tell me why those 30 per cent fail?” But he did not tell me why. He just said “The main thing for you to do is to focus on the fact that other than that, Jason is well.” So it looks good, basically. …
>
> ‘I cannot remember the exact words. He just said – I think he said something like, “All being well, we would expect 20 per cent chance of failure, but ...” We did not really sort of understand why there was a difference in what he said, but it just did not seem to matter at the time. We just thought, “Just do it”, basically.’[229]

194 It is recorded in the medical records that the nature of the operation was explained and 25 per cent[230] failure rate quoted to the parents. The following exchange then took place:

> ‘Q. Are you sure that it was 20 per cent that he mentioned, as opposed to 25 per cent?
>
> ‘A. I am positive.
>
> ‘Q. Because you have had difficulties, I think, recollecting precise words, precise conversations, precise identities throughout the brief period we have already been discussing?
>
> ‘A. Yes.
>
> ‘Q. But you are convinced that it was 20 per cent?
>
> ‘A. Yes.
>
> ‘Q. And it was that way round: 20 per cent risk of failure as opposed to 80 per cent chance of success?
>
> ‘A. Yes.

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[229] T6 p. 27–8 Douglas Bwye

[230] MR 0403 0068; medical records of Jason Bwye

‘Q. The reason I ask if you are sure is, if we can go to MR 0403 0068, this is Mr Dhasmana’s own entry, 27th July 1992.

‘”Seen [that relates to you rather than Jason] for arterial switch repair tomorrow. Nature and risks (25 per cent) explained to parents, agree. Consent”[231] and a tick.

‘So he has made a note at or about the day that he saw you that he had said 25 per cent?

‘A. Yes.

‘Q. If he said 20 per cent, he might — it might be suggested on his behalf, why should he write 25 per cent? Again, I just ask you: it may be, perhaps that he may have said, “Well, the risk is 20 per cent, it could be more, it could be 20 to 30 per cent, something like that”, which would, if you are going to pick one figure, you pick a figure in the middle and you pick 25 per cent. Did it come out like that at all, do you think?

‘A. All I can say to that is two things. Firstly, in view of the fact that first we were told 70, then he told me 80, it does not surprise me that the final thing that was written was 75.

‘Q. But he did not know you had been told 70. You did not tell him?

‘A. No. What I mean is, if one can tell me one thing and one can tell me the other, it does not surprise me what gets written down is something else. In view of the type of person that I have learned Mr Dhasmana is, that does not surprise me, that he would write down something that had not been said.

‘Q. In any event, you are certain that he said 20 per cent to you?

‘A. Yes.

‘Q. Why was it that you agreed to the operation?

‘A. Because we wanted Jason to live.

‘Q. If he quoted 50 per cent or 60 per cent, you would still have given consent, would you?

‘A. Yes.’[232]

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[231] MR 0403 0068; medical records of Jason Bwye

[232] T6 p. 28–30 Douglas Bwye; Mr Dhasmana’s response to Douglas Bwye’s evidence is at WIT 0002 0013 – 0014

195 Clare Steel's son, Jonathan, underwent a Switch operation performed by Mr Dhasmana in March 1993 which was successful.

196 Clare Steel was trained as a nurse and health visitor. In her written evidence to the Inquiry she described how she was told of Jonathan's diagnosis and the need to refer him to the BRI:

> 'Dr Martin diagnosed that Jonathan had a condition known as Transposition of the Great Arteries …
>
> 'Dr Martin recommended that Jonathan should be immediately transferred to Bristol for this treatment. He explained that Jonathan's cardiac condition was very serious but he nevertheless gave me confidence. In hindsight, I feel Dr Martin was not entirely straight with us. He must by then have known of the poor success rate for these operations at the BRI. He must have known that this rate was significantly below the national average. He did not tell us about this and I was left feeling confident that my husband and I were making the correct informed decision in allowing our son to go to the BRI for the surgery described by Dr Martin. He could have referred Jonathan to Birmingham but there was no discussion of this and I believe that Dr French [referring consultant paediatrician at Taunton and Somerset Hospital] was ignorant of the problems at the BRI.
>
> '... I feel that my husband and I were let down by the staff at Bristol who were the only people who could have known of the poor success rate of infant cardiac surgery at the BRI. I include Dr Martin specifically in this criticism as well as Mr Dhasmana.'[233]

197 She continued:

> 'I do not think that the nursing staff or Junior Doctors who we saw most of the time were aware of the failing success rate for infant cardiac surgery at the BRI. This was probably due to the split sites. I suspect that Dr Martin knew of the situation as he was a Consultant Cardiologist and should have been aware.'[234]

198 Clare Steel recalled her meeting with Mr Dhasmana before the operation and the discussion of the nature of the operation and the attendant risks:

> 'Mr Dhasmana explained to Norman and myself that Jonathan's condition was very serious and that it was a major operation. He told us that during the course of the operation, the heart would have to be stopped and then re-started. He said that he wanted us to understand the risk of death and of brain damage. He did not in so many words say that the risk of brain damage would stem from any delay or difficulty in re-starting the heart but Norman and I understood this in any event.

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[233] WIT 0510 0003 – 0004 Clare Steel

[234] WIT 0510 0005 Clare Steel

> He told us that 8 out of every 10 babies undergoing the operation did well. He told us that he did not know how long Jonathan would be in intensive care following the operation – it could be 2 or 3 weeks. He also said that until recently the operation used to be performed at 8–9 months but experience now showed that the lifelong result was likely to be better if the surgery was carried out at 10 days due to the possible enlargement of the heart associated with any delay…
>
> ‘Norman and I understood that Jonathan would die or remain very sick without the surgery described by Mr Dhasmana. We were therefore bound to conclude that the surgery should proceed. We were given confidence in the knowledge that it was now known that the operation was better performed at 10 days and not 8–9 months. Although Mr Dhasmana told us that 8 out of 10 children undergoing surgery did well, we were not informed that the record at the BRI was far worse. If we had been told of the poor success rate at Bristol, our consent to the surgery being performed there by Mr Dhasmana would not have been given. Jonathan could have been transferred to Birmingham or London following his septostomy. In hindsight, we would have expected him to have informed us of his own poor success rate in performing this type of cardiac operation upon infants. We would have expected him to have informed us of the option to have the surgery performed elsewhere such as Birmingham. Because we were not so informed, there was no discussion at all about the option of other centres. As far as we were aware, Bristol was a specialist centre for such cardiac surgery and we assumed that the 8 out of 10 success rate applied to Bristol given the context of the conversation. Had we known the true success rate at Bristol we would certainly have opted to have Jonathan transferred elsewhere.’[235]

199 Janet Edwards’ daughter, Sophie, underwent a neonatal Switch operation performed by Mr Dhasmana in April 1993 but died during the operation.

200 Sophie’s cardiac problem was recognised at birth and she was transferred to Bristol with her mother immediately. Janet Edwards stated that although at the time she was dazed[236] and distressed,[237] she remembered meeting Dr Jordan:

> ‘At some stage Dr Jordan came to see me and told me that they were going to take Sophie down to what he described as the Echo Room. The purpose of that was to have a better look at her heart. He also said that whilst she was there they may have to undertake some surgical procedure. He may have said exactly what they were going to do but I was too upset to take it in [and] due to my condition it was all above me at that stage.’[238]

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[235] WIT 0510 0007 – 0009 Clare Steel

[236] WIT 0005 0001 Janet Edwards

[237] WIT 0005 0002 Janet Edwards

[238] WIT 0005 0002 Janet Edwards

She said that later:

> 'Dr Jordan came to see me at 5.00 pm, and told me what they had done. He brought me some Polaroid pictures of Sophie. They were not very good but I was glad to have them and I was glad to see him as he gave me a reasonable amount of information. He was charming and polite and I was grateful. … During one of my meetings with Dr Jordan, after they had undertaken the surgical procedure on Sophie, he confirmed to me that she was going to need surgery. I cannot recall exactly what he said.'[239]

201 Janet Edwards described meeting Mr Dhasmana before the operation and the information and the quotation of risks which he gave her:

> 'Mr Dhasmana came to see me at about lunchtime on Friday. He explained the operation which Sophie required. He called it a Switch Operation and he drew a diagram. He went on to tell me that this was an operation which had recently been invented and that it was now thought that the best time to undertake the operation was in the first month of life. He said that Sophie's chance of not surviving was 1 in 5 and I discussed with him my concerns about resuscitation and brain damage… I asked him whether this was the only operation she would have to undergo. He did say to me that some children when they are about five have to have a further operation because the scar tissue does not expand. He pointed out to me that the little boy in the bed next door in the Baby Unit was recovering from a Switch Operation and was doing well. He seemed positive and confident; he gave me hope and I never thought that Sophie would not pull through. I thought that he was a god and that he was going to make things right.
>
> 'I accepted everything Mr Dhasmana said and I would not have dreamed of questioning him unless he had said something which made me think twice in view of my medical training.[240] I had the utmost faith in him in view of his position and never once doubted anything that he told me.
>
> 'On the Sunday morning we were with Sophie when Mr Dhasmana arrived to see Ken. I cannot recall whether Mr Dhasmana had previously told me the time for the operation but he confirmed that it was to be Tuesday.
>
> 'I cannot remember specifically what Mr Dhasmana said as I was not feeling well. I do remember that Mr Dhasmana mentioned an 80% success rate. I think I recall him doing a further drawing to assist Ken in understanding what he was going to do and I do definitely remember him explaining once again about the possibility of a further operation when Sophie was about five years old.'[241]

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[239] WIT 0005 0002 – 0003 Janet Edwards

[240] Janet Edwards is a community nurse

[241] WIT 0005 0003 – 0004 Janet Edwards. In response, Mr Dhasmana said he would have given a mortality figure of 'around 30%', WIT 0005 0011

202 As regards signing the consent form, Janet Edwards stated:

> '… I had become aware of a small problem with the Consent Form. I had assumed that Ken would be going to Bristol but he had decided not to. I think that he wanted to stay near to Sarah and myself. In any event, the Consent Form had to be faxed to Barnstaple and was then signed by Ken and returned.'[242]

203 Stephen Willis' son, Daniel, underwent a Switch operation performed by Mr Dhasmana in May 1993. Daniel died on the operating table.

204 As regards the referral of Daniel to Bristol, Stephen Willis stated in his written evidence to the Inquiry:

> 'I recall specifically enquiring of Dr Richardson [consultant paediatrician] why Bristol and I was told that Bristol was the nearest. There was more to the conversation but that was the only specific reason that I can recall being given for the transfer to Bristol. At no time were we given any other information as to the level of care that we were to expect at Bristol or the possibility of referral to any other Centres.'[243]

205 At the BRI, Dr Joffe confirmed that Daniel had TGA. Stephen Willis stated that he and Michaela Willis then met Mr Dhasmana:

> '… Mr Dhasmana came onto the Ward. He explained to us that the cardiac catheter had gone well but confirmed that Daniel would, nevertheless, need an immediate operation. We were left in no doubt that the operation should be performed as soon as possible. He then went on to explain that there were two operations that Daniel could have. One was known as sennings and the other operation was the switch operation. Mr Dhasmana could say nothing good about the sennings and was extremely positive about the switch.
>
> 'Insofar as the sennings operation is concerned he stated that it was one that has been done for a long time and that there were drawbacks with it. He said that Daniel's quality of life would not be as good … and that Daniel would require further surgery probably in his teens. I think he did give a success rate for the sennings operation but I cannot recall with any certainty what that was. In contrast Mr Dhasmana was very upbeat about the switch operation. He said that it would be a total repair and that Daniel's quality of life would be fine after the operation. My abiding memory of his comparison between the two operations was that with the sennings Daniel would always be short of breath would not really be able to play sport very well whereas with the switch operation he should have a reasonably normal life.

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[242] WIT 0005 0005 Janet Edwards

[243] WIT 0285 0002 – 0003 Stephen Willis

> 'I do recall that Mr Dhasmana was not forthcoming with the success rates … I specifically asked for the success rate of the switch operation and was told unequivocally 80–85%. I did not ask Mr Dhasmana whether that was his personal success rate but as he had given me the success rate I assumed that as he was undertaking the operation then it was his. On the basis that I had specifically asked him what were Daniel's chances the response that I received of 80–85% meant to me that it was Daniel's chances of success were 80–85%.
>
> 'It should be said that Mr Dhasmana explained by diagram how each of the operations would be performed and that we were under no doubt what he was going to do.
>
> 'After the explanation by Mr Dhasmana we were left in no doubt that we had little or no alternative but to opt for the switch operation. The positive nature with which he had dealt with the operation itself and Daniel's chances as opposed to the very downbeat way he dealt with the sennings left us with no choice … I asked him once again to confirm, which he did, that the success rate that he had given me for Daniel's chances of survival was accurate. He repeated the figures again to me. I then specifically asked him whether this was the best place for Daniel to be or whether there was somewhere else that the operation should be performed. Mr Dhasmana's reply was in words to the effect that Daniel would be fine. I took this to mean that Daniel would be no better off anywhere else.'[244]

206 Mr Dhasmana was asked by Counsel to the Inquiry on what he based his assessment of risk in the case of Daniel Willis:

> 'A. I have a huge problem with the neonatal Switch in a way to know, really, how can I quote my own statistics, because I have not got any running series of success. So there, I was going mostly on the basis of published literature and the American paper which I quoted before, which was going on the medium sized centre, what they would expect, and knowing about the term which is not really accepted, earlier experience, I am using the term here.
>
> 'Q. So the position would be for someone like the Willises that they were getting a perception of the risks in the literature but not the risks in your particular unit?
>
> 'A. That is correct.
>
> 'Q. Was that not effectively misleading, do you think?
>
> 'A. I did not think at that time — we are talking of 1992/93, there was no guideline, and almost all surgeons were quoting, whenever they were starting a new operation, what they were expecting from published literature.'[245]

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[244] WIT 0285 0005 – 0007 Stephen Willis

[245] T87 p. 89–90 Mr Dhasmana

207 Stephen Willis described an event in relation to signing the consent form:

> '… whilst I was away … I believe Michaela saw a Doctor and signed the Consent Form. Michaela amended the Consent Form by adding the words "based on the information given to me by Dr Dhasmana". After the transfer to the BRI we were informed that the Consent Form had been lost and I was required to sign a further Consent Form. I believe that the Consent Form signed by my wife has subsequently reappeared.'[246]

208 Stephen Willis recalled that after Daniel's operation:

> 'Mr Dhasmana was wearing his operating gown which was green and blood was splashed all over his chest and left shoulder. He was obviously distressed, there were tears in his eyes and he said that Daniel was dead. I can specifically recall him saying that the operation had been a success but he could not get his heart to beat again and he did not know why he could not save Daniel.'[247]

209 Stephen Willis stated that:

> 'We believed that Daniel had received the very best of care, in the best place and that our son was one of the unlucky 15%. We believed that we had taken the decision that we had in his best interest and it was no fault of anybody else that he died. It was for those reasons that we felt that his death could not be avoided and we did not feel that immediate feeling of devastation usually experienced when loosing [*sic*] someone very close and we accepted it as inevitable.'[248]

> 'Although we accepted at the time and still do that there was a risk to Daniel in the operation it is true to say that had he gone to Birmingham, Southampton or to Great Ormond Street his chances of survival in 1993 would, in my view, have been greatly enhanced. Secondly, I would like to highlight the excellent standard of care that Daniel received at the Bristol Children's Hospital. This was, as I have pointed out in my statement, in total contrast to the situation to be found at the Bristol Royal Infirmary.'[249]

> 'If my wife and I had received the true statistical information or a true reply to my second question I can say without any fear at all that we would have insisted that Daniel be operated on at the Centre where he had most chance … Taking into account either of the criteria which I requested Bristol was not that place.'[250]

210 Erica Pottage's son, Thomas, had a Switch operation performed by Mr Dhasmana in July 1993. Thomas died on the operating table.

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[246] WIT 0285 0008 Stephen Willis

[247] WIT 0285 0011 Stephen Willis

[248] WIT 0285 0012 Stephen Willis

[249] WIT 0285 0014 Stephen Willis

[250] WIT 0285 0015 Stephen Willis

211 Dr Joffe diagnosed Thomas as having TGA. Erica Pottage stated that Dr Joffe informed her that Mr Dhasmana would carry out the necessary operation. She stated that Dr Joffe explained that:

> 'Mr Dhasmana would decide whether to perform the switch operation (he explained what this would entail and the fact that it had to be carried out within the first two weeks of birth) or another operation at 18 months which he described as "extra plumbing" which would require further surgery as Thomas grew older. Dr Joffe said that the switch operation was quite new (2 to 3 years) but they had been very pleased with the success rate.'[251]

212 Erica Pottage described her meeting with Mr Dhasmana:

> 'We went to see Mr Dhasmana who drew pictures of Thomas's heart problem and explained the operation to us. At this point I asked "What are the chances of Thomas's survival?" Mr Dhasmana said "We do not like to quote statistics. It is a serious operation and Thomas is a small baby." Mr Dhasmana said "Only one child has had to return for further surgery following a Switch operation". My husband and I believed Thomas was in the best possible hands. We signed the consent form on this basis. Had Mr Dhasmana told us the truth about the statistics, we would not have given our consent. We feel that Mr Dhasmana should have referred us to another Hospital where Thomas had a greater chance of survival.'[252]

213 She said:

> 'I do not believe that we were told the whole truth regarding Thomas' chances of survival. I felt we were given little background information about the operation. My husband and I were not told about the lack of success of the operation in Bristol. We were not told where the best chance of a successful operation was.
>
> 'The doctors and consultants were the experts and we looked to them to advise us truthfully about Thomas' chances of success and whether, if Thomas went to another children's unit, he would have a higher chance of success. We were not told that, apart from Thomas's heart problem he was a healthy baby. We thought we had given our son the best possible chance of survival based on the information we were given at the Bristol Hospitals and we took some comfort from that when Thomas died. Now we find that this was not the case and I feel that we have been "cheated".'[253]

214 Malcolm Curnow's daughter, Verity, underwent a shunt operation which was performed by Mr Dhasmana on 12 September 1990. Verity died on 16 September 1990.

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[251] WIT 0260 0002 Erica Pottage. See Chapter 3 for an explanation of clinical terms

[252] WIT 0260 0003 Erica Pottage; Mr Dhasmana's response to this evidence is at WIT 0260 0007 – 0008

[253] WIT 0260 0004 Erica Pottage

215 Malcolm Curnow, in his witness statement, stated that:

> ‘While I was concerned about Verity, Mr Dhasmana’s views on the risks of the operation were very reassuring, and I was confident of a favourable outcome.’[254]

216 Malcolm Curnow stated that when he met Dr Jordan and was given the diagnosis, the explanation of the condition was minimal. Malcolm Curnow stated Dr Jordan recommended that since Verity appeared to be coping well they should take her home and ‘feed her up’.[255] Malcolm Curnow stated that subsequently:

> ‘Mr Dhasmana explained that it [the operation] was a simple procedure.’[256]

217 In his oral evidence, Malcolm Curnow’s attention was drawn to a letter dated 23 February 1990 written by his GP (Dr Stephen Straughan) to Dr Jordan which read:

> ‘This baby is now seven weeks of age, diagnosed by yourselves as having pulmonary atresia with VSD, with I understand a very small or non-existent pulmonary artery which makes immediate surgery impossible. She has been reviewed in Exeter by Dr McNinch. The parents, who are extremely sensible, understand the situation well and are coping admirably. Verity is gaining weight.
>
> ‘They have requested for genuine reasons that they are followed up in your clinic in Bristol rather than being seen in Exeter and if it were possible to arrange this, I would be most grateful.
>
> ‘I am sure this stems from the positive and helpful way the family were treated during their stay in Bristol when Verity was a week old.
>
> ‘They remain optimistic, but do realise the precarious position that Verity is in.’[257]

218 Asked whether the letter was a fair reflection of what he was feeling at the time, Malcolm Curnow told the Inquiry:

> ‘A. We were certainly aware that Verity, as I said, was not going to be normal for the rest of her life. We knew that surgical intervention was certainly a possibility.
>
> ‘We did not know whether it was a probability or not, and we understood the situation to be precarious as it is said there, in view of the fact that the next 9 months were very much in the hands of the Gods. … We did not know whether a shunt operation was going to be required or whether it was not. Our concern was to keep Verity well, which we were doing, but we knew that the future was uncertain and that was our understanding of the situation.

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[254] WIT 0004 0006 Malcolm Curnow

[255] WIT 0004 0003 Malcolm Curnow

[256] WIT 0004 0005 Malcolm Curnow; Mr Dhasmana’s response to this is at WIT 0004 0015

[257] MR 2374 0102; medical records of Verity Curnow. See Chapter 3 for an explanation of clinical terms

> ‘Q. So your use of “precarious” by the GP, if it were interpreted to give the impression that you knew that Verity was on a knife-edge between survival and death, that would be wrong?
>
> ‘A. That would be wrong.’[258]

219 After the death of Verity, Dr Jordan wrote a letter to Malcolm and Jane Curnow, which read in part:

> ‘As you know, we felt that although the prospects looked generally poor, we should make the attempt as I and all my colleagues felt that her outlook without some attempt at operation was extremely poor and we could be fairly certain that she would not have managed to survive another 6 or 12 months without some sort of intervention.’[259]

220 Responding to the suggestion that the words ‘As you know, we felt that…’[260] meant that Dr Jordan knew that Verity’s chances of survival without an operation were limited, Malcolm Curnow insisted that he and his wife had not been told so. Malcolm Curnow told the Inquiry that his understanding was that without an operation, Verity would be able to live up until her teens.[261]

221 Michelle Cummings’ daughter, Charlotte, underwent a Sennings operation performed by Mr Wisheart in June 1988. Charlotte died in March 1989.

222 Michelle Cummings stated in her written evidence to the Inquiry that Dr Jordan informed her of the heart defect and the diagnosis:

> ‘He told me that Charlotte had transposition of the great arteries a large hole in the lower chambers which cut through the bicuspid and tricuspid valves and narrowing of the aortic artery.
>
> ‘Doctor Jordan told me that he felt that something could be done to put things right, but that would involve two operations before she was one year old.’[262]

223 Dr Jordan referred Charlotte to the care of Mr Wisheart, whom Robert and Michelle Cummings already knew. Michelle Cummings stated that:

> ‘Robert [Mr Cummings] and I were confident in Mr Wisheart because Robert had been under Mr Wisheart’s care for many years in connection with his congenital heart defects.

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[258] T3 p. 19 Malcolm Curnow

[259] T3 p. 42 Malcolm Curnow and MR 2374 0084; medical records of Verity Curnow

[260] T3 p. 43 Malcolm Curnow

[261] T3 p. 43 Malcolm Curnow

[262] WIT 0123 0008 Michelle Cummings. See Chapter 3 for an explanation of clinical terms

> ‘I asked for a meeting with Mr Wisheart and saw him that afternoon. I remember being very nervous. I well recall Mr Wisheart coming across as being calm, soft spoken, patient and extremely kind. He went over again what Doctor Jordan had already told me several times, until he was sure I understood exactly what Charlotte’s condition entailed. I recall him drawing diagrams to illustrate the problem. He explained why the aorta had to be corrected before the main operation could take place. He said that he feared that as Charlotte got older, the aorta would constrict, making her problems worse.
>
> ‘Mr Wisheart said that Charlotte’s case was very unusual. He said that he had experienced all the problems that Charlotte had in one form or another in different patients, but never all of them together in one patient.
>
> ‘I recall Mr Wisheart saying to me that Charlotte would most likely not reach her second birthday if there was no surgical intervention and even then provided she did not deteriorate before surgical intervention could take place.’[263]

224 Michelle Cummings described the meeting she had with Mr Wisheart (in February 1988):

> ‘Mr Wisheart described the operation that he was going to perform for Charlotte. I was pleased about the meeting because it gave me an opportunity to ask Mr Wisheart about the availability of a switch operation. I had heard that a switch operation was available in America. I asked Mr Wisheart if this was possible for Charlotte. Mr Wisheart said that these operations were only at that time being performed in London. He said that at that time London had only done four such operations on children and hadn’t had great results. Mr Wisheart went on to say that in America the procedure was still in its early stages. Some seven procedures had been carried out on children in America and again, not with great results. I remember offering that I would pay for the switch operation if it would help Charlotte. Mr Wisheart was quite forthright in saying that he felt that the risk wasn’t worth taking. He also said that even if the operation was available, the nature of Charlotte’s defects were such as to exclude her as a candidate for such a procedure. He explained that a switch procedure was to put the arteries back the right way round, but that procedure would be too much for Charlotte because of her condition. I was happy to accept Mr Wisheart’s explanation. I remember that he was kind, but candid in the matter.
>
> ‘Mr Wisheart went on to explain the operation that he was going to carry out for Charlotte. It was to be a Sennings Procedure. He explained that Charlotte’s heart had the wrong chamber acting as the pumping chamber, which in Charlotte, was opposite to where it should have been. Mr Wisheart said he couldn’t change that. He had to get the blood and oxygen going the right way round. He said he would do that by carving little canals and making little bridges to allow that to

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[263] WIT 0123 0009 – 0010 Michelle Cummings

happen. He explained he also had to graft a wall in the lower chambers where the hole in the heart was (AVSD) and try and patch the valves because Charlotte had leaking valves.

‘I remember Mr Wisheart taking a great deal of time with me drawing diagrams and explaining the problems and procedures and indeed going over them several times.

‘Mr Wisheart explained how the operation would go. He said that the first stage was to cool the body down to enable it to be put on by-pass. I think he said it took three hours to slow down the body and to open up and clamp preparatory for the heart being put on by-pass. I remember him saying that that procedure was done by a separate team.

‘Mr Wisheart explained that there could be problems. He explained that not all patients were compatible with heart by-pass and that there was some risk attached to that, but that they would only know whether or not Charlotte was incompatible when she was put on the by-pass.

‘Mr Wisheart explained that there was a risk of brain damage because of the length of the operation and the amount of the anaesthetic required.

‘Mr Wisheart said that once the heart had been stopped and Charlotte put on by-pass, there was only a certain amount of time allowed within which the surgery could be carried out before she had to be taken off the by-pass. I do not remember how long Mr Wisheart said that period was.

‘Mr Wisheart said that there could also be problems taking Charlotte off the by-pass. Charlotte would have to be warmed up after the surgery and then taken off the by-pass and that could be a problem time.

‘Mr Wisheart was very specific about brain damage risk associated with by-pass and anaesthetics. He said that compared with past times anaesthetics were very much better and the risk very much less, but nonetheless there was still risk.

‘I remember asking Mr Wisheart what backup plan he had if he opened Charlotte up and realised that the planned operation couldn’t be done.

‘Mr Wisheart said that there was always a risk of opening up a patient to find that the situation was worse than that anticipated. He said that couldn’t always be planned for and that one would have to address and assess each situation as the need arose.

‘Mr Wisheart said there was a risk of Charlotte dying on the operating table if the problems were greater in fact when she was opened up, than had been anticipated.

> ‘Mr Wisheart warned that it was possible that Charlotte would end up on a pacemaker for the rest of her life, or might be paralysed for the rest of her life.
>
> ‘Mr Wisheart warned that after the operation there was another problem, namely with ventilation in that not all paediatric patients are compatible with ventilation and that there were difficulties sometimes associated with taking a paediatric patient off ventilation because paediatric patients could become ventilation dependent.
>
> ‘I remember asking Mr Wisheart whether in his opinion Charlotte would live to grow up. Mr Wisheart said he couldn’t tell me that. I remember him saying “One hopes that by doing this operation she will live a normal healthy life.” He said he couldn’t say for sure that that would happen. He said that he would do everything that he could for Charlotte and would do his best for her.
>
> ‘Mr Wisheart said that the success rate of the operational ie (Sennings) procedure was 75%. I think that was the figure, but I might be wrong.
>
> ‘I remember I discussed with Mr Wisheart the Mustard Procedure and reasons why that was not appropriate. I forget the detail of that. I didn’t make a note.
>
> ‘I remember Mr Wisheart saying there was a risk that the channels that he created would narrow, in which case a further operation would be indicated and that further operation was not always very successful.’[264]

225 As regards giving her consent for the operation, Michelle Cummings stated:

> ‘On the morning of the 13th June 1988 before Charlotte went down to the operating theatre for surgery Mr Wisheart saw my husband and I to sign the consent form … in February he [Mr Wisheart] had gone into great detail as to the operation to be performed and its associated risks and prognosis. On at least one occasion since then I had gone through the whole thing again in detail with Mr Wisheart and indeed we had gone through the whole thing again after Charlotte’s actual admission to the BRI for the surgery, consequently I signed the consent form with full knowledge of everything which was involved.’[265]

226 In a letter dated 31 October 1998, she said:

> ‘James Wisheart was particularly meticulous in planning the operations. All the avenues were explored and every consideration was taken into account and most importantly that it was the best choice for the child and that we as parents were informed every step of the way. Never were we mislead [*sic*] or misinformed.

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[264] WIT 0123 0014 – 0018 Michelle Cummings. See Chapter 3 for an explanation of clinical terms

[265] WIT 0123 0019 Michelle Cummings

> ‘The statistic given for success did not mean the survival of the child, but for the success rate of the operational procedure being performed. We were never led to believe that this was an indication of our daughter’s survival rate. Mr Wisheart went to great pains to point out that even if the operational procedure was a success there was no guarantee Charlotte herself would be able to cope.’[266]

227 Carol Kift, mother of Steven, stated in her written evidence to the Inquiry that Steven went to the BRHSC under the care of Mr Wisheart on 26 August 1986 and was operated on the next day for Coarctation of the Aorta at the BRI. She stated that she and her husband were in shock and her memory of what happened just before the operation was ‘rather hazy’.[267] But she stated:

> ‘… I certainly don’t remember Mr Wisheart explaining anything about the operation or its risks. The staff kept their distance from us as if they did not have the time to be involved with individual patients. We just consoled ourselves with the fact that Harefield had recommended the operation.’[268]

228 Carol Kift said that she was alarmed when the operation seemed to be taking hours longer than planned:

> ‘… Mr Wisheart came out of the operating theatre to meet us. He told us that the surgery was still going on because they had discovered complications with Steven’s arteries during the course of the surgery. This rather confused us because no abnormality in the arteries had been revealed by the scan. He gave no further explanation but went back into the operating theatre. Although Mr Wisheart had not been rude, we felt that his manner left quite a lot to be desired.
>
> ‘… Neither Mr Wisheart nor any of the other staff explained what effect, if any, the problems with Steven’s arteries would have. However, our main concern at that point was Steven’s size. When he had gone in for surgery he was normal size, but by the time he had got to intensive care the next day he seemed much bigger. It was as if he had suddenly grown. I commented on this to the nurse and she told me that Steven’s kidneys had failed, and that he had not been to the toilet since the operation. No one had seen fit to tell us this until we asked.’[269]

229 Carol Kift stated that, ‘Our major criticism of the BRHSC is that we received so little explanation and guidance about Steven’s care … Mr Wisheart, in particular, seemed to talk at us rather than to us.’[270]

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[266] WIT 0123 0035 Michelle Cummings

[267] WIT 0461 0003 Carol Kift

[268] WIT 0461 0003 – 0004 Carol Kift

[269] WIT 0461 0004 Carol Kift

[270] WIT 0461 0006 Carol Kift; Mr Wisheart’s response to this evidence is at WIT 0461 0011 – 0012

230 Amanda Boyland, mother of James, stated that in 1990:

> 'Five hours after our arrival at the Children's Hospital, Mr Wisheart came to the families room to speak to us. He confirmed that James had a hole in the heart, but he also said that James had a narrowing of the aorta, which had constricted, in other words it had closed up. Mr Wisheart then left the room, but came back and said that James had horseshoe kidneys which were at the front of the abdomen instead of at the back. He said that this was not a problem, it wouldn't affect James in any way.
>
> 'Mr Wisheart then told us that he would operate on James's heart in the morning to widen the aorta. Mr Wisheart came over as a real gentleman, he was very quiet and he smiled a lot. I trusted him completely. He drew diagrams to explain things so that I would understand what he was telling me. At the time I thought I had understood, but I didn't realise how ill James was. I didn't realise at that time that he could die.'[271]

231 As regards the consent form, she stated:

> 'The next morning, 9th May 1990, the hospital phoned me in the late morning. They said that they needed me to go back to the Children's Hospital to sign a consent form for the operation … The nurses asked us to wait in the families room. It was then that my mother-in-law arrived. An anaesthetist came to the families room to see us. He explained the anaesthetic procedure to us. My mother then informed him that there was a family history of hyperpoxy, an allergic reaction to anaesthetic. He explained that due to this he would use a neutral anaesthetic. I was then asked to sign the consent form for James's operation, which I did.'[272]

232 Amanda Boyland stated that, after the operation, Mr Wisheart came to see her:

> 'He told us that … during the operation he had done what he had wanted to, and that the operation had gone well. He said that it was slightly more complicated than expected, as the narrowing of the aorta was lower than had been first thought. He had put a band on the aorta to keep it open to increase the blood flow to the heart and to keep the aorta from narrowing further in the future. Mr Wisheart said that he had not repaired the hole in James's heart, but they had had a closer look at it during the operation and discovered that the hole went through all four chambers of the heart. We were told that Mr Wisheart would remove the band and repair the hole at a later date, before James reached the age of 5. We [were] also told that the next 24 hours would be crucial for James.'[273]

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[271] WIT 0232 0003 Amanda Boyland

[272] WIT 0232 0004 Amanda Boyland

[273] WIT 0232 0005 Amanda Boyland

233 Amanda Boyland referred to an incident after the operation:

> 'In the afternoon, James suddenly took a turn for the worse. At the time Dr Martin, Dr Jordan and Mr Wisheart were with James as they were doing their ward rounds. They asked us to leave, so once again we went to wait in the families room. Mr Wisheart came to tell us that James's kidneys were failing. My mother asked him to put James on a dialysis machine. Nursing staff brought the dialysis machine to the ITU. I cannot recall the exact time that it was brought to the ward. We do not know if James was attached to it. The doctors and nursing staff were huddled together. I heard one of them say that it was only brought to keep the family happy.'[274]

234 Amanda Boyland described a subsequent consultation with Mr Wisheart, at which he explained the next operation:

> 'My parents and I took James to Bristol Children's Hospital to see Mr Wisheart in early November 1991. He explained the operation that James was going to have. He drew diagrams to make it easier to understand. I could never take everything in at any of the meetings with Dr Jordan, Dr Joffe or with Mr Wisheart. My mother would understand what we were being told, and when we got home she would explain everything to us. At this meeting we were told that during the operation the band on the aorta would be removed and the hole in James's heart would be repaired. I thought that Mr Wisheart said that the operation had a 95% success rate but my mother's recollection is that Mr Wisheart said that the success rate was 85%. I understood this to be Mr Wisheart's opinion [of his own] success rate, as did both of my parents. Mr Wisheart would be doing the operation, it was his success rate that mattered. He said that he knew what he was doing, he said that he had confidence in himself, he believed that the operation would be a success. We were not told that there were other centres where the operation could be carried out. We were not given the choice for the operation to be performed anywhere else. No comparison of success rates at Bristol with anywhere else was provided to us.
>
> 'We had been told by nursing staff on previous visits that Mr Wisheart was the best in his field. Dr Jordan and Dr Joffe had endorsed this opinion. Mr Wisheart told us that James would have to have the operation before he was five years old, otherwise he would die. This was the first time anyone had actually said outright that James would die without the operation. We were told that James' operation would take place the following year.'[275]

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[274] WIT 0232 0006 Amanda Boyland

[275] WIT 0232 0008 Amanda Boyland

235 Amanda Boyland recalled that:

> 'James had also been to see the hospital dentist. The food supplement, Polymer, had rotted James's teeth and he now had an infection in his mouth …
>
> 'Mr Wisheart came to see me on the ward. He asked me whether I wanted to cancel the operation because of the infection in his mouth. I asked him what his opinion was. He told me that he thought it would be best to go through with the operation as planned. On this advice I signed the consent form. Mr Wisheart at this time reiterated that the success rate for this operation was 95%. He said that nothing could go wrong. I believed him, I trusted him completely. ...
>
> 'On the day of the operation, 9th February 1993, my mother and I arrived on the ward early in the morning. … Around 8.30 am my mother took James down to theatre. We had been told that the operation would take between 4 and 6 hours.'[276]

236 Amanda Boyland stated that whilst they waited for James to come out of theatre: 'Every so often we would ask a nurse to ring down to theatre to ask after James. We kept being told that everything was fine.'[277]

237 She continued:

> 'James had been in theatre for 14¹/₄ hours. He had been connected to the by-pass machine for the duration of this period. A couple of hours after being brought up to the ITU James had to be taken back down to theatre.
>
> 'Mr Wisheart came to see us. He told us that the operation was successful but that they had had difficulty getting James off the by-pass machine. I was told that when they had disconnected James from the machine they could not start his heart. They had attempted to do this 4 times. Thus, James was brought back to ITU still on the by-pass machine. At that time the operation wound had not been stitched up.
>
> 'I have been recently been told by Dr Martin, one of the consultants in Bristol, that the machine was an untested and unused adult heart by-pass machine and that in effect James was being used as a guinea pig to see if it worked. The machine was the only one available at the time and therefore the operation should not have gone ahead.'[278]

238 The UBHT responded to Amanda Boyland's statement by stating that the heart bypass machine had been used on both adults and children for many years prior to James' surgery, that the appropriate disposable pieces were available in various sizes and that the cardiac unit had had two such machines for many years.[279]

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[276] WIT 0232 0009 – 0010 Amanda Boyland

[277] WIT 0232 0011 Amanda Boyland

[278] WIT 0232 0011 Amanda Boyland

[279] WIT 0232 0032 UBHT

239 Amanda Boyland described the events surrounding James' death:

> 'I had been told that James was now well on his way to recovery, apart from the fluctuations in his blood pressure. However in the early hours of Sunday 14th February, there were serious complications … I was told that James had suddenly deteriorated. James was still on the ventilator at this time, but I was told that one of his lungs was filling up with blood. In effect James was drowning in his own blood … Mr Wisheart was then on the ward with James. My mother asked him to drain the lung. Mr Wisheart told us that it would take a week to drain the lung, my mother replied that it didn't matter how long it took, all we wanted was for James to get better.
>
> 'On the Sunday I was holding James in my arms when all the alarms started going off. I asked the nurses what the alarms were for. They said that it was only the alarm for his feeding tubes. They turned the alarms off. They then said that James had gone. He had died in my arms. It then dawned on me, although they did not tell me this, that they had switched off the machines so that James would die. They had not asked my permission to do so at all.
>
> 'I have since been told that at the time the alarms went off, Mr Wisheart had refused to give James any further medication to keep up his blood pressure and the food bags which contained medication once empty were not replaced …
>
> 'We asked the nurses if we could see James. They said we should wait until they had got him ready. James was detached from all the equipment and monitors and wrapped in a blanket. We were all given the chance, in privacy, to hold James and to say goodbye to him.'[280]

240 The UBHT responded that machines were only turned off after all tests had been done to ensure that a patient was dead. It stated that the family would have been involved in the detailed discussions surrounding the planning and turning off of the machines. It went on to say that family members might have found this so traumatic that they may not now be able to remember it clearly. In relation to the withdrawal of treatment, in the form of drugs and food, the UBHT stated that it is very unlikely that discussions took place without the family being involved in them.[281]

241 Penelope Plackett, mother of Sophie, explained what she was told in 1988 by the clinicians caring for her daughter:

> 'The cardiac catheterisation was carried out at the Bristol Children's Hospital by or under the supervision of Dr Benatar when Sophie was about 3 months old. Dr Benatar confirmed the diagnosis of Truncus Arteriosus Type I. He told me this was the easiest form of Truncus Arteriosus on which to operate. On the second day of that hospital visit, at which I was accompanied by Sophie's father, we were seen

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[280] WIT 0232 0011 – 0013 Amanda Boyland

[281] WIT 0232 0032 UBHT

by Mr Dhasmana. Mr Dhasmana had Sophie's notes and the results of the cardiac catheterisation. We met him in a little room in the baby unit at the Children's Hospital. Mr Dhasmana confirmed that Sophie had Truncus Arteriosus Type I. He also told me this was the easiest form of Truncus Arteriosus on which to operate. He stressed the urgency of operating but said that he wanted a lung biopsy to be carried out to establish that she had not suffered hardening of the arteries. He said that an operation to correct the heart defect would only be of benefit if there had been no lung damage. Mr Dhasmana gave the impression of being remote and vague. He did not inspire confidence …

'Mr Dhasmana carried out the lung biopsy in Bristol on 24th October 1988, when Sophie was about 3$^1/_2$ months ...

'After a fortnight, I telephoned Mr Dhasmana to ask if he had received the results of the lung biopsy. He told me that the pathologist at Bristol had been unable to draw any conclusions and that he had asked Great Ormond Street to assist. As Mr Dhasmana had stressed the urgency of the operation, I was very anxious. A further 3 weeks went by. I saw Dr Orme[282] at his clinic in Exeter, and he told me that Dr Berry, the pathologist at the BRI, had informed him that the results had arrived. He also stated that I should make contact with Mr Dhasmana. I therefore telephoned Mr Dhasmana. He told me that he had just heard from Great Ormond Street.[283]

'He said that although the biopsy was favourable, he still had serious misgivings about operating on Sophie because there had been a considerable time lapse since the biopsy was done. He said those four or five weeks could have had a disastrous effect on Sophie's lungs and she could, by now, be inoperable.'[284]

'… Mr Dhasmana told me that he had decided to operate on Sophie "to give her a chance". He said he was going to operate on 22nd November (1988). Sophie was then 5 months old. I have since become aware of a letter from the GOS pathologist in Sophie's medical records, in which he confirms that any damage to her lungs was reversible. I find it hard to reconcile this letter with Mr Dhasmana' s account of it.

'Throughout this period, Sophie's paediatrician, the cardiologists and Mr Dhasmana all said that, although there were risks, Sophie would have a normal life if the operation was successful. Nobody mentioned the risk of brain damage. I was not given any information about Mr Dhasmana's record in Truncus Arteriosus procedures. Nor was I informed of the complexity of Truncus Arteriosus in comparison to other types of congenital cardiac open-heart surgery. Mr Dhasmana did not tell me that he had by this time carried out 4 Truncus Arteriosus operations.

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[282] Sophie's paediatrician

[283] WIT 0012 0004 – 0005 Penelope Plackett

[284] WIT 0012 0014 Penelope Plackett

I now know that, of these, three of the patients had suffered from Truncus Arteriosus Type 1. All four of the children had died during or soon after the operation.'[285]

'We were admitted to the BRI with Sophie on Friday 19th November 1988. Sophie's father and I shared a room with Sophie. We saw Mr Dhasmana at about 6:00 p.m on Monday 21st November 1988, the evening before the operation, when he was doing his ward rounds. Our discussion with Mr Dhasmana lasted about half an hour. He explained that Sophie would be put on a heart/lung machine and that he would divide her single heart chamber into two and would then fit an artificial valve and artery. He said this would mean the pressure in her lungs would be reduced and her condition would improve. He said the operation would take up to 12 hours. Sophie's father was with me throughout this discussion. Mr Dhasmana examined Sophie, who looked healthy, strong and well. She had continued to develop normally; she was capable of holding her head up, grasping toys and enjoying her baby bouncer. Having told us on the previous occasions when we had met him that she had a 50/50 chance of survival, Mr Dhasmana now said that, because she was so well, her chances of surviving the operation were 80/20. Once more, he told us that if the operation was a success she would lead a completely normal life. He said she would need another operation – possibly as early as at age 3 – to fit a larger artificial valve and artery when she had outgrown those that would be fitted in this first operation. Mr Dhasmana mentioned no other risks and, therefore, I did not think there would be any. In my mind, Sophie was either going to live or die. If she survived the operation she was going to lead a completely normal life. Mr Dhasmana had said that she might not see her first birthday if she did not undergo surgery, and this convinced me that it must be right to proceed with the operation. On the basis of the information given to us by Mr Dhasmana, I signed the consent form.

'… Later that evening, Dr Benatar came to see us. We relayed what Mr Dhasmana had told us, including the fact that if Sophie did not have her operation she would be dead before her first birthday. Dr Benatar confused us totally by saying that this was not necessarily right, and I asked him if there were any other options. He said that we could leave her, but that she would be continually exhausted and would have a miserable life; she might eventually need a heart/lung transplant. We felt there was no option but to proceed with the operation the next day.'[286]

242 Penelope Plackett stated that after the operation:

'Mr Dhasmana told us that the operation had gone very smoothly and that she was making a good recovery. We found this reassuring. We asked him how long it would be before they would know that all was going to be well with Sophie and he said "usually 48 hours". During the first two postoperative days in ITU Sophie had a number of episodes of tachycardia, during which her heart rate would soar to 170–180. These were controlled by drugs … Once the first 48 hours had passed, we

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[285] WIT 0012 0005 Penelope Plackett. See Chapter 3 for an explanation of clinical terms

[286] WIT 0012 0006 – 0007 Penelope Plackett; Mr Dhasmana's response to this is at WIT 0012 0016 – 0019

> began asking if Sophie was going to be alright. We found the staff extremely reticent, and none of them volunteered any opinion as to the outcome. With hindsight I am sure they knew something was wrong. From about 7:00 a.m. until midnight each day, I was always at Sophie's side. Mr Dhasmana and Dr Masey came to see Sophie on their rounds, but I don't remember any visit from a cardiologist.[287]
>
> '… After a week, Sophie was weaned off her sedation and began to breathe for herself as the ventilator was turned down. I do not know why she remained on the ventilator for so long. At one point, within the first day after coming off the ventilator, Sophie suddenly opened her eyes. They were completely blank and unfocused and her arms and legs began to thrash more or less continuously for the next 2 days. During this period of fitting, Sophie did not sleep at all and we were extremely worried …
>
> 'A neurologist from the Children's Hospital or Frenchay, a Dr Schutt, came over to the BRI and examined Sophie. He carried out an EEG and asked us how we thought she was. We tried to be positive and pointed to the minute signs of improvement. In a conversation which lasted barely 2 minutes, Dr Schutt shot us down in flames. He told us (in front of a nurse, whose name I do not recall) that Sophie would never see, hear, move, or even suck or swallow. He said all her brain had ceased to function, apart from the cerebral stem. He said she would be severely epileptic. He stated that nothing could be done for her and that we should take her home and look after her. He said that, if she went into cardiac arrest, we should not resuscitate her, and should let her go. He did not say why this had happened. He asked us if we had any questions but we were too shocked and distressed to respond. This was just over 2 weeks after the operation. We were absolutely shattered and decided to go home that night to pass on the news to family and friends.'[288]

243 Sophie was then transferred to the BRHSC. Penelope Plackett continued:

> 'Despite the news we had been given by Dr Schutt, Mr Dhasmana told us at one point that this might just be a temporary swelling of the brain which would get better in time. Looking back, this was a particularly cruel thing to say. It gave me false hope. Mr Dhasmana persuaded me, much against my will, that I needed a break and should go home to Exeter for the weekend. I did so, although I did not feel that I could trust the staff to give Sophie proper care and attention. When I returned to Bristol, she had an appalling case of nappy rash with noticeable burns on her skin. She had obviously been left in a soiled nappy for a long time. I hated every second of the time Sophie and I spent at the Children's Hospital. I hated the nurses and the whole place. It was a nightmarish blur.'[289]

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[287] WIT 0012 0009 Penelope Plackett

[288] WIT 0012 0009 Penelope Plackett

[289] WIT 0012 0011 Penelope Plackett. The UBHT's response to this evidence is at WIT 0012 0022; Mr Dhasmana's is at WIT 0012 0020

244 Penelope Plackett stated that:

> 'Other than information as to the drugs that had to be administered, we were given no advice on how to care for a child in this severe condition either by the staff at Bristol Children's Hospital or at the Royal Devon & Exeter Hospital. Whereas Dr Orme had been supportive before the operation, his attitude had now changed. He said this kind of thing can happen and he was defensive of Mr Dhasmana.'[290]

245 Philippa Shipley, mother of Amalie, had moved to Swansea in 1986. Amalie's care was transferred to the Bristol team. Philippa Shipley stated that Dr Joffe was happy with Amalie's condition at the first meeting and the consultation was brief.[291]

246 In February 1988 Amalie was admitted to the BRHSC, as arranged by Dr Joffe.[292] After carrying out a catheterisation, Philippa Shipley stated that Dr Joffe discussed what he had learnt:

> '… he said that everything was looking good and that Amalie's open heart operation could be delayed for a good while yet … The meeting only lasted about 2 or 3 minutes … We did not see Dr Joffe again and Amalie was discharged the following day.'[293]

247 Philippa Shipley recalled that she and her husband heard of Mr Dhasmana when they received a letter asking them to attend an appointment with him,[294] which they attended on 20 April 1988:

> 'With very little introduction, he explained that he thought Amalie should have her Fontan operation as soon as it could be arranged. This was completely contrary to everything we had been told before, and I argued with him, pointing out that Dr Joffe had said Amalie would be fine for a good while longer yet. Mr Dhasmana cut me short, saying "Don't come into me with hearsay." … He … dismissively said, "There is significant medical evidence that children who weigh as little as 10kg can undergo this operation". The meeting lasted less than 15 minutes. Soon after… Andrew [Mr Shipley] wrote[295] to Dr Joffe asking if the operation might be postponed … I was very upset after the meeting with Mr Dhasmana … I cried tears of anger at the way we had been treated … We found him impatient and arrogant but we felt we had to take his professional advice, because we could not pretend to know what was the best course of treatment for our daughter.'[296]

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[290] WIT 0012 0011 Penelope Plackett
[291] WIT 0392 0009 Philippa Shipley
[292] WIT 0392 0010 Philippa Shipley
[293] WIT 0392 0011 Philippa Shipley
[294] WIT 0392 0011 Philippa Shipley
[295] WIT 0392 0042; letter from Andrew Shipley to Dr Joffe
[296] WIT 0392 0012 Philippa Shipley; Mr Dhasmana's response to this is at WIT 0392 0073

248 As regards the risks of the operation, Philippa Shipley stated that in January 1989, on the ward, after an echocardiogram had been performed, Mr Dhasmana:

> '… said that Amalie was "just above the line where this operation is possible". Nonetheless he said that she had more than a 50% chance of coming through it. He did not mention any other risks, such as organ failure or brain damage.'[297]

249 Philippa Shipley described events during and after the operation:

> 'Helen Vegoda … sat with us while we waited, but I did not find her presence at all helpful. Ms Vegoda passed the time by talking about family days out at St Fagans, Cardiff … Mr Dhasmana came to see us … He told us that things had not gone as well as he had hoped … He said we could go to see her in ITU. He warned us that she was a dusky pink colour. Amalie was a horrific sight … She had not been cleaned properly … there was blood in her hair and on her chest and the incision was not very adequately covered … Amalie's appearance was so awful that after her death I asked close family and friends not to visit her and pay their last respects since I knew they had only seen her at Christmas and would be appalled by her appearance. I was standing, trying to take this in, when I became conscious of Helen Vegoda physically pushing me towards the bed. I had not approached it myself, and she had taken it upon herself to encourage me to get closer to my daughter … When we went back to see her [Amalie], we were told that her kidneys had failed. The doctor who explained this to us asked if Amalie was our only child. When we said that she was, he put his head in his hands and sighed.'[298]

250 Lorraine Pentecost, mother of Luke, told the Inquiry how she came to know, in 1985, that Luke had a heart problem and required an operation:

> '… The day he [Luke] had his operation was the first I was told that there was definitely a heart problem. I was at home and I had a telephone call asking me to come over because he had deteriorated during the night. … I arrived at Bristol and I signed for him for a catheter. They sent him to have a catheter. I signed a form for the catheter. Luke came back from the catheter and it was — it seemed to be panic stations. I was told he had TAPVD and they were going to have to operate the same day, they were going to operate that afternoon … I did not have a choice, they said they have to operate immediately.'[299]

251 Lorraine Pentecost described what Mr Wisheart told her about the operation which Luke needed in the following exchange:

> 'He told me that Luke had TAPVD; that if he did not operate he was going to die.

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[297] WIT 0392 0015 Philippa Shipley

[298] WIT 0392 0016 – 0017 Philippa Shipley. The UBHT's response to this evidence is at WIT 0392 0074

[299] T95 p. 138 Lorraine Pentecost. See Chapter 3 for an explanation of clinical terms

‘Q. Did he give you some idea of what TAPVD was?

‘A. He ripped a piece of paper out of a notebook and with his pen he drew a quick diagram.

‘Q. You say “quick”; how long was your chat with him?

‘A. Couple of minutes, five minutes at the most.

‘Q. Were you on your own?

‘A. No, my husband at the time was with me.

‘Q. You discussed afterwards what had been said to you. No doubt you discussed what had been said to you afterwards?

‘A. Yes.

‘Q. Did you both take the same messages away from the meeting?

‘A. We were both led to believe that even though he said he had never seen this type of operation before —

‘Q. That is Mr Wisheart?

‘A. Yes. He said he had never done this type of operation before and he had never seen one, but he did know of a surgeon who had done one. He said he was going to contact him. I was led to believe that Luke’s condition was so rare that only a few — only one doctor had ever operated on it before.

‘Q. Did that give you the idea that it obviously was something which was really quite serious?

‘A. No, I was always led to believe that it was just basically a vein that had to be cut off, twisted round and stitched back on again. I know he said it was a 1 in a million chance of Luke actually having this, but he was so full of confidence, he was so full of himself to say that “Yes, this is an unusual type of operation, but I can do it”. I mean he never put any doubt in my mind that he was capable of doing it.

‘Q. If he was expressing confidence or giving you the impression of confidence, for what reason did you think he was saying to you, “Look, I have never actually dealt with such a case before but I know somebody who has and I will speak to him”? What did you think he was trying to convey by that?

‘A. At the time I never really thought about it, I mean I had just been told that he had this heart condition; that if they did not operate he was going to die. I never

> really thought that much about it at the time. I just thought if he does not have it, he is going to be dead.
>
> 'Q. So in effect you had no choice?
>
> 'A. No, I was given no choice.
>
> 'Q. Whatever Mr Wisheart had said, you would have, assuming you had got the message from him that the situation was critical, you would have agreed to the operation, would you?
>
> 'A. Yes. This surgeon that he spoke to or said he was going to speak to, I did not even know if he was in the country. There is major heart surgery all over the world. I just took it that Mr Wisheart was the only one who could do it, you know. I had no choice.'[300]

252 John Mallone, father of Josie, told the Inquiry that he felt that all he had received from the healthcare professionals in 1990 was 'reassurance', as opposed to useful information, and that he was not informed of the risks associated with the operation:

> '… Our daughter … was born in hospital and she never went outside. After a couple of days when she was not feeding properly, we constantly were given reassurance that it will be just some problem with a teat, try a different method and so on. Then it became obvious that she was not well, a heart murmur was detected and she was taken down to the SCBU, Special Care Baby Unit, and we were still being given reassurance all the time and we subsequently learned that the staff on that unit had suspected she had a coarctation because her femoral pulses were weak. They did not tell us about that at the time; they kept trying to make us feel that everything was okay.
>
> '… When it became apparent that she did have a serious heart problem, she had an echocardiogram and then Mr Wisheart – eventually after another couple of doctors saw us – came and explained to us she was going to need an operation for coarctation and later when she was older she would have to have open heart surgery as well, but he was immensely reassuring. He used the future tense, not conditional or anything. "She will never climb Mount Everest," he said, "but she will be able to ride a bike and run around like other children." There was never any doubt coming from him that, you know, she was safe, they would make her better, which we found immensely reassuring.
>
> '… But there was never any mention of any possible risk … She was paralysed as a result of the operation and the band itself was not of the right tension, so she subsequently died. But there was no mention of any possibility that she would be

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[300] T95 p. 152–4 Lorraine Pentecost

> paralysed, for instance, or brain damaged or anything like that. We were only given the opinion, a positive outcome was going to happen.'[301]

253 In his written evidence to the Inquiry, John Mallone stated that he had no recollection of Mr Wisheart's ever quantifying the chances of a successful outcome for the operation, but that his wife: 'clearly remembers him saying that there was a 95% chance that everything would be fine.' He also stated that: 'No risks other than that of Josie dying were mentioned.'[302]

254 John Mallone subsequently told the Inquiry:

> 'We were given a figure of 95 per cent success rate by Mr Wisheart himself, I think – if not him, by a junior doctor whom we saw on the same day. We saw two doctors who both explained what would happen in the operation and it was either Dr Ruth Gilbert or Dr Wisheart, I think, who gave that figure … We had [it] explained to us twice, by both this junior doctor and this surgeon who was going to perform the operation, and I felt I understood what was going to happen.'[303]

255 John Mallone indicated that the state in which he found Josie after her operation shocked him as 'she looked like a corpse in suspended animation'.[304] He stated that Mr Wisheart spoke to him and his wife after the operation and explained that the operation had not gone exactly as planned but had nonetheless been successful.[305]

256 John Mallone recalled that:

> '… Mr Wisheart was there … at 3.00 in the morning. One concern … that we both had at the time – was that he was operating at the end of a day when he had been at work since 9.00 in the morning. He started this operation at 7.30 in the evening and did not finish it until 3.00, finally went home some time after 4.00 and he was back on the ward at 8.00 in the morning. I could not understand how anybody could do that, physically stay awake that long and perform complex surgery, but he was there and he said he thought the operation was okay; he had performed the coarctation and everything was going to be all right, I think, at that stage.'[306]

257 John Mallone told the Inquiry that on 8 December 1990, Dr Martin told him that Josie had become paralysed 'from the waist down or possibly even higher … during the operation …'[307]

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[301] T95 p. 131–3 John Mallone
[302] WIT 0155 0005 John Mallone
[303] T95 p. 158–9 John Mallone
[304] WIT 0155 0006 and at T95 p. 161 John Mallone
[305] WIT 0155 0006 John Mallone
[306] T95 p. 161–2 John Mallone
[307] WIT 0155 0008 and at T95 p. 161 John Mallone

258 He stated further:

> '… We had a conversation with the unit's third Cardiologist, Dr Joffe. His prognosis was the gloomiest we had yet heard; indeed, he seemed to think Josie had no chance of surviving. He told us that she was not responding to any of the treatment, and that the "law of diminishing returns" was setting in. He asked whether there was anyone we wanted to see her before "the end". Did we have photographs of her? Were there any special clothes we wanted her to wear? He said he was going to consult with Mr Wisheart.
>
> 'At about 6 p.m. that day, there was a conference at which Mr Wisheart, Dr Martin, Dr Joffe, another doctor and at least two nurses discussed Josie's care. Our participation was not sought. At one point, I walked past the meeting and clearly heard Dr Joffe asking "But would you be considering this if it were ab initio?"
>
> '… When the conference had come to an end, Mr Wisheart and Dr Martin came and spoke to us about what they [had] been discussing. They went through what had happened so far, and Mr Wisheart told us what they wanted to do next. He said that all the problems with Josie's weight had been due to problems of chemical balance which had now been rectified. In his opinion, the chylothorax was likely to mend itself: he had never had to re-operate to repair the chyle duct. However, he said that they were fairly certain that Josie was now suffering from chylothorax on the right side of her chest as well. His suggested remedy was the insertion of a further chest drain on that side. He said that it was not yet clear what would happen with the paralysis; he knew of no child as young as Josie who had suffered permanent paralysis as a result of this operation, and the youngest he had ever read of was nine months old. His overall view was that there was every reason to proceed with treatment.
>
> '… When he was talking about inserting a further chest drain, Mr Wisheart stressed that he was just there to provide us with advice. I said, "You mean, if we say don't do it, then you won't?" He replied, "No, I would try to persuade you otherwise." This provides a fair summary of Mr Wisheart's dealings with us; he would supposedly present advice but, in fact, he was merely informing us what they were going to do. At the end of our long meeting with Dr Martin and him, we did not feel very convinced of the arguments with which we were being presented, but felt powerless to affect the outcome anyway.
>
> 'At about 10 p.m., the new chest drain was put in place by Mr Wisheart's registrar (a man who had, until that moment, had nothing to do with Josie's treatment).
>
> 'At about 11.30 on Sunday morning, Josie's saturations suddenly dropped, and a subsequent X-ray showed left-sided pneumothorax (i.e. a punctured left lung). I have no doubt that this must have been attributable to an incident that had occurred the previous morning: a doctor who we had never seen before had introduced himself to us as "a consultant" and, after pronouncing Josie's ventilator

> "a bit low" had turned it up drastically. The ventilator was set to 50 breaths-per-minute, which was 100% higher than it had been the day before, and 50% higher than at any point in the fortnight since Josie's operation. The pressure was also drastically increased. We never saw the doctor again, and never discovered his name.'[308]

259 John Mallone described the events leading up to Josie's death:

> 'Mr Wisheart, Dr Martin and a nurse called Joyce spoke to us. They said that the looseness of the band meant that too much blood was getting to Josie's lungs and, as a result, she could not adequately ventilate herself. We were offered two alternatives. The first was that they remove the artificial ventilation, giving Josie a chance of making it on her own without really expecting her to do so. The second was to do another operation to tighten the band; however, if this course of action was chosen, it would be necessary to do a diagnostic catheterisation first. They made it clear that this procedure, in itself, had a risk attached to it. I do not know why they even mentioned this course of action as a possibility, since we had, by this stage, already made it quite clear that we did not want Josie to go through another operation. By now, Dr Joffe's earlier pessimistic approach to us began to seem by far the most human we had encountered. I got quite angry with Mr Wisheart, since he was now saying that it was possible to stop treatment whereas, before, he had seemed determined to go on to the bitter end. The only thing that appeared to have changed was that they now thought the paraplegia was almost certainly permanent. This meeting was a most unpleasant one. Ann would not speak. I was angry.
>
> 'After over a month of looking on, feeling as if we had no say in Josie's treatment, we had been presented with a huge decision: the choice between, on the one hand, letting our daughter die and, on the other, demanding the continuation of the increasingly painful and apparently futile fight for her survival. Mr Wisheart had stopped giving us instructions masquerading as advice and seemingly abdicated all responsibility for planning Josie's care. I now know that deaths at units like Bristol's are only counted as statistically significant if they occur within thirty days of an operation and, in my most cynical moments, I wonder how much of a coincidence it was that the point at which Mr Wisheart deferred to us for the first time came immediately after this watershed. For me, it is a travesty that Josie was, as far as Mr Wisheart's record is concerned, a success.
>
> 'We decided to refuse further treatment. Nothing we had been told gave us any hope that there was a genuine chance of Josie surviving without being put through what we considered an unjustifiable amount of further suffering, and the risk of an even less dignified death. Joyce, the nurse, said that we mustn't feel that we'd given her a death sentence, but we both felt dreadfully guilty, even though we hoped that we were doing the right thing.'[309]

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[308] WIT 0155 0010 – 0012 John Mallone

[309] WIT 0155 0014 – 0015 John Mallone; Mr Wisheart explained his approach at WIT 0155 0064 – 0065

260 John Mallone told the Inquiry that he found Dr Joffe:

> '… actually the most human of any of the doctors that we met and I found the way in which he broke this news to us, I think it was done very sensitively, I thought he came across as a very caring human being and I did not feel it was done brutally at all. The shock came when at the end of the conversation he said "I will go off and talk to Mr Wisheart about it", the shock came when we were then told, after they had had a discussion about it for over an hour at which I could hear Dr Joffe arguing strongly that she ought to be allowed to die, the shock came when Mr Wisheart said he wanted to continue treatment. I found it appalling that we could have been told "There is nothing more we can do for her" and then a matter of hours later being told "We can go on and do this, this and that." I think they should have got their story straight before they spoke to us … I do not know why treatment was continued. I guess Mr Wisheart may have felt some kind of sense of his own pride in his work perhaps that he did not want to have this child die if he thought she could survive, I can understand that. What I do not understand is why, after having said "We can continue treating her", another two weeks later when nothing had changed in her condition whatsoever, at that point we were told if we wanted to, we could take her off the ventilator now and let her die … when one of them says "Your daughter is about to die" and the other one is saying "No, she is not", I felt they should have spoken to one another beforehand.'[310]

261 Maria Shortis' daughter, Jacinta, was operated on by Mr Dhasmana in November 1986. Jacinta died in January 1987.

262 In her written evidence to the Inquiry, Maria Shortis recalled Dr Joffe sitting with her husband and her and that he:

> '… started to draw a normal heart for us to see. He then drew a diagram of Jacinta's heart. It was readily apparent that Jacinta did not stand a chance of survival. She was completely dependent upon her patent ductus arteriosus to keep her alive until she was two or three. Dr Joffe listed the conditions from which she was suffering as absent septum, pulmonary atresia, transposition of the great arteries, and defective tricuspid and mitral valves. He said that Jacinta was 1 in 3 million, and that he would never see another baby like her in his lifetime. He also stated that he was surprised she had been born alive. Because her patent ductus arteriosus would close after a few days, Dr Joffe said that it would be necessary to perform a shunt operation during the first week of Jacinta's life. Dr Joffe said that he was impressed Jacinta had weighed so much at birth, and had been born so effortlessly. When we asked him about our options, he said that we could turn off the Prostaglandin that was keeping her ductus open. He stated that, if we chose to follow this course of action, she would "succumb" in about 48 hours. Dr Joffe then said that Jacinta was a strong little baby and, in his opinion, worth fighting for. He said that the shunt operation was not risky, and made it very clear that it would give Jacinta a few years

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[310] T95 p. 184–5 John Mallone

> of life. I specifically asked him what her quality of life would be for those two or three years. Dr Joffe assured me, categorically, that she would have as near normal a childhood as possible. I felt that I could not ask Dr Joffe to switch off Jacinta's life support at this stage, if there was some quality of life she could experience with her parents and her brother. We therefore agreed to go ahead with the operation.'[311]

263 Maria Shortis stated that Dr Joffe told her that a cardiac catheterisation would have to be done, and that she asked Dr Joffe about the risks involved:

> 'We asked about this, and about the inherent risks involved. We were told that there were no risks, which prompted me to comment that nothing in life is ever risk-free. At no point did Dr Joffe tell us about the effects of infections, jabs, drugs or post-operative care upon Jacinta. If we had known what questions to ask, we would have raised these issues. Instead, we agreed to the catheterisation procedure going ahead, and signed the appropriate forms.'[312]

264 Maria Shortis stated that Dr Joffe then later informed her that he: 'had spoken to Mr Dhasmana, the consultant paediatric cardiac surgeon, and that Jacinta had been listed for surgery the following afternoon.'[313] Maria Shortis recalled that Dr Joffe said that they were to see Mr Dhasmana the next morning who would give them details of the operation he was to perform. Maria Shortis went on:

> 'Dr Joffe stated that we were very lucky to be at a centre of excellence. I felt very relieved by this.'[314]

265 Maria Shortis described meeting Mr Dhasmana:

> '… we were shown into a small room by a nurse from ITU, who I think was called Jeanette, for our consultation with Mr Dhasmana. As we sat down, Mr Dhasmana said, "Had I got to you before the consultant cardiologist, I would have told you that your daughter is inoperable, and have asked you why you want to put her through such misery. I have cancelled the operation." It came out in a burst of frustration and anger, and I found the way Mr Dhasmana informed us of his decision was totally unprofessional. I heard Tim groan, and saw him slump back in his chair. My initial response was, "But you didn't get to us first." I was trying to collect my thoughts, and wondered what Dr Joffe had based his decision on. I had the impression that Mr Dhasmana was telling us the truth, but that his communication skills were appalling: he appeared to have blurted out his own decision, rather than presenting us with reasons. At no point had Dr Joffe stated that the surgeon did not think that Jacinta was inoperable. Now, I was faced with the possibility that my child's operation would not go ahead, and a surgeon who was

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[311] WIT 0222 0009 Maria Shortis. See Chapter 3 for an explanation of clinical terms

[312] WIT 0222 0010 Maria Shortis

[313] WIT 0222 0010 Maria Shortis

[314] WIT 0222 0010 Maria Shortis

> evidently angry with his colleague. I felt as though I had been drawn into inter-departmental hospital politics, particularly between these two men.
>
> 'Following his outburst, I said, "Mr Dhasmana, do you not want to operate on Jacinta because she is going to die anyway?" I believed this question would give him the opportunity to answer in the affirmative. Had he believed it to be a waste of time, I could and would have accepted it. However, Mr Dhasmana's reply struck me as illogical and cowardly, and made me cross. He moved back in his chair and shouted, "I am not talking about death, I just like to see my patients through." The implication of this was that he liked to have a good success rate. However, when I asked him about this, he informed me that there was no problem with this operation, and that Jacinta would come through it easily; he quoted me a 95% success rate …
>
> 'I felt that I was dealing with someone who could not give a straight answer, and said, "Mr Dhasmana, having cancelled her operation, what do you want to do with Jacinta?" He replied that he wished to take her off all her drugs, and monitor her progress. I interpreted this as meaning that he wanted to let her die, since Dr Joffe had already told us that Jacinta would die within 48 hours if she was taken off her medication. I therefore informed him of Dr Joffe's opinion. Mr Dhasmana stated that he had seen patients whose patent ductus arteriosus was still open and functioning at the age of 18. I remarked that I suspected these patients did not have five major heart defects. However, by this stage, I was so stressed by this conversation that I consented to Jacinta being taken off her drugs to see how she coped. I remember that Mr Dhasmana appeared to be very relieved, but also surprised at my reaction. I added that, as her mother, I wanted her to be put back on her drugs if she became cyanosed, and in danger of dying, since I was not yet ready to say goodbye to her. Mr Dhasmana seemed pleased that I had agreed with his plan, but stated, "As you have been promised the operation, I suppose I shall have to do it." He said this in a sulky manner, and it seemed such an unprofessional way to end our conversation that I left the meeting in some distress.'[315]

266 Maria Shortis stated that on the day before the operation, she saw Dr Joffe, who apologised for what happened in her meeting with Mr Dhasmana:

> 'He said that Mr Dhasmana was an emotional sort, who upset parents, but he could reassure me that Jacinta could and would have an operation. Dr Joffe seemed dismissive of Mr Dhasmana, and I was surprised by his apparent lack of professional loyalty. I did not raise my concerns that the lack of communication in the BCH was adversely affecting the level of care Jacinta was receiving, as I was too exhausted. Additionally, I had been told many times that the BCH was a centre of excellence by both Dr Joffe and the nurses. I believed that the staff were skilled experts in cardiac surgery, even if they did not have much skill in talking to parents.'[316]

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[315] WIT 0222 0011 – 0013 Maria Shortis

[316] WIT 0222 0014 Maria Shortis

267 Maria Shortis stated that Dr Joffe informed her that Jacinta's operation would go ahead the next day, and that:

> '… the operation carried very little risk, and quoted a 90% success rate. He also stated that we should give her the best opportunity.'[317]

268 Maria Shortis recalled that:

> 'I was very aware, throughout the course of this conversation, that the cancellation and subsequent reinstatement of Jacinta's operation had very little to do with me directly.'[318]

269 Maria Shortis stated that:

> 'Following Jacinta's death, I realised how optimistic Dr Joffe had been in his appraisal of her quality of life, post-operatively. For Jacinta, death must have been a welcome relief. For us, it was terrible … I now believe that, had Mr Dhasmana seen us before Dr Joffe, he would have told us that there was no operation which could give Jacinta a reasonable opportunity of normal life. However, he did not, and it appears that he did not feel able to assert his views against those of his colleagues.'[319]

270 Maria Shortis expressed her feelings on the matter now, in her statement to the Inquiry:

> 'I am still appalled at the lack of information that was available to us. I believe that Mr Dhasmana should have told me that one of the risks of the large shunt he fitted was heart failure … Dr Joffe, who recommended that Jacinta should have the shunt operation, never explained that heart failure would be one possible outcome. I also wish I had known what the side-effects of Digoxin were, as I found it terrible to watch my daughter's condition deteriorate, due to a lack of proper nourishment. Jacinta experienced all the side-effects associated with Digoxin, and it is awful to imagine that I gave her a drug which might have caused her death. At the time, I asked what the associated side-effects of Digoxin were, but never received a straight answer from any of the hospital staff. If I was the parent of a child who should be alive today, I do not know how I should feel towards the medical and nursing staff of UBHT. However, I do feel that Jacinta did not receive competent treatment, and that I and my family were burdened by unnecessary grief and guilt.'[320]

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[317] WIT 0222 0015 Maria Shortis

[318] WIT 0222 0015 Maria Shortis

[319] WIT 0222 0021 Maria Shortis

[320] WIT 0222 0023 Maria Shortis

271 Paul Roberts, father of Andrew, explained to the Inquiry the steps he took in 1985 to be sure that he understood what the various healthcare professionals told him and his wife:

> '… It was a lot to take in at the time, but we had a lot of help by the people who were looking after us … a lot of the people around us at the time, we had an extremely good health visitor. We had a health visitor who also lived across the road from us. We just talked to everybody we could. That was the biggest help, really. We just kept on talking to everybody at the hospital, friends, and eventually, as I say, that helped us through it, really.'[321]

272 Tony Collins, father of Alan, told the Inquiry:

> 'We had had it explained to us several times, but I understood the problem to be Alan had a blocked and narrow aorta … Mr Wisheart had actually drawn pictures when we saw him of what the problem was and what he was going to do to repair it, and also [Dr] Jordan and Dr Joffe came to see us and all drew pictures at that time of what was going to happen … Mr Wisheart and Dr Jordan and Dr Joffe had all told us that Alan's chances were not particularly good because of the amount of time he had been unwell leading up to being in Bristol, so the chances of his survival were not very good at all. I could not actually put a percentage on it, but I think it was less than 50 per cent … They told me but I cannot remember now what it was. I just know it was a little below 50 per cent.
>
> '… The situation we were in to begin with was the fact that Alan either needed to have the operation or he was not going to survive, so you can look at that and say there is no option, really. Given an option now, we would still have let Alan have the operation.
>
> '… There were so many things happening on the day with Alan having to have this operation and all the rest of it, that odds and — lots of different things we were told did not really register in the sense of all we were worried about was that Alan survived the operation.
>
> '… They said because of — not the amount of time of the operation, but they said there was a possible chance Alan could have brain damage or be paralysed from the waist down, the ultimate one being the fact he may not survive.'[322]

273 Susan Francombe's daughter, Rebecca, was diagnosed in 1986 about 18 hours after birth as having a heart problem.[323] She died aged 5 days, after an operation performed by Mr Dhasmana.

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[321] T68 p. 86–7 Paul Roberts

[322] T68 p. 73–6 Tony Collins

[323] WIT 0349 0001 Susan Francombe

274 Susan Francombe told the Inquiry:

> ‘Certain things are very clear. Certain things stand out in my mind, certain pictures from throughout almost five days of her life. Other things are a blur and I do find difficult to remember.
>
> ‘Some things I have not gone over and over, but in the light of the past two or three months, since I decided to contribute to the Inquiry, things have come to light, things have got stirred up. For example, I have since read her medical records, in the past two weeks, which I had never seen before.’[324]

275 Susan Francombe said that matters were always explained in an informative and caring way, with efforts being taken to make sure that she understood.[325]

276 Susan Francombe described meeting Mr Dhasmana for the first time:

> ‘He had said that he had seen Rebecca as well as seen the results of the catheterisation and the cardiogram, the previous investigations. He drew us pictures of what that had shown and explained that surgery definitely was the only option; that he had not seen a heart formed in that way ever before, but he either said he was going to or later told us that he had consulted other cardiac surgeons in a London hospital.’[326]

277 Susan Francombe agreed that her impression was that Rebecca’s condition was something which Mr Dhasmana had not met before, and that he was informing himself about how best to deal with it.[327]

278 Susan Francombe told the Inquiry that she discussed the likelihood of success of the operation with Mr Dhasmana:

> ‘A. I thought he had said 50:50, but my husband remembers it was less than 10 per cent. I am quite prepared to think that I have blanked that out. My husband is better at remembering things than me.
>
> ‘Q. What you do remember is Mr Dhasmana indicating that he had never come across the particular problem before?
>
> ‘A. Yes.
>
> ‘Q. So plainly, any estimate of success he was giving you was in that context?
>
> ‘A. Yes.

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[324] T68 p. 9–10 Susan Francombe

[325] T68 p. 11 Susan Francombe

[326] T68 p. 11–12 Susan Francombe

[327] T68 p. 12 Susan Francombe

> ‘Q. And what was the alternative to the operation?
>
> ‘A. That she would have died.
>
> ‘Q. So there was no alternative?
>
> ‘A. There was no alternative.’[328]

279 Susan Francombe wrote a letter to Mr Dhasmana on 21 January 1987, in which she and her husband said:

> ‘… we could not leave it unsaid how grateful we are at all you did for our daughter Rebecca. We often think of the marvellous care and attention you gave her …’[329]

280 John McLorinan’s son, Joseph (Joe), was born with Down’s syndrome. He had AVSD, which was successfully operated on by Mr Wisheart on 14 February 1991.

281 John McLorinan described in his written evidence to the Inquiry the diagnosis and explanation which he was given by Dr Joffe:

> ‘… he came in … he was very calm and soothing and very professional, and he explained very carefully that the initial diagnosis was correct and that Joe did have profound heart problems, and he explained that there was a hole in the middle of the heart and the valves were not working properly and blood was sort of slushing around and not doing a proper job and that was affecting the breathing and everything else …
>
> ‘He explained it [AVSD] very thoroughly. Probably he explained what it was there and then, and so we grew into the term …
>
> ‘He made it quite clear that there were … options.’[330] The first option was to let nature take its course and the second was to do banding on the pulmonary artery.’[331]

282 John McLorinan told the Inquiry that Dr Joffe explained the option of heart surgery:

> ‘… the possibility was suggested that eventually, if we wanted to, we could be referred to the heart surgeon who would open the heart up and do a full repair, put it all back together again. But right from the outset, it was explained all sorts of hurdles and difficulties and dangers and it was looking so far ahead and in fact Joe was so ill at the time we were looking almost an hour or a day ahead.’[332]

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[328] T68 p. 13 Susan Francombe

[329] MR 2181 0012 – 0013; letter to Mr Dhasmana dated 21 January 1987

[330] T2 p. 128–9 John McLorinan

[331] WIT 0122 0001 – 0002 John McLorinan

[332] T2 p. 131–2 John McLorinan

283 John McLorinan went on:

> '… we did not really consider any other option than the full repair, because having brought a child into the world, we thought we would "go for broke", you know, it was not fair on Joe just to let him live a few months or a few weeks or whatever, he ought to have the opportunity of as full a life as possible, so we did not really consider either of the first two options, in all honesty. We wanted to go for it … we understood that he might not even get as far as corrective surgery. It was in many ways, talking to Dr Joffe, and people later on, in many ways it was depressing, because they were saying, "But, if, it might not, we have not got there yet, there is this problem." So they were very good at calming us down, "There is this problem, there is that problem, we cannot guarantee this."… I think surgery at that stage was so far in advance and perhaps so indeterminate that certainly no statistics were mentioned. We just knew it was a very difficult time.
>
> '… I think I should also explain that Joe not only had the heart problem, we were also made very aware of the Down's syndrome and that Down's syndrome people reacted very differently to things and were more susceptible to infection, and also he had this Hirschsprung's disease which was a major problem as well. Apart from the cardiac problem he was a whole mess as well and things all piled on top of each other, so it was very difficult to comprehend anything beyond an immediate fault. We were just very, very aware of how delicate his life was.'[333]

284 John McLorinan described the time when his son was getting worse:

> 'They were explaining what was happening, one step forward, two steps back. They were explaining the different drugs they were going to use, but on the heart business they were failing because the heart was not able to shift the blood and fluid around the body, so it was accumulating, getting worse and worse. The situation was just deteriorating and they were in the best possible way saying "We cannot do anything else" sort of thing. We really got to the stage where we thought we would be called into a discussion to say, "Well, do we call it a day?"'[334]

285 Joe's deterioration is recorded in the minutes of the joint cardiac meeting of 21 February 1990:

> '… in the light of Joseph's poor progress and difficulty being weaned off ventilation, it was felt that a palliative operation would be preferable to attempting a complete correction, which is likely to have a low likelihood of success.'[335]

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[333] T2 p. 133–5 John McLorinan

[334] T2 p. 143 John McLorinan

[335] MR 2469 0171; minutes dated 21 February 1990

286 John McLorinan discussed the effect information could have:

> ‘One small incident I recall which happened before this operation is that we had had a consultation with Dr Joffe to discuss Joe’s future and treatment. He made reference to some of the problems lying ahead but he had talked about this in a balanced way and also talked of what we might hope for in due course. Following this meeting, I left Gill in the waiting area … When I came back to pick her up I could not see her in the waiting area, and found that she had been taken by a nurse to have some privacy in a small ante room.
>
> ‘She was upset and I talked things through with her and it became apparent that she found herself focusing on the difficulties ahead and the negative side of things, particularly the fact that the Cardiac Catheter procedure could come up with the result that Joe would be inoperable: on the other hand there had been much in our discussion with Dr Joffe that had been positive, and by the two of us talking it through together, we drew out these positive aspects. It seems to me illustrative of how a person’s reaction to advice can depend very much on the listener as to what he or she focuses on, and how they react to that information.’[336]

287 He told the Inquiry:

> ‘It struck home to us very much the importance of listening carefully and the fact we tended to select what we wanted to remember. We were in such a state of tension … we were both in such a state of worry and anxiety, it had gone on for so long, and we were so desperate for Joe to get fixed, that we were there listening and just by chance the brain would snatch on to one piece of information, it might be a good piece or a bad piece, but just the sort of things that stuck.’[337]

288 John McLorinan said that Mr Wisheart quoted a risk of 50:50:

> ‘I think we were very well aware of the fact that even though Joe had had the banding, he was not doing particularly well and obviously his prognosis of life was not very good, and we realised that to make a success of Joe’s life and any sort of permanency of life, we would have to have the surgery done. We have these figures here, 50:50, and these percentages, that is a big thing. I suppose our understanding of the statistics – we are both teachers and I sort of specialised in statistics and psychology in my final year – we are very much aware of statistics as something you can use one way or another without co-efficients of validity and reliability and all that. You spend years studying these things in education, and they say statistics do not mean very much anyway. By 50:50, we understood that Mr Wisheart, through the totality of his experiences and his skill – we understood there was as much chance of Joe succeeding in the operation as failing. Putting it crudely,

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[336] WIT 0122 0005 John McLorinan

[337] T2 p. 150–1 John McLorinan

> it was on the toss of a coin, but we wanted him to have that chance and we were confident.'[338]

289 As regards referral to other centres, John McLorinan responded in the following exchange:

> 'There were all sorts of rumours going on about reforms in the NHS and we were hearing stories and that, so we realised which hospital we would have been under had we moved up North [Yorkshire]. Our belief was that there was nobody up there with sufficient skill to perform these sort of operations; they would not have been offered. People in that situation were told, "I am sorry, it is inoperable."
>
> 'Q. Can I just ask you, you said that your belief was that there was nobody who had sufficient skill to carry out that operation up north?
>
> 'A. Yes.
>
> 'Q. On what was that judgment based?
>
> 'A. I believe there was somebody appointed at a later date in this hospital who was in fact trained under Mr Wisheart in Bristol.
>
> 'Q. Well, you were making a judgment at that time?
>
> 'A. Yes, at that time, we were told —
>
> 'Q. At that time you were told by whom?
>
> 'A. As I said, Gill was a bit worried about this, so she asked Dr Tizzard, I think she was part of Dr Joffe's team. She made enquiries and came back and said, yes, she understood it would not be possible.
>
> 'Q. Was that because nobody had enough skill to operate up north, or was it because —
>
> 'A. That is what we believed: that they did not do that operation in that particular place.
>
> 'Q. That may be two different factors: one is that nobody has the skill to carry it out; the second factor, which perhaps you mentioned, was that nobody would want to carry it out?
>
> 'A. Yes. I think there are two quite distinct issues here, and I think that is one of the reasons why I actually gave up the job and moved back down here. Certainly

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[338] T2 p. 158 John McLorinan

> I believe that the information was correct that they were not doing that operation there, but secondly, as the previous witness said, this is Down’s Heart Group, and we were members of the Down’s Heart Group. The Down’s Heart Group obviously were promoting the support of children with Down’s, with heart problems, and they were doing research and coming up with alarming statistics, that people with Down’s syndrome were not being offered equal chances of these operations.
>
> ‘Q. So from that, you thought there might be a problem in persuading another hospital to offer Joe this operation? Is that a fair summary?
>
> ‘A. We were certain of that, and we were also certain that we would not get a better surgeon, a better team; we could not do better anywhere else. Quite apart from the actual operation itself, the follow-up afterwards’.[339]

290 John McLorinan told the Inquiry of his discussion with Mr Wisheart on the day before Joseph’s operation:

> ‘… we understood it was a very, very serious operation with a very high risk. We were aware of little marks on Joe’s notes saying that he was at very high risk, even from anaesthetic. Again, we have this thing of 50:50 and tossing a coin, but Mr Wisheart quite plainly said what he was going to do, it was a by-pass, a very intricate operation, and even if everything went well and he took him off the by-pass for some reason, some of these operations did not work. They had not got far enough in advance of understanding why these things did not work. He said sometimes it is one of those things that just does not work. He could not guarantee anything … there just was not an alternative because he was not thriving. He would have died sooner or later.
>
> ‘… we were fully aware of the risks and fully aware of the operation, but we signed it [Consent Form] willingly. We did not feel pressured. All the time we got the impression that Mr Wisheart and the other staff were putting forward all the alternatives, all the risks and that, and we were making the choices, but we desperately wanted to give Joe the chance. We thought he might die, but it is better – it is a horrible thing – for him to lose his life than die horribly later on, and we had this wonderful chance of getting him fixed.’[340]

291 After the operation, John McLorinan said that Mr Wisheart took his time and explained how things had gone.[341]

292 John McLorinan concluded that his experience in Bristol: ‘sort of refocused my understanding of the role of the doctor, to almost be the servant of the patient or the patient’s guardians. We were very much empowered to make the decisions. We

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[339] T2 p. 159–61 John McLorinan

[340] T2 p. 165–6 John McLorinan

[341] T2 p. 168 John McLorinan

really felt we were given what we needed to make the decisions, and it was our genuine free decision.'[342]

293 Belinda House's son, Ryan Batt, successfully underwent a Sennings operation performed by Mr Wisheart in 1990.

294 Belinda House told the Inquiry that she remembered Dr Joffe explaining the diagnosis in a calm and caring way and being receptive to questions.[343]

295 Belinda House described her meeting with Mr Wisheart on 3 January 1990 in the following exchange:

> 'Q. What did Mr Wisheart explain to you?
>
> 'A. He confirmed … [that Ryan] had simple transposition, and that there was an operation he could perform called the Sennings, and it was quite a successful operation, but he still did say, I think, there was a 30 per cent chance it could fail.
>
> 'Q. You say "I think". Is that something you have a clear recollection of, or is that something that is rather faint in your mind?
>
> 'A. Well, I could not decide whether it was 30 or 35 per cent, but at the time there was a reason for that, because he would not have survived until — he would have survived until he was 2 years old and to me, there was no question about him having an operation.
>
> 'Q. So whether it was 30 or 35 per cent, it made little difference to you?
>
> 'A. Whether it was 1 per cent of survival, I would still have had it done.
>
> 'Q. Because that was Ryan's only chance of surviving for about two years?
>
> 'A. Yes.
>
> 'Q. So he told you that there was an operation called a Sennings procedure?
>
> 'A. Yes.
>
> 'Q. What did you understand that that procedure would involve?
>
> 'A. We understood that it was to redivert the flow within the heart of the blood, because at the moment it was two closed circuits and they wanted to divert the oxygenated to the pumping side.

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[342] T2 p. 179 John McLorinan

[343] T6 p. 65 Belinda House

‘Q. And that would take place within the heart?

‘A. Yes.

‘Q. Did you ask any questions about whether or not a procedure could take place outside the heart?

‘A. Yes. We said “Why cannot the aorta and coronary artery just be swapped over?” because it seemed a lot simpler. He explained to us there was an operation that could do that, called the switch, but there were a lot of problems at the time, because the carotid artery was severed and it stopped the blood actually going to the muscle of the heart. At that point, Ryan would have been too old for that operation.

‘Q. When you say there were a lot of problems because of the treatment of the carotid artery, was that something you understood would be a particular problem in Ryan’s case, or was that a general problem with the development of the switch operation?

‘A. We felt that was a general problem in the development of the switch operation.

‘Q. Did you discuss how far developed the switch operation was at that time?

‘A. I remember discussing it a little bit further, and we were given the impression that the switch operation would be – would, in the future – well, when it was developed, it would be carried out on babies that were very young, and I felt that Mr Wisheart thought that this would be very traumatic for babies at an early age, because in two weeks — I know he was waiting for Ryan to be strong enough to have his operation and the two did not add up.

‘Q. You say Mr Wisheart was telling you the switch operation was being developed. Did he discuss with you where it was being developed at the time?

‘A. He did mention America, but I cannot remember any other places.

‘Q. Did he discuss, therefore, whether or not it was being developed in the UK at the time?

‘A. I cannot remember if that was said or not.

‘Q. Can you remember whether there was any discussion of whether it was being offered in Bristol at the time?

‘A. I am pretty sure it was not being offered in Bristol at the time. I think he said that.

‘Q. Would it come as a surprise to you, therefore, Miss House, to learn that at that time there had been approximately nine Arterial Switch operations carried out in Bristol?

‘A. Yes.

‘Q. Because your recollection is of Mr Wisheart telling you it had not yet been developed in Bristol?

‘A. I had the impression it was not developed in Bristol.

‘Q. Why do you say you had that impression? Can we just explore that further?

‘A. Because I cannot remember him exactly saying it had been developed in Bristol. It was just a feeling I had.

‘Q. So is it a fair summary to say you were being told that the operation was being developed, but it was at an early stage in its development?

‘A. Yes. I think so.

‘Q. And there was a discussion of the fact that that development was taking place in the USA?

‘A. I cannot say the development is in the USA. I know USA was mentioned, but I cannot remember any other hospitals being mentioned, or any other —

‘Q. At any rate, you got the impression that Ryan was considered to be too old for the arterial switch?

‘A. Yes.

‘Q. And that therefore, partly because of that, partly because the switch was at an early stage of development, a Sennings operation would be the appropriate one?

‘A. Yes.

‘Q. You mentioned that it was suggested there would be a 30 to 35 per cent risk of mortality, even if that was carried out?

‘A. That is right, yes.

‘Q. Was there any discussion of any other risks attached to the operation?

‘A. I know at the time we were very aware that even if he came out of the operation, you know, the recovery time was very crucial and as the days went on, he would

> become stronger, but it was the first few hours that were very crucial after he had had his operation.
>
> ‘Q. How did Mr Wisheart help you to understand the way in which this operation would be carried out?
>
> ‘A. He spoke very clearly about it and he drew diagrams to explain to us, and of course, he allowed us to ask any questions, so we explored it. I think that is all.
>
> ‘Q. Did you feel that you were being given an adequate opportunity to understand the nature of the operation?
>
> ‘A. Totally, yes, because it was an atmosphere where you felt you could ask any questions, whatever question it was. You did not feel as if you were going to be made to look kind of silly by asking any questions. I cannot remember what questions we did ask, but I know we asked a range of questions.’[344]

296 Belinda House commented on the communication between Mr Wisheart and Dr Sally Masey (the anaesthetist) and the teamwork:

> ‘I can remember them being there, and I can remember them discussing things together … Everything that Mr Wisheart would say would be reiterated by Sally, and the team seemed a very tight-fitting organisation, really. They were all speaking the same language … we never heard a different word from both of them, although I cannot remember them discussing something together in front of us.’[345]

297 Belinda House recalled that before the operation, they were allowed to take Ryan down to the anaesthetic room and witness the pre-medication being administered.[346]

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[344] T6 p. 73–8 Belinda House

[345] T6 p. 96 Belinda House

[346] T6 p. 84 Belinda House

Parents' evidence on the management of care and their encounters with other healthcare professionals at the UBH/T

298 Belinda House stated in her written evidence to the Inquiry that there appeared to be a shortage of staff and resources at the BRHSC, which she noted when her son Ryan was transferred from Southmead Hospital for his scan and catheterisation:[347]

> 'A Senior Nurse had to accompany Ryan with the equipment when he was transferred, but there needed to be someone of equivalent standing remaining in the SCBU, and it seemed that they could not find the necessary staff. At one point we even offered to pay for an Agency Nurse ourselves as no progress was being made. It also then appeared that there was no ambulance available in the whole area with the equipment needed for such a Transfer. It was a horrific situation for everyone concerned, until eventually a suitable ambulance was located. This was the beginning of our education to the fact that the NHS, at the time, was desperately underfunded, so much so that Ryan's life was put at risk.'[348]

299 Belinda House referred to events during the post-operative care of Ryan in the ICU:

> 'While sitting at Ryan's bedside my partner Julian noticed that the ventilator had run out of water as the nurse, who was a trainee on the ITU, had failed to check and notice this. Julian alerted the nurse who quickly filled it up. Unfortunately this was too late and Ryan's ventilator tube had become blocked with mucus which caused him to begin to suffocate. He had to be rushed back down to theatre to have a new tube inserted. Following this Ryan needed further sedation making him more dependent on the ventilator. This was a huge setback in Ryan's recovery and appeared to result in him developing a kidney problem, even though it was ultimately sorted out. The kidney problem meant that Ryan stopped passing urine and had excessive fluid in his body. They had to drain fluid from between the membranes of the chest cavity and apply intensive physiotherapy to get rid of the fluid.
>
> 'On another occasion we returned to Ryan's bedside after a short break and found that the window next to his bed had been opened and his blankets removed. The nurse caring for Ryan was used to adult heart patients becoming very hot, but the opposite was the case for Ryan, and he needed to be kept warm. Maintaining ideal temperatures for patients with very different requirements while in adjacent beds was a continual dilemma for the nurses. Ryan quickly turned blue, making the nurse, who appeared to have little experience of babies, quite distressed and she

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[347] WIT 0025 0002 – 0003 Belinda House

[348] WIT 0025 0003 Belinda House

> was about to call for a Doctor until a more experienced nurse took control of the situation and warmed Ryan.'[349]

300 Belinda House told the Inquiry:

> '… at one point Ryan appeared to have some kind of kidney failure. He had stopped passing urine … it was after his tube had become blocked. To us it seemed like the system had gone into shock; other children on the ward had kidney failure. And the children started to blow up, and it was something that was a great concern to the staff because once that happens, their whole system goes into deterioration. We knew this; we had the feeling we had kind of non-verbal messages from the nurses that Ryan was in deep trouble at this point. He had stopped passing urine. There was nothing further they could do, apart from diuretics, which were not working. Ryan was getting bigger and bigger and not passing urine, so we had a friend who was an acupuncturist, and we asked him what he would suggest, and he said he could treat him for that. Mr Wisheart said "I cannot allow the skin to be actually punctured, but I will discuss it with the rest of the team." He did discuss it and he allowed our friend to treat Ryan and within, I suppose, four hours, he started urinating and he was on the road to recovery. I remember Mr Wisheart coming round and he was very pleased with his progress.'[350]

301 She described her interactions with the staff:

> 'I feel in the beginning … I think the staff were very aware, "Do the parents really want to know the answers?" and as the time went on, when they realised we did want to know the answers and we were going to get the answers, they were very forthcoming. In the end, the nurses were asking us how we felt all the time, as I am sure they did with other parents, "How do you think the baby is?", "What do you think ought to be happening next?"
>
> '… One incident comes to mind. Ryan would not settle with his level of sedation, so I think … they could not seem to get it right. His heart was either going too slow and his body was writhing about, they could not seem to get it right, so I think they were going down in certain units, I do not know, half a ml, 0.2 of a ml, I did not know. We said, "Why not go down in 0.05 of a ml?" They said that would not make any difference. We said, "Why not try it? It can't do any harm." They said they would do that and he responded to it. He was obviously more sensitive than most babies.'[351]

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[349] WIT 0025 0006 – 0007 Belinda House

[350] T6 p. 96–7 Belinda House

[351] T6 p. 98–9 Belinda House

302 Belinda House said that she was given the opportunity to do practical things for Ryan, including:

> '… cleaning him, changing nappies. As he got better, I took more and more care in the nursery, which was a high dependency unit. It was total care in bathing, cleaning, changing nappies and feeding. On ITU when he did not have any tubes, we were feeding him.'[352]
>
> '… we did things like got our friend to give him acupuncture; we fed him garlic for an antibiotic. We gave him garlic to improve his bacteria, yoghurt and all sorts of things, cod liver oil, everything. We felt we had to fight to make him survive as much as any other professional there, and of course, we expected Ryan to die any minute, and babies died.'[353]
>
> '… I think the nurses read each parent very carefully and they wanted [the parents] to become involved with the babies, not to off-load any work for them [i.e. the nurses], but just because they knew that was a very important step in the recovery of the child …'[354]

She described the nurses as 'totally dedicated and always listened to us'.[355]

303 Amanda Evans, mother of Joshua Loveday, gave her impressions of the BRHSC in her written evidence to the Inquiry:

> 'In general, I remember that the level of information I received, as a parent, in the BCH, was very good. The staff would always let you know if they thought anything was amiss and never gave any false hope. They all seemed competent, and I got quite friendly with Joshua's nurse. She taught us how to administer a drip-feed and how to change nappies when there are wires in the way; I remember that the last procedure was, in practice quite complex.'[356]

304 Amanda Evans explained how she and her partner were notified of the date for Joshua's operation:

> '… a couple of weeks before Christmas … we returned to my grandfather's house, he informed us that he had just received a call from Mr Dhasmana's secretary. Apparently, there was a bed available for Joshua. If we wished the operation to proceed, we were to go to the hospital that evening.
>
> '… we could not contemplate an operation now as it was too close to Christmas. Consequently, we telephoned Mr Dhasmana's secretary and said that we did not

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[352] T6 p. 99 Belinda House
[353] T6 p. 106 Belinda House
[354] T6 p. 100 Belinda House
[355] T6 p. 92 Belinda House
[356] WIT 0417 0008 Amanda Evans

> want the operation to take place, as it was too near Christmas. She said that she would pass the message on.'[357]

The operation date was then changed to January, and they were able to spend Christmas together.

305 Malcolm Curnow told the Inquiry of his experience concerning the date of his daughter's operation:

> 'There was no problem in the fact that we had a month's notice; the problem was that we had no information prior to that, or confirmation that this was going to happen. We were left very much in abeyance and in the dark. If someone had said to us, "She will have an operation, it will be around September time, and we will give you a month's notice", then that would have satisfied myself. I was receiving no information back from the hospital about the likelihood of her having an operation at that point in time and I was wanting to know … I needed to plan, we needed to plan. A month is acceptable, I have no criticism of that, but I would have liked a lot more information in the lead-up to it that this was going to happen. We were left with the impression that it could, or it may not. All I wanted to know was that it was going to happen; nothing more.'[358]

306 Malcolm Curnow described an incident with one of the medical staff, which he said was distressing:

> '… once we had established ourselves in the hospital, on the very first evening, obviously, a number of nursing and medical staff came and undertook a number of checks. The one that sticks in my mind and will remain with me forever, until the day I die, is the arrival of a doctor. He was of foreign descent, I did not know his name then and I do not know his name now. He arrived and at the time my wife was nursing Verity in the chair beside her cot. He wanted to take blood from Verity and he tried several times to extract blood from her left arm. He was having great difficulty in doing so. He did not appear to me to be competent and proficient in trying to extract the blood. I had seen GPs take blood from her, I had seen doctors on previous occasions take blood from her with the catheterisations, and in my professional capacity, I had seen samples of blood taken on hundreds of previous occasions, but I immediately was unhappy with the way that this was being done.
>
> 'He persisted several times trying to take blood from her left arm and could not withdraw a sufficient sample to satisfy him. Obviously, this was distressing Verity greatly. She was becoming increasingly blue and agitated; she was crying in a most

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[357] WIT 0417 0011– 0012 Amanda Evans

[358] T3 p. 33 Malcolm Curnow

> piercing, painful sort of way. My wife was becoming distressed. He then asked and attempted to take blood from her heel.
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> ‘On the first attempt, the pain was so excruciating for Verity that she began to obviously, move violently, to the point that was itself exacerbating the situation. I had to take over, my wife could no longer restrain Verity. I had to take hold of her physically in a restraint position and actually force her leg into a position where it would remain static whilst he took the blood.
>
> ‘My lasting memory, as he inserted the needle into her foot, was her looking at me as if to say in her eyes, “Daddy, why are you letting them do this to me?” and that look in her eyes will last with me until I die. He took the sample and he left the room, and we never saw him again.’[359]

307 Malcolm Curnow also referred to the physiotherapy that Verity underwent:

> ‘We were led to believe in the first day that Verity was suffering a build-up of fluid on the lungs, and in order to dissipate that, that she required quite vigorous physiotherapy … we knew that when Verity exerted herself and became stressed, that this exacerbated her problem. So when we see her coming off the ventilator and being very vigorously exercised by the physiotherapist, which certainly to my wife’s view, and mine, was causing further distress to Verity, and I say that because once the physiotherapy was completed, she was struggling to hold, you know, any stability, and she was obviously visibly worse after the physiotherapy than she was before it. She required hand bagging, and sometimes for a considerable period of time, during the physiotherapy. My wife’s intuitive feeling was, “This is not good for her; this is not doing her any good; this is making her worse, this is exacerbating the problem.” When you see your child being exercised as vigorously as she was, and it is supposed to be doing her good, but you can only see it making her worse, you are naturally concerned. We expressed our feelings to the physiotherapist. Her reaction was very abrupt: “I have to do this; it will make her better. It is for her own good.” ‘[360]

308 Diana Hill recalled events after Jessica’s death:

> ‘Someone brought me Jessica to hold. She was cold, and wrapped in a blanket. I cannot remember if I was asked whether I wanted to do this. I still find this a horrific memory and I know I will never be able to forget it.
>
> ‘… When we went to collect our belongings, no nurses came to see me, everyone who had been looking after Jessica seemed to disappear.’[361]

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[359] T3 p. 35–6 Malcolm Curnow

[360] T3 p. 55–6 Malcolm Curnow

[361] WIT 0263 0013 Diana Hill

309 Michelle Cummings described the ICU ward:

> '… sometimes you found that you had a nurse 1 to 1, so there was one nurse looking after Charlotte on a continual basis; other times there was one nurse between two patients.'[362]

310 Michelle Cummings told the Inquiry of an encounter (when the ICU was being closed down) where, in her words, the hospital took a 'gamble' with Charlotte's life:

> '… the new Ward 5 intensive care unit had finished being built. So it was obviously due to be opened. What happened next was, we noticed that as the days were going on, less patients were being brought into the Intensive Care Unit, and eventually it stopped. We were told that the Intensive Care was being shut down to open the new Ward 5, and that two politicians would be coming around to open it, and that was Kenneth Clarke and Edwina Currie … We were really concerned about this, because Charlotte, after she had had the cardiac arrest, was seen to be in limbo. She was not moving either way at that point, and we were extremely concerned. She was extremely poorly, and there was another child who was also extremely poorly, and we were told, without question, that the ward, the Intensive Care, was being closed and that was it. I was not happy about this at all.
>
> 'What happened next was that we were told that they had tried to find life support machines in other parts of the hospitals and had only been able to find one and as the other little girl at that point was considered in a more critical condition, it was opted that she should be given that life support machine.
>
> 'Charlotte was to be sent to the Children's Hospital and put in intensive care there on a life support machine, but they could not move her for a couple of days. Anyway, inevitably, the visit was happening and the children had to be moved.
>
> '… she had to go to the Children's Hospital and they assured me that she would be given — she had to have a life support machine, obviously, at the Children's Hospital, so when the day came for the move, which, off the top of my head, was Monday 27th June, they came around and they took her off the life support machine, and she had to be hand ventilated because she could not breathe on her own.
>
> '… She was moved by ambulance to the Children's Hospital, straight through casualty, and up to the Intensive Care and they did not even know we were coming. There was no intensive bed for her, no life support machine, and they were still hand ventilating her, so we went through to the baby unit and they were full

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[362] T3 p. 143 Michelle Cummings

> up. There was no cot for her in there, because they were hoping they could have set up a mini intensive care in one of the rooms for her.[363]
>
> '… There was not [a ventilator] and there were no beds in the baby unit, and she ended up being put on the bed of a child who had gone down to have his tonsils out whilst they decided what to do with her. I have to say, at this point Mr Dhasmana, who at the time was caring for Charlotte because Mr Wisheart was away, he actually had no knowledge of what had gone on until his return, and he was furious, that is the only way I can describe it. The man was furious. He had not even been told she had been moved at that point, and he was absolutely livid when he got to the Children's to find us there and in that predicament. In fairness to the man, there was very little he could do at that stage. It caused untold distress for the nurses and doctors who were actually looking after her, let alone the unacceptable gamble that we had to witness being taken with her life.'[364]

311 Robert Briggs, father of Laura, told the Inquiry that in 1988:

> 'We saw Helen[Vegoda] several times. She was available quite a lot of the time that we were there if we needed to see her. We also saw people from the Heart Circle, and Helen Vegoda arranged for a family to come and meet us where one of the children had had very similar heart surgery. So it was very, again, reassuring to be able to speak to somebody who had already been through it and to draw on their experiences.'[365]

312 John Mallone referred in his written evidence to the Inquiry to an incident in the ICU that reflected on the communication between management and the ICU's staff:

> 'Josie's life was entirely dependent on the pieces of apparatus that surrounded her. On one occasion, I counted them all: the equipment was connected to thirteen electrical sockets. On one occasion during the fortnight before Christmas, the management of the Children's Hospital decided to cut the power, in order to test the emergency generator. It appeared that no one in ITU had been warned that this was going to happen. There were as many as seven or eight children dependent on artificial ventilation at this time. The power can only have been lost for about twenty seconds, but there was a real panic as staff scrambled to find hand-bagging equipment to keep the children breathing. They repeated the experiment later on during Josie's stay but, on this occasion, they alerted the staff to their plans, and the nurses were standing by when the time came.'[366]

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[363] T3 p. 147–9 Michelle Cummings

[364] T3 p. 151–2 Michelle Cummings. The UBHT responded to this evidence at WIT 0123 0060

[365] T68 p. 60 Robert Briggs

[366] WIT 0155 0009 John Mallone

313 This incident was explained by Mr Warr, the UBHT's maintenance officer:

> 'It was the accepted procedure at that time to carry out an "on load" generator test once a month on a regular basis, it was the practice of the day to let a number of departments know of the imminent change over of supplies due to the 15 second delay in the restoration of power to hospital systems.
>
> 'Then, as now, ALL departments are notified of a full years test dates in advance, then as now PICU, Theatres, Baby unit and Cardiac Catheter are notified of the imminent test procedure.
>
> 'The particular test took place at the predetermined time and date in December 1990, the generator situated in St Michaels Hospital was new, around three months old and had been fully tested and commissioned. It had been run "on load" a number of times without incident.
>
> 'Part way through the normal test the generating set stopped, this of course led to a failure of the essential electrical supply to all area's, fortunately I was in the vicinity of the generating set and heard it stop, I immediately went to the generator room to assess the situation, it was not obvious why it had stopped so I took all the necessary steps to restore the normal electricity supply.
>
> 'From memory I would estimate that the hospital was without the electricity supply for approximately two to three minutes.
>
> 'Subsequent investigation of the breakdown revealed that the engine fuel pump and metering device had malfunctioned and was replaced under warranty.'[367]

314 Tony Collins told the Inquiry that an ambulance was arranged to take his son, Alan, from Princess Margaret Hospital, Swindon to Bristol but that:

> 'There were difficulties in the sense that when the ambulance arrived at Princess Margaret's Hospital, the ambulance crew were not sure if the incubator Alan was in, would actually work in the ambulance they were going to use. And we had an agency nurse who had only come on duty and a doctor who had only just come on duty and none of them knew much about what had happened to Alan during the previous night. For all that, they were very good and Alan got to Bristol with no problems.
>
> '… I was actually told I would have to catch a train to Bristol because there would be no room in the ambulance with me and the doctor and the nurse and the rest of the people who were involved, to which the Sister who had actually come down from the ward with us insisted I did go in the ambulance. So I did go in the

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[367] WIT 0155 0055 (emphasis in original)

> ambulance eventually, but there was a bit of an argument beforehand as to whether I should go in the ambulance or go by train.
>
> '… I found it very difficult that they were saying to me I possibly could not go in the ambulance with my son, given that I was being told he may not be alive when I got to Bristol. Also I had never been to Bristol in my life before, so I did not know where the Children's Hospital was, but also I did not know if Alan was going to be alive when I got there.'[368]

315 Tony Collins went on to describe the treatment which Alan received on arrival at Bristol:

> 'I would say the care that Alan received when he actually arrived in Bristol was second to none in the country. He could not have asked for a better surgeon and the staff there were brilliant, so I have no problems with Bristol at all.
>
> '… When we arrived, we were met by several staff at the hospital who took time to explain to us exactly what was going to be happening with Alan, and what the procedures would be. We were given a room to stay in, and there was always somebody there if we needed to talk, and everything was just explained to us from the moment we arrived.
>
> '… up to actually arriving in Bristol, I did not feel as if we were really being that involved in what was happening with Alan. Once we arrived in Bristol and the staff talked to us and explained things to us, I felt as if we were being brought in and had a lot more to do with our son's care and what was going on with him.
>
> '… from the lady cleaning the ward to the surgeon [they] would always be available to talk to you if you needed to talk, whether it was about Alan or any other issue on your mind at the time. A member of staff was always available.'[369]

316 Susan Darbyshire, mother of Oliver, told the Inquiry that she received a telephone call at about 10 am on 15 July 1993 telling her to go to the BRI by noon the same day so that Mr Dhasmana could operate on Oliver on the day after, 16 July:[370]

> 'We made it with five minutes to spare … We filled in a couple of forms down in reception, at the BRI, and then we were shown up to the cardiac unit, shown Oliver's cot and then literally left alone all afternoon and we just could not understand what was happening. Oliver's surgery was due to happen on the Friday morning, and we knew there were blood tests, probably an echocardiograph to do, ECG, everything and nothing was being done; we were just being totally ignored.

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[368] T68 p. 67–9 Tony Collins

[369] T68 p. 70–2 Tony Collins

[370] T5 p. 142 Susan Darbyshire

> Nobody explained anything to us, nobody introduced themselves to us, only the nursery nurse that actually came to fill out Oliver's admissions.
>
> '… Oliver's cot, his little space, was situated right opposite the Heart Circle office, and we saw a lady during the course of the afternoon coming and going, [she] appeared to be extremely busy. We assumed she was the Heart Circle counsellor for the parents, and the last we saw of her was about 5 o'clock when she locked the office door and went home. She did not introduce herself to us. We assume that is who it was. She did not introduce herself to us, so we were left literally stranded.
>
> '… We were told … by Helen Vegoda at the Children's Hospital, that there was a paediatric cardiac counsellor situated at the BRI … She was coming and going all afternoon, she was so busy… We never had eye contact with her. She could not fail to see us, we were right opposite her office, but you could not make eye contact with the woman. She seemed to have a mobile phone stuck to her ear constantly all afternoon.[371]
>
> '… She must have known we were coming, Helen Vegoda must have been notified when we were transferred over to the Children's Hospital … Oliver was not due to be admitted until the Friday, but she must have been notified we were coming in as a cancellation or whatever for an opening, and Oliver was going to be operated on on the Friday. So we did not really even have time to get our bearings; we were in there, we expected tests to be done and Oliver to go to the theatre on the Friday. Surely she should have supported us.'[372]

317 Susan Darbyshire described what happened later that day:

> 'A doctor literally stuck his head around the door, did not introduce himself or say who he was, just to say "There is a message from Mr Dhasmana. Oliver's operation will not be going ahead tomorrow. He will be around to see you later." That was it. He disappeared. [I] thought, "Well, what is going on?" My husband came back. I was in a real bad state. We telephoned family, friends, everyone, "Oliver is being operated on tomorrow", and now we were told it was not going ahead, we did not know when it was going ahead. My husband went to reception to find out what was going on and nobody seemed to know anything.'[373]

318 Susan Darbyshire said that they later saw Mr Dhasmana who explained the situation:

> 'Mr Dhasmana came to see us … straight from theatre. He was extremely apologetic. He said he had been called, I believe it was to Birmingham to assist on a life-or-death operation on a new-born baby, and he was really sorry that Oliver at that time … was not classed as a life-or-death operation and he had no choice but to reschedule Oliver's surgery for the Tuesday morning. We were quite happy with

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[371] This, as they later found out, was Helen Stratton

[372] T5 p. 142–5 Susan Darbyshire

[373] T5 p. 146 Susan Darbyshire

> that. If Oliver had been in the same sort of situation, we would have wanted that sort of service for him. Once it was explained to us properly, then we were quite happy with that.'[374]

319 Susan Darbyshire then described what happened later that evening at about 7 o'clock:

> 'We went down to the shop. We got back and we were told by a nurse that Oliver's operation was back on again, but this time Mr Dhasmana was not operating at all, it was Mr Wisheart. We had never even heard of Mr Wisheart, we did not have a clue who he was. All our faith was in Mr Dhasmana. He had operated on Oliver for the first operation. We trusted him completely, implicitly, and it was just a nightmare.
>
> '… Then she came back and told us it was not going to happen on the Friday, it was going to be now the Saturday morning, and it would not be Mr Wisheart but his understudy. By then, I mean, it was just a joke. We just totally ignored the whole lot and thought "Until we hear from Mr Dhasmana what is going on, we will just take it with a pinch of salt", but it did not help. It really did raise the stress levels. We refused and said, "No-one is going to touch Oliver apart from Mr Dhasmana. We are happy with him operating, and it will go ahead Tuesday as planned." No one seemed to know what the other person was doing down there. It was just dreadful.
>
> '… It was an awful situation. We felt really uncomfortable. We are not the sort of persons that like to complain. We were there for Oliver's benefit, we just wanted to get ready for Tuesday. We did not want problems thrown at us. We wanted to spend some time with him and enjoy the time we had left with him. We did not need all this. We just felt "As long as everything goes okay from now on in, let us all try and get on." It was just getting out of hand.'[375]

320 Susan Darbyshire said that on the night before Oliver's operation she and her husband were told they had a free licence to do with him as they wished, as he might not survive the operation. She said that they had been promised the 'Blaise Room'and that it had been cleaned especially for them:[376]

> 'At 9 o'clock the evening prior to Oliver's operation, we asked for the key. We had baggage and things we wanted to get sorted out. They could not find the key anywhere, and it transpired the nursery nurse had taken the key to the Blaise Room home in her pocket so we could not have the room until the night after Oliver's operation. So my husband spent the night before Oliver's operation in the corner of the ward on a mattress, and I sat up all night in a chair.'[377]

321 In their written evidence to the Inquiry, Susan and Kenneth Darbyshire recalled an incident when a nurse prepared Oliver's drugs but the Digoxin was not the paediatric

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[374] T5 p. 147–8 Susan Darbyshire
[375] T5 p. 148–9 Susan Darbyshire
[376] T5 p. 151–2 Susan Darbyshire
[377] T5 p. 152 Susan Darbyshire

mixture, but the adult mix'. They went on that this led them to draw up Oliver's drugs themselves.[378] Mrs Darbyshire told the Inquiry that she found it 'unbelievable' that her husband was given a 'free licence' to the key to the drugs' cabinet so that they could draw up Oliver's drugs.[379]

322 Susan Darbyshire told the Inquiry about her first meeting, on 16 July, with Helen Stratton:

> 'She just sort of came over to us and she introduced herself. I spoke to her. My husband had no intentions of speaking to her, he was so disgusted with the fact she had not introduced herself the day before.
>
> '… She must have known we were being admitted on that day, otherwise there was a great breakdown of communications somewhere.
>
> '… She asked us to go into her office. I looked at my husband, he looked at me and before he opened his mouth and said a word, she made a statement: "I can tell you don't like me. I do not really care what you feel about me. I have been told, I have had this reaction from other parents, and I really do not care."
>
> '… I went out of my way to be polite to her, to make up for the fact that my husband did not want to speak to her … she should take into account parents are going to be stressed out, in a situation like that. … She just asked if we were involved in the Heart Circle. Up to that time we had not been. Oliver took up all our time and the other children. She gave us a few leaflets and I think she mentioned a book we could buy and that was it, basically. We had no further contact with her until the morning of Oliver's operation. We still got our support from Helen Vegoda at the Children's Hospital. We phoned Helen up on a regular basis and spoke to her.'[380]

323 Susan Darbyshire recalled meeting a nurse:

> '… we were introduced to another Helen … She was going to be Oliver's personal nurse in ITU. She came in and introduced herself to us. She took us to ITU. We spent a couple of hours with Helen, I think on that evening. She took us into ITU and showed us the bed where Oliver would be. None of it shocked us because we had seen it at the Children's Hospital, the actual bed and tubes and everything, we knew what was going to happen to Oliver. She explained about the procedure, what would happen when Oliver came back from theatre. She was really nice; she was really helpful.'[381]

324 Susan Darbyshire told the Inquiry that Helen Stratton offered to carry Oliver down to the theatre for his operation but that she and her husband declined. She said that they

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[378] WIT 0125 0015 Susan and Kenneth Darbyshire

[379] T5 p. 153 Susan Darbyshire

[380] T5 p. 156–9 Susan Darbyshire

[381] T5 p. 159 Susan Darbyshire

also indicated that they were unhappy with the way in which Oliver was taken from them in the theatre:

> 'She [Helen Stratton] could see we were getting ready to take Oliver to the theatre. She came over and said she would accompany us to the theatre and would it be all right if she carried Oliver, which we adamantly refused and my husband carried Oliver to the theatre … we were under the impression, we were told [at the Children's Hospital] we could stay with Oliver until he was asleep. We expected to be able to do that [at the BRI], and we got into the anaesthetist's room. Oliver was taken from my arms, I was not asked to hand him over, he was taken from me. He was screaming, he was crying, he was flailing around. My husband took him, they said "Have one last cuddle with Dad", and they gave him to my husband. He gave him a really quick cuddle and I had him back again and they ushered us out of the room and that was the last thing we saw: Oliver was flailing around in the nurse's arms, screaming and crying. That was totally unnecessary. We were told we could stay with Oliver until he was asleep. I kept feeling "If he does not come out of here, this is going to be the last impression we ever have of Oliver", and that was really upsetting. The time before, his other operations, we had always walked out of there and he was asleep, we could see he was peaceful and that was a good memory to take. It was a nightmare to watch him. They did not wait until we had got out of the room, they were poking things in him, I did not know what they were doing. I was just too upset by them … [Helen Stratton] just ushered us out of the room, we were left there and we did not know what to do. We did not know what to do. We were told not to report back to IT for hours and hours. She did not give us any support whatsoever.'[382]

325 Susan Darbyshire said that they went to see Helen Vegoda for support:

> 'We went to the hospital canteen, had coffee, and then we walked straight up to the Children's Hospital and sat outside Helen [Vegoda's] office until she arrived … She knew Oliver's operation was that day. We were obviously really upset and we went in. She made us tea and we sat with her for an hour and a half and we told her how disgusted we were with the treatment we had down at the BRI.'[383]

326 Justine Eastwood told the Inquiry of the strain of being in the ICU:

> '[Oliver] was in an intensive care environment, which perhaps was a little bit of a strain on me. You could not really leave his bedside. This perhaps was my problem. I was perhaps relied on a little bit too much. I could not really even just pop out. Because I was looking after Oliver, he had maybe a Sister looking after him. They had other jobs to get on with, so I was left more to get on with it.'[384]

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[382] T5 p. 165–6 Susan Darbyshire

[383] T5 p. 166 Susan Darbyshire

[384] T95 p. 85 Justine Eastwood

327 Justine Eastwood referred to the insight of the nurses in her written evidence to the Inquiry:

> 'I was very upset on 14 February [1994] to be told after an investigation by the ENT surgeon Mr Moore … that Oliver would probably need another operation in the future and that because his condition was so unique, the future was uncertain. The nurse was perceptive enough to see how upset I was so that Dr Hayes came to talk to me later that day and informed me that … all would be well, unless he got a really bad chest infection.'[385]

328 Justine Eastwood referred to another occasion, on 21 June 1994, when Dr Mather discussed the options which were available and told her 'that we were coming to the end of the line'. Justine Eastwood said that Dr Mather told her 'that Oliver was not getting any quality of life at the moment'.[386] She stated: 'As before, a nurse was perceptive enough to work out that I was shaken up by the talk by Dr Mather and got Dr Hayes to come and talk to me.'[387]

329 Marie Edwards, mother of Jazmine, recalled an encounter she had in 1993 with Dr Joffe:

> 'He did not tell me she was inoperable; he basically said "Go home, take her home, she will be dead by the weekend." He did not use the words "She is inoperable." He just told me "There is the door, please leave. You are wasting our time, you are wasting our resources and another child could do with the bed that your daughter is laid in."'[388]

330 Philippa Shipley compared the nurses and nursing care which she witnessed at Liverpool with that in Bristol:

> '… when Amalie was admitted, [somebody] dropped a child off and left. We … just looked after him. I think he was operated on the same day as Amalie. I thought that that would not have happened at Liverpool. The ward sister … held it together with a real iron fist … There were three, they were all chopsy Liverpool girls, but that was the one who was particularly in charge. She would take great steps to organise the care of the children. Obviously parents could not be there all the time and if children were going to be there 10, 11 or 12 weeks, as was the case with us, you would not expect the parent to be there all the time. I certainly heard one conversation about a little boy, the sketches of Paul Broomhead in a book. She rang them up and said, "Your son needs a pacemaker. Get to the hospital. It needs doing now", and rang them at home. I remember that conversation.
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> 'I can also remember a little girl called Claire who was dreadful sickly – all heart children are dreadful feeders, really. Her mother, I think, had a lot of other children

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[385] WIT 0022 0010 and WIT 0022 0056 Justine Eastwood

[386] WIT 0022 0091 Justine Eastwood

[387] WIT 0022 0013 Justine Eastwood

[388] T95 p. 136 Marie Edwards

> and could not get to the hospital very often, so it was arranged that Claire would go to Warrington and the nurses were brought to Liverpool and told how to feed her, so they could take her back to Warrington and her mother could learn how to start to feed her. Although there was quite a good element of control there [Bristol].
>
> '… I did not really see a great deal of the nurses. We had one very brief stay at St Michael's Hill. The chap who admitted her, who shot over, was doing his exam for the Royal College of Surgeons the following morning. "We are going to get a complex case like this. I am going to admit your daughter." He wrote out the wrong drugs, which the nurses did point out, and we had to continue to administer our own supply. The nurse who brought her back from the catheter lab did not seem to realise that Amalie was very hot. She said she had a temperature. I said she will have; she was wrapped in a huge amount of blankets, far too many. If somebody is hot, you do not cover them in something, do you, you remove layers, which I did. Then we left the following day.
>
> 'At the BRI, when we first went into the ward for admission, she was quite theatrical; she came from Wales so she told us about Bryncethin and was chattering away, quite flamboyantly dressed. As we got into the ward, a nurse said "Nobody likes her." It was an odd thing to say. She was the receptionist of the ward. At Liverpool, the Almoner there, who had a similar role to Helen Vegoda, she looked like Miss Marple but nobody ever said so; they did not make observations like that. I thought at Liverpool – I am not trivialising this – it existed more as an organic whole, like it was a more cohesive unit.
>
> '… It was one team really, that was the impression I would have from Liverpool. I think there were things they could have controlled better at Bristol. Certainly there was a baby in the bed next to Amalie and another little girl who had been there 10 weeks, and the mother had two of her other children staying with her. Really, they disturbed Amalie and I wanted her to be in the best most rested position. At night they would be jumping on her bed and all sorts of things. I thought the nurses should really have taken steps to control that. That is one thing I thought. We did not really see a lot of them, to be honest. The night Amalie was in ITU, there were three of them down the end of the ward watching TV. That was the main ward. I can remember one sister in ITU. I can't really remember a great deal about seeing a lot of them.'[389]

331 Marie Edwards told the Inquiry of an encounter which she had with the nurses and Dr Joffe:

> 'I used to cross-sign all the medication because I found I could not remember which of the two drugs Jazmine took. It was kept in the fridge and it was particularly cold and if you put that down the NG tube, it would make her react, to retch. So I used to run it under the tap in the actual syringe in the sterile packets, to

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[389] T95 p. 165–8 Philippa Shipley

> lift the medication back up to body temperature. I found a lot of the time the nurses did not have time to dedicate to that, so I cross-signed and made sure the medication was brought up to body temperature, because she was vomiting quite a lot. It scared me to think I did not know how much medication was actually being absorbed.
>
> ‘In the morning, the early hours of the Wednesday, I heard the medicine trolley being brought through the ward. This nurse administered Jazmine’s medication in a matter of — it could not have been longer than three minutes. For me it is usually closer to 10 by the time I have filled the syringes and warmed one of them and pushed it down slowly so it did not hit the stomach and make her retch. I heard the trolley go away and I could hear Jazmine really struggling; she was retching. I could see she had been placed on her back, which really puzzled me. I remember hitting the emergency sirens to bring the nurses back as soon as possible because I was fearing from the colour she was going that she was going to have another heart attack. As she was being sick the NG tube was coming out and going back in.
>
> ‘This nurse came in with the sister and I said “What is going on? Why was she left in her back?” In 1993 it was on your side. Jazmine could not sleep on her front because of her heart complaint; she did not find it comfortable. The sister actually informed me that my daughter was in the cot death research. I said who had given her permission to be in a cot death research when she is very very sick? She said, “All the babies are, here, and it is Dr Joffe who has given permission.” I demanded to see him as soon as possible. They explained to me that he had worked to the early hours and they would get him to see me.
>
> ‘… She was being placed at risk in my eyes, unnecessary risk …
>
> ‘Dr Joffe explained that whilst Jazmine and the other babies are on this ward, he is guardian, and basically, if he wants them on the cot death research, that is what he was going to do. I was really shocked and I said “I do not want her to be researched on. You cannot give me any guarantees of what would happen to her health if she did not react by turning her head when she threw up. Would she have asphyxiated? You do not know. That is what you are researching.”
>
> ‘[Dr Joffe’s reaction was] “Fair enough, we will remove Jazmine.” That was all that was said about it. But I was horrified to hear that sickly children were being used.’[390]

332 John Mallone gave the Inquiry his views on the nurses:

> ‘I found the nurses were extremely sensitive and thoughtful to me all the time. Initially I do not think they were quite sure how to react to us. We were both staying in the hostel, which is immediately adjacent to the ITU ward in the Children’s

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[390] T95 p.170–2 Marie Edwards

> Hospital, so we were there perhaps 20 hours a day or something, by Josie’s cot. They made every effort to involve us in her care … I found it distressing at first because she had been paralysed. You had to press on her abdomen in order for her to urinate; she could not pass water otherwise. I found that quite distressful, but I soon got used to that.
>
> ‘… We were encouraged to touch her, to handle her, I think they thought it would both involve us and help her. We gave her her feeds through a tube.
>
> ‘… once I had overcome my initial reluctance to do that, I was very grateful. I wanted to be looking after my daughter, and so did my wife.
>
> ‘… I wanted to be involved. I was glad I was involved. They did not pressurise us to do it, they said, “Would you like to?” … It was encouraged. It was two or three days before I felt happy to do it and I thought they were very sensitive about it at all.’[391]

333 He went on:

> ‘I felt there was tremendous continuity in the nurses because they work 8-hour shifts … and so they got to know us and they got to know their patients, the children who were in there, they treated them as human beings. I found the doctors, they would come round perhaps on a 10-minute ward round twice a day and I always had the impression that they did not see the children, the babies, as human beings, more just as anatomical problems that had to be solved. For example at one stage Josie’s weight ballooned enormously, she went up over 3 kilograms and then came down, she lost almost 50 per cent of her body weight in 24 hours at one point simply because she had been too heavy before, I do not know, there was a problem controlling her fluid. They talked about it as a chemical imbalance problem.’[392]

334 Penelope Plackett described encounters which she had with nurses at the BRHSC:

> ‘When I returned to the BRI, I was told Sophie was being moved to Bristol Children’s Hospital. I was very unhappy about this. At the cardiac catheterisation and biopsy at the Children’s Hospital, the staff on the baby unit were uncaring. They seemed to spend their days drinking tea and chatting to one another, emerging every 4 hours to feed the babies. The transfer to the Children’s Hospital went ahead. I only saw the nurses when they came with Sophie’s drugs, and her care was left entirely to me. She was being bottle fed but I could not get her to suck or swallow. I asked for help with her feeding over and over again, but nobody came to my assistance. I later found out that the problem resulted from Sophie pressing her tongue against the roof of her mouth. A simple instruction from one of the nurses would have enabled me to deal with this. I felt I had no support at all. Babies were crying all the time but no one seemed bothered to check that they were all

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[391] T95 p. 172–4 John Mallone

[392] T95 p. 180 John Mallone

> right. On many occasions, Sophie's drugs chart was not signed, and, when I questioned this, I was told that agency nurses were not allowed to sign. If this was right, I could not understand why they were allowed to give out drugs. Sophie was never given the Nystan she was supposed to receive. I remember this period as nightmarish. The care seemed slapdash and entirely unsatisfactory. Sophie screamed constantly, and I felt demoralised and very unhappy. In contrast to the nurses at the Children's Hospital, the ITU nurses at the BRI had been fabulous, particularly two called Lou (Louise) and Eunice (who left soon after). They all worked very hard and were very supportive.
>
> 'Whilst Sophie was at the Children's Hospital, Mr Dhasmana made occasional visits. He was reticent and said very little to me. On one occasion, he said he had no idea how Sophie had suffered her brain damage. Mr Dhasmana mentioned the possibility of oxygen starvation, and suggested that, in opening the heart, they must have dislodged a "floret". He explained that this was part of an existing valve which must have made its way to the brain. He described the appearance of a valve as being surrounded by "cauliflower florets". I had the distinct impression that they did not know what had happened, or that they did know, but were not going to tell me.'[393]

Communication after the operation and when the child died

The clinicians' evidence

335 Dr Joffe told the Inquiry about the measures taken to co-ordinate the child's care with the health visitor service, or the GP, in order to ensure that parents were supported:

> '… with regard to the general practitioner, the parent is given a brief note at the time of discharge, something of the diagnosis noted, the major elements of treatment provided during the admission, and with a list of the drugs which he or she should continue to take, and the doses. That information is given to the parent who is asked to take a copy to the general practitioner as soon as reasonable.
>
> 'In addition a more detailed summary of the patient's admission is sent, usually within two or three weeks, with more detail of what took place during the admission and with information. Incidentally, the first form would have information about the next expected visit to outpatients, and the nature of the condition and the treatment would be expanded in the case summary, which would be sent to the general practitioner. Occasionally, if the health visitor has been involved

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[393] WIT 0012 0010 Penelope Plackett

> previously, and is known, a copy of that summary could be sent to her, and was sometimes done.
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> 'In patients where there are community elements involved, social services, et cetera, a communication is normally sent from the senior nursing staff or the cardiology counsellor to these various services, to inform them of the patient's status at the time and, again, their medication that they would be taking.'[394]

336 As regards follow-up and monitoring, Dr Joffe indicated that generally any patient without symptoms might be told to return in six months, whereas a symptomatic patient would be given an earlier follow-up and appropriate information at each visit.[395]

337 Dr Joffe described his practice when a child died:

> 'If a child died, I was always ready to arrange to talk to the parents at a mutually suitable time, if requested by the surgeons or the parents themselves.'[396]

338 Mr Dhasmana stated that he dealt with parents as sensitively as possible, although he acknowledged that being open and frank, which he felt was necessary when speaking to parents, did upset some of them.[397]

339 As regards communicating with parents after operations whatever the outcome, Mr Dhasmana stated that he:

> '… always made a point of talking with parents after a bereavement, or if the child had suffered a permanent disability.'[398]

340 As regards communicating with parents whose child had died, Mr Dhasmana stated:

> 'I learnt that it was important to speak in clear terms about the event, with as much sensitivity as possible. … I would talk with the parents accompanied by a senior nurse and expect her to provide further support and information to the parents after my meeting with them. … I always offered to see the parents again, if they desired, when I would discuss the post-mortem findings with them. My junior staff would also ring the family doctor so that arrangements could be put in place for the family to be visited soon after their return home. I would personally write a brief summary of the medical report and forward this, with the autopsy findings, to the family's GP…'[399]

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[394] T91 p. 58–9 Dr Joffe
[395] T91 p. 61 Dr Joffe
[396] WIT 0097 0317 Dr Joffe
[397] WIT 0084 0104 Mr Dhasmana
[398] WIT 0084 0103 Mr Dhasmana
[399] WIT 0084 0103 Mr Dhasmana

341 As regards communicating with parents whose children suffered some disability after the operation, Mr Dhasmana stated that:

> ‘In the case of a child suffering a disability i.e. neurological damage, I would talk with the parents and inform them of the problem. Unfortunately the information I could provide was incomplete, as the extent of neurological injury and permanent disability would not be known for a few weeks post-operatively. I used to be as sympathetic as possible … I would ensure that parents understood that a recovery might not occur and explain that a neurologist would explain the situation and prognosis to them in more detail …’[400]

342 Mr Wisheart stated that he had discussions with the parents and both the surgical and nursing teams once the child’s discharge time had been determined. The topics discussed included:

> ‘… medication, the activities which the child may indulge in, the care of the [surgical] wound, the role of the General Practitioner and District Nurse, the next outpatient’s appointment … the future and particularly about any foreseeable complication or need for further surgery. It was my personal practice always to ask children to attend my outpatient clinic at least for one or two visits following surgery.’[401]

343 Mr Wisheart explained that after discharge, patients were seen by the paediatric cardiologist, or the surgeon, from time to time, but that the day-to-day counselling and support was provided by the primary care team and also by the paediatrician in the District General Hospital.[402]

344 Mr Wisheart stated that it was his practice to inform the GP when a child died. He stated that usually the referring paediatrician was also informed, but that this was sometimes ‘overlooked’.[403]

345 Mr Wisheart described his practice after the death of a child:

> ‘I, together with a nurse and/or the counsellor, always talked with the parents of a child who died as soon as possible after that death … Towards the end of the conversation I informed parents … it was highly likely that [the coroner] would require a post-mortem examination … I invited the parents to meet with me again when the stress and emotion was less immediate. I normally suggested that six weeks or later would be appropriate, but it was left to the parents to decide when they felt it would be helpful. I indicated that this would be an opportunity to review all the circumstances leading up to the child’s death and also to consider any new findings that might have been identified at the post mortem examination. I did not

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[400] WIT 0084 0103 – 0104 Mr Dhasmana

[401] WIT 0120 0232 Mr Wisheart

[402] WIT 0120 0232 Mr Wisheart

[403] WIT 0120 0234 Mr Wisheart

> keep a detailed record but I imagine about 50 per cent of parents took up that offer … If the parents wished, the services of the paediatric counsellors were available for a long time after the child's death.'[404]

346 When a child suffered some disability, often in the form of neurological damage, Mr Wisheart stated that the primary objective of the cardiac team was 'to ensure that the best specialist advice available in the field is provided for the child and the family.'[405] This included advice, support and counselling services and community and social services.

347 Mr Wisheart stated that the cardiac team did not withdraw from the care of the child once the neurological specialists became involved:

> 'They continue to see the child and to have a role, sometimes as part of a team and sometimes as the one performing a key co-ordinating role of a number of services who are providing care to the child.'[406]

Evidence from other members of the staff at the UBH/T

348 Ms Joyce Woodcraft[407] stated in her written evidence to the Inquiry:

> 'Some nurses and doctors will find it very difficult to hide their own emotions on the death of any patient. This is particularly true of a baby or child that has been "specialled" by a nurse for a long period of time. A more senior nurse may take over parental support if this was deemed necessary, but [this] did not happen frequently in my experience.'[408]

349 The Reverend Yeomans stated:

> 'I felt that staff showed immense sensitivity when dealing with parents and were supportive every step of the way. They provided comfort throughout and became involved in all cases. Staff too, were upset when patients died, and may have found it difficult because of their own grief or lack of experience, to give parents what they wanted all the time. It can be very difficult to anticipate and give what bereaved parents want in their grief, distress and anger, when at that moment of time they may be inconsolable.'[409]

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[404] WIT 0120 0234 – 0235 Mr Wisheart

[405] WIT 0120 0236 Mr Wisheart

[406] WIT 0120 0236 Mr Wisheart

[407] Joyce Marian Woodcraft, Senior Sister BRHSC ICU 1985–94

[408] WIT 0121 0020 Ms Woodcraft

[409] WIT 0274 0009 The Reverend Yeomans

Evidence from parents

350 Antonio Chiarito, father of Maria, stated:

> '[The staff] said that they had taken Maria to the Chapel of Rest, if we wanted to see her again. We went to see her … but she had already been taken away. We both found this distressing … Since I have taken up my new employment, as a psychiatric nurse, I now understand how to treat people during times of emotional crisis. I do not think the staff at the BRI knew how to do so. I think that someone should have taken the time to explain things, and to answer our questions. As it was I got the impression they were covering up for some mistake.'[410]

351 The UBHT responded to Antonio Chiarito's comments:

> 'Evidence has been given to the Inquiry as to the bereavement and counselling facilities made available by the Trust. Unfortunately, they were insufficient to meet the needs of some parents.[411]

352 Rosemary Walker, mother of Ryan, stated:

> 'After Ryan died, we did not really see anyone in the hospital. We did not know what to do, or where to go. We were not even offered a cup of tea or coffee – there was certainly no offer of counselling.'[412]

353 Philippa Shipley described talking to Mr Dhasmana immediately before and after Amalie died:

> 'Mr Dhasmana came out of the ITU and spoke to us with tears in his eyes. He explained that Amalie was dying, and that he had tried everything he could to save her. I said that I wanted to be with her. Andrew and I went to the ITU and sat with Amalie. Within seconds, her heart had stopped beating. A male nurse said "She has died now." We sat there for a few minutes, holding her.'[413]

354 Philippa Shipley told the Inquiry:

> '… I spoke to Mr Dhasmana in the corridor after Amalie had died, when we were still waiting for my parents at about 7 in the evening, he walked over and said "Amalie would never have been able to run and play like other children, she would not have been as strong as them" and went on to say there was significant evidence that the Fontan operation caused chronic damage to the liver and she may have needed a transplant when she was 13. I should certainly have known about the

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[410] WIT 0291 0015 Antonio Chiarito

[411] WIT 0291 0022 UBHT

[412] WIT 0458 0013 Rosemary Walker

[413] WIT 0392 0018 Philippa Shipley

> liver damage prior to that operation and I still cannot understand what was the point of doing the operation if it was not going to improve her quality of life.'[414]

355 Paul Bradley, father of Bethan, told the Inquiry:

> 'Within a few days [after the death of Bethan] our GP, Dr Hayes, came along to see us at the house, and at that time we just wanted to be left alone; we just wanted to be on our own. But we did appreciate his call to us. He just wanted to make known his sympathy. I think at that particular point, if he offered help, counselling, I am not sure if we were in the right frame of mind to take in what he said. But we do acknowledge his sympathy coming to us … I think we were of an expectation that something would come to us in a written form, and — we say this with hindsight, but we feel that if it had been done even before Bethan's operation, and I think we are thinking about the counselling role, that if there had been some sort of liaison with us as to what the facilities were that were available, even before the operation had taken place, because at that particular point, after Bethan died, it was so difficult for us to be of sober thinking and of a proper mind, and to have had as a reference point in the house something which had been sent to us, even well before the operation, I think that that might have helped us.'[415]

356 Paul Bradley explained further:

> 'We did not receive any letter, no appointment was offered to us in writing to go back to the hospital, and we had a terrible ordeal with a series of events, when it seemed as if Bethan had just been forgotten. Bethan before the operation, the day before, she had done some drawings. We asked for these drawings to be returned to us. We were informed they had been thrown away and we were shocked by that. We were very upset by that. We had no meeting with Mr Wisheart until we asked for one and then we had no meeting with Dr Joffe until, again, we asked for one. That was 18 months after the operation. When we asked for the meeting with Dr Joffe, we did that through Helen Vegoda. We expressed our grief that he had not met with us. When Helen Vegoda responded, this was 18 months after the operation, she said she did not know that Bethan had died. We just could not believe this. We could not comprehend how she did not know. We were confident that Dr Joffe did know, but we could not understand why they had not come back and therefore this awful feeling that Bethan had been forgotten, as if she had not existed. We could not understand — it did not make sense with our experience before, when they did seem to be so caring and they did seem to be so concerned.'[416]

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[414] T95 p. 202–3 Philippa Shipley

[415] T53 p. 32–3 Paul Bradley

[416] T53 p. 40–1 Paul Bradley

357 In his written evidence to the Inquiry, Paul Bradley stated:

> 'We did not receive the option of any bereavement counselling. No help was offered to us to know how best to cope, discharge and manage grief positively. It would have meant a great deal to us if someone still expressed an interest in Bethan and showed us ways and means of positively remembering Bethan in future years.'[417]

358 Jean Sullivan, mother of Lee, stated:

> 'Since leaving the ward and Lee to meeting Mr Wisheart, I have had no contact with the hospital whatsoever. Notwithstanding the fact that they knew that I had psychiatric difficulties they never sent anybody to see me and the only contact I did have was a condolence card from the hospital'.[418]

359 She also stated that:

> 'The lack of aftercare which was shown to me also caused me considerable distress. Had I received some counselling it may have helped me to come to terms with Lee's loss … I was not given any assistance whatsoever to cope with what had happened and I feel that when I look back on the manner of Lee's death and the dreadful scene which I witnessed I am filled with bitterness.'[419]

360 Lorraine Pentecost told the Inquiry about communication surrounding and immediately after Luke's death:

> 'I had a telephone call to say something like, Luke was slipping away. I went over to Bristol and when I walked into ITU his cot was empty and they were washing down a mattress. I asked them where he was and the nurse said, "Oh, he has gone, he went a few moments ago" and I said "I know because I felt it." She took me into a side room and she said "If you unwrap him and look at him, you will notice an extra plaster on his heel." I said with everything else I was not going to notice a pinprick. Then she left me and she came back in about 10 minutes later and she showed my dad where we were. About an hour later my husband came over with my mother and we were asked if we wanted a cup of tea. About half an hour after that we left, but we were not rushed, we never saw anybody to rush us.'[420]

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[417] WIT 0229 0020 Paul Bradley told the Inquiry that, with Mrs Vegoda, he and his wife produced a booklet entitled *'Remembering Your Child'* sponsored by the Bethan Amanda Bradley Fund set up in his daughter's name, to assist other parents in knowing how to remember and grieve for their child. See T53 p. 38–9 Paul Bradley

[418] WIT 0016 0012 Jean Sullivan

[419] WIT 0016 0014 Jean Sullivan

[420] T95 p.194–5 Lorraine Pentecost

361 Lorraine Pentecost stated:

> 'Nobody had said anything to me. When I was outside the hospital I realised that I did not know what I had to do. I therefore went back to the Intensive Care Unit and asked a doctor who told us that the hospital needed to do a post-mortem to establish why Luke had died. I remember being told to go home and have another baby. I said that a baby was not something you went out to get from a supermarket … I was sent an appointment card for Luke to have a check up. The date of his examination fell a few days after his funeral.'[421]

362 Sharon Peacock, after the death of her son, Andrew, in 1995, stated that she had meetings with Dr Martin. At one such meeting Helen Vegoda was present. Dr Martin later wrote a letter[422] to Sharon Peacock summarising the meeting. Sharon Peacock told the Inquiry:

> '… every time I would see Dr Martin I would come away with more questions because he would answer in such a way that you would come away thinking you had not really got an answer, so I thought by putting them on paper I might have got some.'[423]

363 Other parents told the Inquiry that after the death of their child, not only were they not offered support, but staff appeared anxious for them to leave the hospital.

364 Rosemary Ridette-Jones, mother of Luisa, stated:

> 'One thing which I felt very strongly about was that we were not supposed to speak to other parents on the general ward. One just didn't speak about the death of one's child.'[424]

365 Karen Meadows, mother of Sarah, stated:

> 'We went back to the hostel and picked up our stuff. We drove the hundred miles back to Torquay in despair. We felt that once our child had died the hospital ceased to feel that we had any medical needs'.[425]

366 Malcolm Curnow stated:

> 'Both my wife and I felt under pressure to leave the hospital. We were not given adequate time to mourn, or to be left alone. I felt as if we were on a conveyor belt. One of the nursing staff asked us to clear our room, as it was needed by another family.'[426]

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[421] WIT 0267 0014 – 0015 Lorraine Pentecost

[422] MR 0572 0004, 0006; letter from Dr Martin to Sharon Peacock

[423] T95 p. 43 Sharon Peacock

[424] WIT 0421 0012 Rosemary Ridette-Jones

[425] WIT 0415 0009 Karen Meadows

[426] WIT 0004 0009 Malcolm Curnow

367 Philippa Shipley stated:

> 'We were told that we would have to leave the hospital as our presence there would upset other patients and their families.'[427]

368 Responding to these statements, the UBHT set out its policy in its written evidence to the Inquiry:

> '… the Trust's policy was for the parents to get home as soon as possible, and for the General Practitioner to be informed of the situation immediately so that appropriate support could be given locally.'[428]

369 Sharon Peacock, however, stated that:

> 'Since I have lost Andrew, I have received much support from Helen Vegoda … and Helena Cermakova, the hospital chaplain. Helen helped me to prepare for my meetings with Dr Martin and talked with me about all the questions that I wished to ask. She also helped me with my fertility treatment appointments that I underwent, and would visit me to give support both before and after my operations. Helena and I have meetings often, and I speak to her on the phone regularly. I do not think I could have coped without their help and support. Helena conducted Andrew's funeral service, and has always been very supportive.'[429]

370 Carol Kift stated:

> 'No member of staff came to see us after Steven died. The only person who had been supportive, the hospital chaplain, was away for the weekend so we did not see her either. She had helped us to organise Steven's baptism and had been supportive for us whilst we were at Bristol. We were touched when she wrote to us to offer her condolences after Steven's death.'[430]

Involvement of the GP, health visitor and social services after surgery

371 Susan and Kenneth Darbyshire stated that:

> 'The support we had when we took Oliver home was faultless. Our GP Dr Chris Irvine and the health visitors Anne and Rosemary. Anne would make three time weekly visits and Rosemary would always be there if Anne was not available.'[431]

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[427] WIT 0392 0020 Philippa Shipley

[428] WIT 0421 0019 UBHT

[429] WIT 0011 0031 Sharon Peacock

[430] WIT 0461 0005 – 0006 Carol Kift

[431] WIT 0125 0006 Susan and Kenneth Darbyshire

372 Julie Johnson said that Mrs Vegoda had arranged for her to be visited by a health visitor when she returned home. She described this arrangement in the following exchange:

> ‘Q. I think it is right, is it not, that there was some follow-up support at [*sic*] which Helen Vegoda took some steps to organise?
>
> ‘A. Yes.
>
> ‘Q. In particular, with the Social Services department?
>
> ‘A. Yes.
>
> ‘Q. And I think it is not necessary to go to the correspondence, but you are aware of correspondence, for example, in 1993, between Helen Vegoda and the Social Services department?
>
> ‘A. Yes, that is true.
>
> ‘Q. And that Helen Vegoda was in contact also with your GP and health visitor?
>
> ‘A. Yes.
>
> ‘Q. Did the health visitor continue to visit you and Jessica after her discharge from hospital?
>
> ‘A. Yes.
>
> ‘Q. How did you find that? Was that of assistance?
>
> ‘A. I found that of assistance, yes.’[432]

373 Linda Burton, mother of David, told the Inquiry about contact from the health visitor:

> ‘The day after David’s surgery … the health visitor from our local practice turned up at my house and informed my parents that the surgery had received news from Bristol that David had had his operation and that things were not going well. We did not know that.’[433]

374 Jean Sullivan described contact between UBHT and her GP:

> ‘The second night [after Lee’s death] I spent at my mother’s and whilst I was there my GP came down and told me that I had to make an appointment to see him. When I eventually saw him he read to me a letter which had been sent by the hospital to him. That was the letter signed by the Registrar Mr Chatterjee. Once he

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[432] T44 p. 136 Julie Johnson

[433] T5 p. 33 Linda Burton

> had completed reading it I told him that it was wrong. I told Dr Perkins that that was not how it had happened and I told him exactly what Mr Wisheart told me. He said to me that what he had read [to] me was in the letter and that the hospital, not I, knew what they were talking about.'[434]

375 Helen Rickard told the Inquiry:

> 'My GP called to see me, I believe the following day that we had returned back from the hospital. He had obviously been notified by the hospital of Samantha's death, and he called to my house, which was next door to the surgery, and asked if there was anything that he could do. I initially asked him for medication, which I was given … and then I sought counselling … [which was arranged through the GP]'.[435]

376 After Jessica's death, Diana Hill told the Inquiry that she saw Mr Dhasmana to find out more about what happened:

> 'When he came back from holiday my sister and I went to see him because I felt nothing had been done correct for her [Jessica], I had this feeling nothing had been done properly for her. We went to see him and he said "You know the critical bit was going to be after the operation" and he was even then very matter-of-fact, very blunt. It was as if he was watching the clock to get me out of the room … He was always very blunt. There was not a compassion to him, it was a very blunt man. He appeared a very sort of blunt, matter-of-fact man which I found uneasy because I was trying to get questions out but I felt I should not be asking those questions … I was feeling rushed … and it was just his bodily manner, everything, I just felt I should not be asking these questions. … He said it was a very rare case, which confused me because I was told she had a VSD … No [he did not explain why her condition was rare]. I mean he drew diagrams, when we saw him he went into depth about the pulmonary hypertension, but he was saying she was a very rare case which I could not quite understand … It came across that she had a very rare thing that no other baby had.
>
> '… I then thought "They are not going to have the right drugs then" and it came across that they would not have done. I do not know, it seemed very — not quite right. I mean at the time when Jessica was on ITU two other babies died as well and I remember that to this day, two other babies died and I remember thinking "Why are these babies dying?" and I asked a nurse and she just said it was a bad patch and that is something I can remember … When me and my sister left him [Mr Dhasmana] we felt really uneasy, we felt we did not really know anything more than we knew. I wanted really to see somebody to tell me something proper. Because Mr Wisheart had never seen us after Jessica died, I think we saw a Registrar who just went over things. I wanted to see somebody who I thought knew

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[434] WIT 0016 0012 Jean Sullivan

[435] T52 p. 160–1 Helen Rickard

> what they were talking about. That is why we went back, we were just uneasy with what happened to Jessica.'[436]

377 Diana Hill explained her reasons for not arranging to see Mr Wisheart after Jessica's death:

> 'Because when Jessica died it was like we were told to get our bits, it was all a bit of a rush because she died at 3.00. We were then at 6.00 told to get … I was trying to keep alive basically because I did not want to be here in this world any more. At 6.00 we were told to get our stuff, we were told to get Jessica's stuff and so we collected our stuff from the room, we collected Jessica's stuff from the room. The thought of going to see Mr Wisheart or somebody just did not cross my mind. Helen Vegoda came to see us.
>
> '… I think it is because I never met him [Mr Wisheart]. I never met Mr Wisheart therefore I thought Mr Dhasmana would be the one to explain and tell me what happened. But really when I think of it, Mr Dhasmana was not there either, so who would be the best person to tell me?'[437]

378 Linda Burton told the Inquiry that a few days after the operation she was called to the hospital because David's condition was deteriorating:

> 'We met a Registrar again, I do not know who it was, never seen him before, who said that they were having problems with David's saturation levels. They were having to bag him more often than previously. They suggested about 6 o'clock in the evening that it would be a good course of action to insert a chest drain, which they did. We were informed that Mr Wisheart was not in Bristol … [at] about 10 o'clock at night a consultant anaesthetist was called in, and it was explained to us that David's lungs were becoming very stiff and that it was taking greater effort on the part of the nurse who was doing the bagging to actually force the oxygen, air, whatever it was, into his lungs. This was then explained to us, that the condition would probably get worse to the point where the lungs would be so resistant to this bagging process that if it went on too long, his lungs would burst … They suggested that the course of action open to them was to give him a massive dose of Frusemide … After the consultant had explained that they had given him a great dose of Frusemide, the idea was to try and drain off, so we understood, fluid from his body to enable his lungs to function. When it was explained to us that his lungs could possibly burst, I took my husband and my mother-in-law into the family room which is attached to the ITU, the unit, and when the nurse came with us, I said that it was pretty obvious that David was not going to make it, was it possible to turn the ventilator off. The consultant anaesthetist came to see us, a very nice chap, and understood what I was asking him to do. He explained that it was not possible, that he was not allowed legally to do what I was asking, and that, having given him this dose of Frusemide, they then had to wait and see what effect this drug would have.

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[436] T83 p. 26–8 Diana Hill

[437] T83 p. 29–30 Diana Hill

> If it proved to be ineffective, they could then put him back on the ventilator; the ventilator would then fail to oxygenate his blood adequately, his blood saturations would drop. They would drop sufficiently that he would become brain dead, and then they could turn the ventilator off … we actually were given no choice. I had asked him to turn the ventilator off. He informed us he could not do that and that he had to — that he had given this dose of Frusemide and if that had no effect, then they would put him back on the ventilator and the ventilator would fail to oxygenate his blood because of the problems he was having and brain death would occur. We agreed that … that is what would happen. The anaesthetist explained to us that unfortunately he had no idea how long it would take for the saturation levels to reach that critical point, but … it would happen eventually. We returned to ITU. The nurse on duty suggested that we sort of, you know, held David's hand. I insisted on holding him. It took seven minutes … After David had died, once the saturation levels had dropped, the consultant anaesthetist came along. He took one look at the readings … they had tumbled — and he said death had occurred. He switched the ventilator off. The nursing staff then suggested that if we returned to the family room, which is a short walk … from the IT unit, that they would dismantle all the life support equipment and then we could go back and see David.'[438]

379 She described an encounter with a 'junior doctor' immediately afterwards:

> 'We had barely got back into the [family] room and sat down when a doctor appeared, a junior doctor. I have no idea who he was; I can only assume he was a junior doctor, because he came through the door with a piece of paper in his hand. He approached my husband and asked him to sign this piece of paper. When my husband asked him what it was, he said it was an agreement for the hospital to do a post-mortem. I mean, we had literally come out of ITU and got back into this family room, I mean, a matter of minutes, five minutes at the outside, and there was this junior doctor suggesting that we should agree to a post-mortem. This had never been raised with us.
>
> '… When the doctor appeared with this piece of paper, asking my husband to sign it, we were both horrified. It had never arisen that a post-mortem would be necessary. We understood that because David had lived as long as he did after surgery that a post-mortem was not required. However, the nurse who was with us, who came with us back to the family room after David died, was horrified at this doctor's lack of sensitivity, and ushered him out of the room. She then came back and said, you know, "You obviously have time to think about this. It is a hospital post-mortem and it will enable learning to be done from David's death." Obviously David's operation had not been successful and it would enable them to find out why. We spent some time discussing this between us, and in the end, we concluded that something good in the way of learning of what, if anything, went wrong … that they could gainfully acquire from David's case, that we would give permission for a post-mortem.'[439]

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[438] T5 p. 39–42 Linda Burton

[439] T5 p. 43–5 Linda Burton

380 Linda Burton recalled an encounter with the duty nurse:

> 'After David had died, the nursing staff dismantled his life support machine equipment, and we returned to ITU to see him. The nurse on duty at the time, when she came to take us back to ITU, had obviously been smoking. We had this discussion over the merits of smoking on a cardiac ward, considering smoking is supposed to be one of the main reasons of cardiac disease, [and she apologised].[440] She said that she never ever had come to grips with the death of a child and that they had had a bad week. We knew ourselves they had lost at least two other children that week.'[441]

381 Linda Burton told the Inquiry that she and her husband later:

> '… wrote a letter to Mr Wisheart thanking him for what he had done.'[442]

382 Mr Wisheart wrote[443] to them expressing his sympathy, apologising for his absence and inviting them to see him if they wished.

383 Linda Burton said that they did not return to see Mr Wisheart but that they:

> '… asked for a copy of the post-mortem. When we got it, we took it to our GP. He readily admitted that bits of it were beyond him, that it was too technical, but he did inform us that a page was missing from it, but we felt that we probably were not going to ever really fully understand the technicalities of David's death. We felt as satisfied as we could have done that everything that could have been done for him had been done.'[444]

384 Stephen Willis stated that some efforts at communication during Daniel's operation were 'insensitive and distressing'.[445]

385 He stated that when he and his wife Michaela returned to the hospital while Daniel was still in the theatre:

> 'We were introduced by Helen Stratton to a nurse who was from the Intensive Care and who we were told would be supervising Daniel's care on his return from the theatre. I and … Michaela, were on an immediate high because we immediately assumed that Daniel had come through the operation. I said to Helen Stratton, "Does this mean that Daniel is okay?" She replied "Oh no there are many problems"… To have caused us to be elated by her first sentence only to dash that elation in answering my question was cruel and indeed was the worst moment that we were to experience other than being told Daniel had died'.[446]

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[440] WIT 0001 0010 Linda Burton

[441] T5 p. 48–9 Linda Burton

[442] T5 p. 49 Linda Burton; the letter is at MR 0267 0027

[443] MR 0267 0026; letter from Mr Wisheart

[444] T5 p. 51 Linda Burton

[445] WIT 0285 0010 Stephen Willis

[446] WIT 0285 0010 Stephen Willis

386 Stephen Willis stated that when he asked her to explain 'many problems', Miss Stratton was unable to satisfy him with her answers and went to get Mr Dhasmana.[447]

387 Stephen Willis said Mr Dhasmana explained that:

> '… there were indeed complications and that he could not get Daniel off the life support machine. For some reason … things were not working and he was going to go back and have another try … things had worked for a while but then they had failed and he had to put him back on.'[448]

Mr Dhasmana then left and they were taken to a parents' room.

388 Stephen Willis stated they were:

> '… left in this room for a significant amount of time and during this period I made repeated attempts to contact Helen Stratton to find out what was going on. At no stage was I able to contact her as she was unavailable.'[449]

389 Having found Miss Stratton, Stephen Willis stated:

> 'She came back to the room with me and it was there that she said to us that we should not hold out much hope. That was … a second and very depressing piece of information that she had given us and she then left.'[450]

390 Stephen Willis stated that there was no further communication until he was told that Daniel was dead:

> '… we were visited by Mr Dhasmana and Helen Stratton at approximately 8.30 pm. Mr Dhasmana was wearing his operating gown which was green and blood was splashed all over his chest and left shoulder. He was obviously distressed, there were tears in his eyes and he said that Daniel was dead. I can specifically recall him saying that the operation had been a success but he could not get his heart to beat again and he did not know why he could not save Daniel … I felt sorry for him because of his distress … at that particular moment we felt more for him than in reality the grief that we should be feeling.'[451]

391 After Mr Dhasmana had left, Stephen Willis stated that Miss Stratton persuaded them to go and see Daniel. He was also offered and accepted a lock of Daniel's hair and a print of his footprints.[452]

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[447] WIT 0285 0010 Stephen Willis

[448] WIT 0285 0011 Stephen Willis

[449] WIT 0285 0011 Stephen Willis

[450] WIT 0285 0011 Stephen Willis

[451] WIT 0285 0011– 0012 Stephen Willis

[452] WIT 0285 0012 Stephen Willis

392 John McLorinan stated in his written evidence to the Inquiry:

> 'In the weeks following the operation … Mr Wisheart was regularly monitoring the situation, and when we met with him, he was helpful and informative. He often seemed to be turning up at all times of the day or evening, whether it was to see our son or other patients of his … We were kept well informed at every stage. Issues and procedures were explained to us well, and medical notes were readily made available to us, and we were made to feel comfortable and involved …'[453]

393 Marie Edwards told the Inquiry that she welcomed the polaroid photograph of Jazmine that Helen Stratton gave her after Jazmine died. After seeing the photo, she said that she made up her mind that she needed to see Jazmine. Helen Stratton asked her if she wanted Jazmine in a shawl or a Moses basket:[454]

> 'They brought her in a shawl. We spent about an hour, an hour and a half with her and the last half an hour I had Helen Stratton coming in, asking that she thought it was enough time now and she would bring a nurse in to actually take Jazmine away from me, and I had actually said to her "I need more time" and she said "Okay, but I actually finished work at 7.00" and I said "Yes, but I really need some more time" and she said to me "I will ask the nurse to come in in 15 minutes, will that be enough?" and I said "I do not know, but I do not think so" and with that I said to Helen "Would it be possible to take Jazmine down to the Chapel of Rest?" "Well, she is not going there", she said. I said "Fine, can I take her to the morgue?" I needed to know where she was going to be laid to rest. She said, no, that was not possible. She said, "No-one is allowed to go down there." I said "Fine". The whole time Jazmine was in hospital I knew where she was, in the theatre, in an anaesthetic room, I knew where she was and the thought of leaving her and not knowing where she was really upset me. With that, my partner said, "It is hospital rules, just let it go." So I said, "Fair enough, I know that she will be on this side of the building." About 20 minutes later, that would have been about 7.20, she brought a nurse in — she said "I am going to go and get a nurse now" and I actually walked over to Helen Stratton … I actually handed Jazmine over to Helen Stratton knowing that she had never held a dead body, a dead baby, but I felt compelled in doing that so she would never bully another parent into handing their child over when they are clearly not ready to let go … [and I felt] frustrated that I had to give up this last moment with my daughter.'[455]

394 In response, Helen Stratton stated that she would not have put pressure on parents in the manner described by Marie Edwards. She stated that it was usual for parents to spend about 2 hours on the ward with their child's body (with no fixed time limit), after which she might start to discuss the need to remove the body to the mortuary. She further stated that she had no finishing time and she commonly worked late hours especially when a child died. Miss Stratton confirmed that it was against

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[453] WIT 0122 0011 – 0012 John McLorinan

[454] T95 p. 190 Marie Edwards

[455] T95 p.190–2 Marie Edwards

hospital policy for relatives to be taken down to the hospital mortuary. She also stated that it was incorrect to say she had never held the body of a dead baby.[456]

395 Samantha Harris recalled in her written evidence to the Inquiry the day when her daughter, Kimberley, died and how the she was told of this by one of the nursing staff. She stated that on returning to the hospital, a Ward Sister met her and she was then informed, by telephone, by one of the surgical team that they were having trouble in getting Kimberley off by-pass. Samantha Harris stated that the Sister said 'things were not looking good.'[457]

396 Samantha Harris stated that subsequently the Sister came to see her again and they sat on the bench between the ward and the parents' accommodation:

> 'I remember that she put her arms around me, and told me that Kimberley was dead. I think that she was crying too … A male member of the surgical team arrived to explain what had gone wrong. He said they could not get Kimberley off by-pass and that they were sorry. A short while after this, Mr Dhasmana came to see us. He was accompanied by some other men and was dressed normally, rather than in his theatre gown. They also said they were sorry and Mr Dhasmana stated that they had not been able to get her off by-pass and that they did not know why.'[458]

397 Samantha Harris stated that she met Mr Dhasmana later to discuss the post-mortem report:

> 'Mr Dhasmana agreed to write to my local hospital, requesting that I should undergo a scan during my next pregnancy, to identify any congenital heart condition. I felt reassured …'[459]

398 Erica Pottage remembered how, during Thomas' operation, Helen Stratton had informed her twice that 'they could not get Thomas off the by-pass machine although the operation was successful.'[460] She stated that she was told that this was not unusual.

399 Erica Pottage continued in her statement, explaining that:

> 'At about 6 pm Mr Dhasmana came to us to say Thomas had a massive heart attack and he had lost him. He seemed genuinely upset. My husband and I could not take it all in. We were asked if we wanted to see Thomas which at the time seemed horrifying. Helen Stratton said most parents in these circumstances want to go home straight away, so we packed up our belongings and my husband drove us back to Teignmouth … Looking back, I felt the care we received as parents was

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[456] WIT 0414 0027 Miss Stratton
[457] WIT 0302 0012 Samantha Harris
[458] WIT 0302 0013 Samantha Harris
[459] WIT 0302 0016 Samantha Harris
[460] WIT 0260 0003 Erica Pottage

> appalling … The nurses were very kind but they were only interested in my medical condition. I did not receive any counselling and had nobody to talk to about my worries and concerns.'[461]

400 In response, the UBHT stated that:

> 'One can understand that Mrs Pottage felt very alone … although it is to be noted that she had been seen by Mrs Helen Vegoda … at the BRHSC.'[462]

401 Susan Francombe's daughter, Rebecca, died shortly after her operation. Susan Francombe recalled that she did not see Rebecca when her condition deteriorated. She stated that 'We were encouraged to go away, which is something that I have regretted ever since.'[463] She also said that she was told that although Rebecca's condition had deteriorated, the operation had gone well.[464]

402 Susan Francombe stated that she was 'provided with no aftercare and support following the death of our child.'[465] She told the Inquiry that her GP came once, prescribed Valium and left.[466]

403 Susan Francombe stated that Mr Dhasmana wrote a personal letter expressing his sympathy, which was 'consistent with his compassionate approach throughout the whole experience.'[467] Susan Francombe also wrote a letter[468] of gratitude to Mr Dhasmana.

404 Anne Waite, mother of Caroline, told the Inquiry of her experience when Caroline died:

> '… We … were staying behind at the hospital at the BRI in Carolina House. We were rung to say that Caroline's blood pressure had dropped dangerously low, there was not much time, could we get over there as quickly as possible. We rushed over there, we were put in a room with a fish tank … I cannot remember who it was came to see us, I think it was a nurse came to see us. She said "She is in a bad way, we are doing internal cardiac massage, we do not know how long she has left", if she was going to stay alive. We were left again for a while and the next thing, we saw Mr Dhasmana. He came out, theatre cap on, gown on, covered in blood. "I am sorry", he said, "she is dead." He said "I tried everything, I did everything I could, we could not revive her." We then were taken to a room while she was being cleaned up because we wanted to see her. We had offered her organs to transplantation but due to the drugs she was taking they were unable to be

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[461] WIT 0260 0003 – 0004 Erica Pottage
[462] WIT 0260 0006 UBHT
[463] T68 p. 17 Susan Francombe
[464] WIT 0349 0003 Susan Francombe
[465] WIT 0349 0006 Susan Francombe
[466] T68 p. 25 Susan Francombe
[467] WIT 0349 0006 Susan Francombe
[468] MR 2181 0012 – 0013; letter from Susan Francombe to Mr Dhasmana

transplanted, he told us. He also told us there would be a post-mortem by the Coroner's request. We also were in favour of that because we wanted to know why she died because we were not given any answers.

'… Once you are given a 5 per cent risk, you think it cannot happen. It is an eventual situation that probably does not happen anyway. You are in pretty high spirits, you are given a 95 per cent chance of everything going right and then suddenly you are one of that 5 per cent that go wrong. It has put me in a position where I cannot trust doctors any more, it has completely dashed my faith in doctors, I could not trust any of them with my other three children. If they had to go into hospital now I do not know what I would do.

'… We were taken to a room where we telephoned our parents back in Newport to say Caroline had died and could they come up as soon as possible for a visit because that is the last time they would probably see her. We were left about an hour and a half with constant pots of tea and pats on the back, sort of thing. We went to see Caroline after she had been cleaned up. She was still in a bad way, she was still attached to tubes, she still had a tap on her hip into the femoral artery — she had no catheter in. She had dried blood around her nose, quite a nasty state to look at. She was very blue and when I actually picked her up then she actually passed urine all over me which I found very distressing. You do not expect that to happen, you know, you expect the bodily fluids to be out of the body by that time. She had been dead for about 1 hour and a half, somewhere round then. But we were left with her … on the ward with the curtains drawn around until we were ready for our parents to come over and see her and then we left.

'… I did ask could we come back up to Bristol and see her because obviously I did not want to say goodbye at that point, I wanted to see her later on in the day … and maybe the next day. We were told not to go down to the morgue because it was a nasty place, very dark place, very creepy, "You do not want to go down there" … "Remember her as she was and see her back in Newport when she comes back home."

'Unfortunately when she got back to Newport she was not in the same state. Obviously travelling makes a difference to a body and she was bruised, very bruised on the head. It did not feel like the same child as I left in that bed.

'… I held her until she actually developed rigor mortis, I could not let her go.

'The last memory we have of Caroline is in a coffin, a massive bruise on her forehead and a soft-feeling chest, which we could not understand, a crinkly sort of material underneath which felt to me like a dressing and padding.

'… She had quite a lot of her organs taken unknown to us.'[469]

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[469] T95 p. 195–9 Anne Waite

405 Tony Collins described his experience after the operation on his son, Alan:

> 'Mr Wisheart came to see us after the operation and said that everything had gone well, but the next twenty four to forty eight hours would be critical. We felt confident from his manner that things would be alright … Helen Vegoda was available at all critical time[s] during Alan's stay … She was there when Alan came back from surgery. She was in and out to see us during Alan's stay.'[470]

406 Christine Ellis' son, Richard, was operated on successfully by Mr Dhasmana. She stated in her written evidence to the Inquiry that she was quite happy that she was informed by way of pictures what Richard would look like in the ICU and that this prepared her. She praised Mr Dhasmana, as he came to see them frequently after the operation and explained what to expect. She stated further that the nurses too were friendly and efficient.[471]

407 Malcolm Curnow described his and his wife's experience after surgery:

> 'My wife was shocked by the tubes coming out of her. I was … worried … by Verity's colour. She was not bright pink, as Mr Dhasmana had said that she would be. Rather, she was ashen grey … In the recovery room, we saw Mr Dhasmana for the last time. When he came in, his head was bowed, and he did not look me in the eye. He said, "Sorry, when I opened her up, things weren't as I expected." He gave little explanation for the disparity between the prognosis and the result other than that he could not do the shunt he had intended, and that he had had to do something different. He said that he did not know whether this would work or not. I had the impression that Mr Dhasmana knew it was unlikely that Verity would survive. No cardiologist came to see us during the day.'[472]

408 After Verity's death, Malcolm Curnow stated:

> 'I went back to our room to find some clothes for Verity … No-one said anything. The staff seemed upset, but took it as a matter of course. I still felt that the question of how such a simple operation could have gone so tragically wrong was unanswered … Both my wife and I felt under pressure to leave the hospital. We were not given adequate time to mourn, or to be left alone. I felt as if we were on a conveyor belt. One of the nursing staff asked us to clear our room, as it was needed by another family … we were taken to the Chapel of Rest to see Verity … It was cold, dimly lit, and felt subterranean. I did not find it reassuring or welcoming. We were left alone with Verity for about ten minutes. We were then taken back to the hospital, where we were informed that the relevant documents would be forwarded to us in the post … As we left, we were approached by the doctor who had tried to

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[470] WIT 0021 0008 Tony Collins

[471] WIT 0023 0010 Christine Ellis

[472] WIT 0004 0006 – 0007 Malcolm Curnow

> resuscitate her in ITU. He stated that one in a thousand children die of heart disease, and that it was just unfortunate that it was ours.'[473]

409 Malcolm Curnow told the Inquiry:

> 'I recall the presence of what I believe to be the cardiac liaison nurse, who made some very what I felt were inappropriate comments, such as, "I know how you feel." No-one can know how we felt at that time, unless they have lost a child of their own, and I am afraid I was probably very intolerant of that person, and I wanted her nowhere near me or my wife, so our contact was extremely brief … From our point of view, the time between the moment your child dies and that you leave the hospital is probably the most critical of all. At that point, you are trying to come to terms with the loss of your child; you are confused, emotional and extremely stressed. But you can be extremely rational through it all as well. What you want is answers; answers to questions: Why did my child die? Why am I in this situation? Why me? If somebody could have spent just a little bit of time explaining or even just being available to sit with us and to answer any of the questions we had at that time, it would have been appreciated.'[474]

410 After Verity's death, Malcolm and Jane Curnow wrote to Mr Dhasmana.[475] Dr Jordan replied, in response to their letter to Mr Dhasmana, explaining why Verity died, giving follow-up advice and discussing fundraising for equipment for the Intensive Care Unit.[476]

411 Michelle Cummings stated that Helen Vegoda was available at all critical times throughout Charlotte's stay in the BRI and the BRHSC[477] and was very supportive.[478]

412 Michelle Cummings was present in the hospital when Charlotte died:

> 'I walked through the doors … and another mother came through the door screaming at me, that something was wrong with Charlotte and I had to come quickly. We went back into where she was, and she was totally delirious and screaming, like I have never heard. She was screaming terribly, in pain, and all the emergency people were arriving and they were trying to stabilise her. This went on for some time, and I think it was about — this happened around half 1, and at one point I had her on my lap trying to give her oxygen, and she was fighting, her bodily functions went and they had to put her in a nappy. It was about 3 o'clock. I phoned Rob – we were told that he ought to come up – and at 4 o'clock they moved her to the intensive care upstairs. Dr Jordan and the other doctors, they fought so hard to save her. She had septicaemia throughout the body and her heart was failing. She just screamed and screamed and screamed, just awful screaming and pain. They

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[473] WIT 0004 0008 – 0009 Malcolm Curnow

[474] T3 p. 62–3 Malcolm Curnow

[475] MR 2374 0092; letter from Malcolm and Jane Curnow to Mr Dhasmana

[476] MR 2374 0084 – 0085; letter from Dr Jordan

[477] WIT 0123 0025 Michelle Cummings

[478] WIT 0123 0031 Michelle Cummings

> could not sedate her because they were desperately trying to keep her going and her heart was getting slower and slower. Eventually, one of the doctors came out and said that she was, you know, going. She was going. We went in and I asked them to switch off, because basically, her heart was beating so slow, she was getting no oxygen to her brain and she had not done, I think it was for over half an hour, anyway. They said, "Will you sit with her for a while?", and "You think about what you want to do", and they lifted her off the bed and she was still all drips and everything, and they gave her to me. She died in my arms at a quarter to 6: that was it.'[479]

413 Michelle Cummings described her contact with staff after Charlotte's death:

> 'They were brilliant. I mean, Helen [Vegoda] came to visit us. She wrote letters on our behalf to the Council for us to move. After Charlotte died and we went to the hospital, she was always there to greet us. She helped us around and one of the doctors would always be there to greet us and support us if we went to the Chapel of Rest and that included Mr Dhasmana on one occasion, I have to say. We met him, he came to look for us, I think it was the day after Charlotte died, and he met us in the corridor. He was incredibly, extremely distressed that Charlotte had died. I remember him giving me a big hug and expressing his sorrow: an incredibly genuine man, and very sensitive to our loss.'[480]

414 Michelle Cummings stated that Mr Wisheart came to see them after Charlotte's death, as soon as he finished operating. She went on that she remembered 'dressing Charlotte and with Dr Jordan cleaning her shoes.'[481]

415 Michelle Cummings stated that Dr Jordan explained the procedure for autopsy and indicated that she could come back when ready to discuss it. Michelle Cummings stated that she returned on three occasions to discuss the autopsy and that Dr Jordan explained how and why Charlotte had died.[482] She told the Inquiry that the meeting she had with Dr Jordan was quite a 'sensitive meeting and very candid and very informative.'[483]

416 Timothy Davies' son, Richard, underwent a Switch operation performed by Mr Dhasmana in 1992 but died shortly afterwards. Timothy Davies described, in his written evidence to the Inquiry, his experience after the operation and after Richard's death:

> 'Mr Dhasmana … invited us into his office. He sat behind his desk, removed his glasses and said something to the effect of "All weekend I have been thinking about sewing him up – what do you want me to do?" I said, "You're the surgeon!" That

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[479] T3 p. 166–7 Michelle Cummings
[480] T3 p. 178 Michelle Cummings
[481] WIT 0123 0031 Michelle Cummings
[482] WIT 0123 0032 Michelle Cummings
[483] T3 p. 170 Michelle Cummings

> was all I can remember being said to us. At about 4 pm, Mr Dhasmana came into the waiting room and I am sure he had tears in his eyes. He bowed his head and said "I am very sorry, he is gone." I went berserk, running up and down the corridor, screaming my head off. Eventually, I calmed down … The nurse came in and said that we could see Richard … he was carried into us in a Moses basket. They had cleaned him up, but his arms were still bruised with all of the injections. The nurse stayed with us for about 10 minutes. She then said she had to take Richard. I said I did not want her to but, naturally, I had to let him go … We were told that I had to ring the Coroner's office the next morning. I remember doing so from a phone box, and being very distressed. I am sure the Coroner's Officer … stated that the cause of death recorded on Richard's death certificate was congenital heart disease. Just hearing it said to me caused me such distress that I broke down in the phone box. I knew this was the position, but that did not stop the impact of what was being said to me. I remember that I had to collect Richard's birth and death certificates at the same time.
>
> 'It was arranged for Julie and myself to meet Mr Dhasmana [five to six months after Richard's death]. Dr Joffe was also there. There were a lot of questions we wanted to ask; we wanted to know what had gone wrong. We were told that Richard had congenital heart disease, and that the death was probably due to an infection. That was it.'[484]

417 Maria Shortis recalled her conversation with Dr Joffe after Jacinta's death:

> 'Early the same morning [22 January 1987], I contacted Dr Joffe to tell him of Jacinta's death. His first words to me were, "She shouldn't have done. That surprises me. But, Mrs Shortis, you always thought she would die early." He did not offer me any condolences. His final comment left me feeling that I had wished my child's death upon her. As her carer, I felt responsible for her well-being, and Dr Joffe's words only made me feel more guilty…'[485]

418 Maria Shortis stated:

> 'The GP and our Health Visitor were great. The GP had always wondered what the hospital was trying to do. Both agreed with me that she could not have gone on living for very long in the state she was in, and neither appeared to be particularly surprised. My GP organised some counselling for me whilst Jacinta was still living, and this continued for a short time following her death. I have no complaints regarding the Health Centre, the visiting GPs or the Health Visitor. Many of them came to Jacinta's funeral.'[486]

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[484] WIT 0160 0013 – 0014 Timothy Davies

[485] WIT 0222 0020 Maria Shortis

[486] WIT 0222 0021 Maria Shortis

419 Maria Shortis continued:

> 'I received no support from the hospital, or from any of the voluntary organisations associated with it. In 1987, Dr Joffe let me read the post-mortem report, but I do not feel that this constitutes adequate emotional support. In 1995, I had a meeting with Dr Joffe, during which we discussed Jacinta's care, and his prognosis. Dr Joffe maintained that she should not have died so soon, but did not appear to be able to give me any reasons as to why she should have lived.'[487]

420 On 28 January 1987 Mr Dhasmana wrote to Tim and Maria Shortis offering his 'heartfelt condolences.'[488] On 17 February 1987, Tim and Maria Shortis wrote to Dr Joffe. Apart from requesting another appointment to see him, they wrote, '… thank you for explaining … the results of Jacinta's post-mortem … Thank you so much for the help and courage you gave us.'[489] Tim and Maria also replied to Mr Dhasmana expressing gratitude and support.[490]

421 Justine Eastwood recorded in her diary that:

> 'We knew that things weren't right when Mark [Mr Eastwood] saw Mr Dhasmana and Pat Weir [the anaesthetist] walking down the corridor with heads bowed. The family room where I was sitting was quickly cleared of other parents by one of the nurses and we had the news broken to us by Mr Dhasmana and Pat Weir who were both crying.'[491]

422 Justine Eastwood stated:

> 'We had the news of Oliver's death broken very gently and privately to us. Privacy, at times like these, was uppermost on the minds of the staff. We were given the option to clean Oliver up and prepare him after his surgery which I declined. We were then allowed as much time as we required just to be with him alone. I remember being spoken to about the necessity of a post-mortem and inquest because of the circumstances under which Oliver died. We did speak with the coroner at a later date about the findings of the inquest.'[492]

423 John Mallone described how 'on the morning of Friday 11th January it was clear that Josie was going to die.' He stated that screens were put up to give them privacy and Josie was taken out of her incubator and placed on a pillow.[493]

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[487] WIT 0222 0022 Maria Shortis

[488] MR 2388 0067; letter from Mr Dhasmana

[489] MR 2388 0064; letter from Tim and Maria Shortis

[490] MR 2388 0066; letter to Mr Dhasmana

[491] WIT 0022 0135 Justine Eastwood

[492] WIT 0022 0015 – 0016 Justine Eastwood

[493] WIT 0155 0016 John Mallone

424 John Mallone described his experience after Josie's death:

> 'Dr Martin came and certified her dead. He said that there had to be a post-mortem. We immediately replied that we did not want one. He said that it was a legal requirement to protect patients. We argued against it, saying that he knew exactly why she died. He made it clear that we did not have a choice, assuring us that Josie would not look any different, as the pathologist would cut into her from behind …
>
> 'A young doctor called Caroline expressed her condolences and said that she felt that they "had learnt something," hastily adding "I hope you don't think that it was some kind of experiment." Eventually, we took Josie down to the Chapel of Rest where we laid her in the little crib … We didn't feel under any pressure to leave the hospital; we found the nursing staff exceptionally kind and sensitive after Josie's death …
>
> 'We came to visit Josie in the Chapel of Rest each day. We had been warned that the post-mortem was to take place on Monday 14th January, so we braced ourselves as we went to see her that evening. To our relief, Dr Martin's promise that she would be "the same old Josie" held true. She did not look any different. We returned the following day, Tuesday 15. When we saw her, we were horrified. She was dressed in another baby's clothes, she had blood on her face and her expression had changed completely. We learned that they had postponed the post-mortem for one day without telling us, and that this was the result. We were very distressed and angry.
>
> 'A month or two after Josie's death, Ann and I arranged an appointment with Dr Martin, so that we could discuss what had happened. He went through the post-mortem report with us, and I remember being surprised that it did not mention the pulmonary artery banding. We wanted to know why Josie had been born with heart defects. He said that no one really knew. He tried to reassure us that it was unlikely to be the result of anything either of us had done, but that, having had one child with a heart defect, there was an increased risk of having another. I thought to myself "How can you increase 100%?"
>
> 'At the meeting with Dr Martin, I asked if I could look at Josie's medical records. He arranged for me to do so, and I spent three or four two-hour sessions reading through them and taking notes. I just wanted to understand what had happened to our daughter; I was not suspicious or looking for anything in particular, I just wanted to know more about Josie … I found the experience quite helpful in my attempts to come to terms with losing her.
>
> 'After Josie's death, I went on many occasions to see Helen Vegoda, the BCH bereavement counsellor, the last occasion being in 1995. We also returned to the

> ITU at Christmas and on anniversaries of Josie's death for several years. We were always received warmly by the nursing staff.'[494]

425 John Mallone stated that he had no further contact with Mr Wisheart after Josie's death:

> 'Mr Wisheart didn't make any contact with us after Josie's death. There could be good reasons why he wasn't available at the precise moment she died, but even a brief letter would have been welcome. It would have meant a lot to think that he actually noticed.'[495]

Parents' suggestions for improvements

426 Paul Bradley told the Inquiry that a written diagnosis of the condition would be helpful as a point of reference so that it could be studied:

> 'At that time we did not think to ask for a written diagnosis, but with hindsight, we realise it would have been helpful because obviously they explained to us and with diagrams as well, but it was verbal so we were trying to think in our minds exactly what was said and so invariably, at subsequent appointments, we seemed to be always in the process of clarifying exactly what was said the time before. So it would have been useful to have had in our minds earlier and quicker exactly what Bethan's condition was.'[496]

427 Paul Bradley referred to the difficulty of making 'informed decisions' and made a proposal:

> 'About … informed consent … It was difficult for us to absorb all the information and so to be fair to them, for us to make an informed decision it was difficult for us because we had no medical expertise. So the ability of ourselves as parents to make an informed decision about an operation we accept is very difficult, but in the light of what we now know, and what we have thought about since, we would have wished that there was perhaps just … outside of the hospital — an outside team, panel of experts, to which Bethan's case, because of the complexity, could have been referred to. They could have decided, perhaps overridden, rather, with regard to Bethan, the decision for Bethan's operation to take place in Bristol, but perhaps to take place somewhere else where there was more experience to maximise the possible chance of survival.'[497]

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[494] WIT 0155 0017 – 0019 John Mallone

[495] WIT 0155 0060 John Mallone

[496] T53 p. 8 Paul Bradley

[497] T53 p. 18 Paul Bradley

428 Paul Bradley suggested a particular role for counsellors:

> ‘A counsellor is there to help a parent, to make sure that the parent understands what is being told by the medical team, that their role is to make sure that parents understand and to clarify any misunderstanding in what is said perhaps in the diagnosis or in what treatment is being proposed, and as to what the parents’ understanding is concerning the risk. We perceive that that is within the role of a counsellor and not so much in the role of the medical team … we have always seen the role of counsellor as a befriending role, helping us to get through this awful situation, and being there to help us. I think that would have been greatly valued, if right down the line they were there, not just as a friendly face but also as a person who would help us to make sure we understood what the different aspects of Bethan’s condition was and the treatment proposed and the risks and so forth.’[498]

429 Paul Bradley expressed the view that any discussion of mortality rates should be realistic and not unrealistically optimistic. He said that there should also be consistency among those who discuss the issues with parents. Discussions of such matters as bereavement facilities, post-mortems and administrative matters surrounding death should, he said, be conducted ‘when one is in sober mind’,[499] some time before the operation when the trauma and other conflicting tensions were not at their highest.[500] He told the Inquiry that:

> ‘We would have liked it if even perhaps a year or so, but certainly a few months before, if there had been what I describe as just a routine appointment with a liaison counsellor and that particular person, as a matter of routine, if they had just said to us, “It is my job, my job description to go through this with you, Mr Bradley, it is not because of Bethan’s particular case, I have to do this with every patient.” If they had that expectation to deliver certain information such as what bereavement facilities were available in the unfortunate event of death, what was entailed with post-mortem, what that exactly was, so that we were clear …
>
> ‘Our impression was that for the staff at the BRI it was almost as if they found it difficult to contemplate failure as well, and as if it was a management problem for them. When Mr Wisheart conveyed to us the problem of there being a 1 in 4 chance of failure, this was earlier on, the nursing staff would turn around and say, “But you must look at it the other way, Mr Bradley, a 3 in 4 chance.” So the emphasis was put on the other side. We can understand both sides of the line, but then again, we would have wished that as a consistency there had been a tempering of both sides, of the optimistic side and of the what I would call, not the negative, but the realistic side …’[501]

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[498] T53 p. 37–8 Paul Bradley

[499] T53 p. 46 Paul Bradley

[500] T53 p. 35 Paul Bradley

[501] T53 p. 35–6 Paul Bradley

> ‘The way that we would have liked it in our circumstances is if it had been conveyed before death, and I say “before death” because if it had been done in a routine manner; what was the procedure for complaints, what the line of communication was, to whom we should go, what the facilities were as regards bereavement, what postmortem meant, but also, especially about the retention of organs. I think we would have perceived it better if it had been a few months or even a year or so before the operation; not just before the operation, but a few months before.
>
> ‘Obviously it is something that we would have hoped never to have come to pass, but we see that it would have been as it were an aspect of the tempering of the things that we were looking for, the optimistic, the mortality rate like the 3 in 4 success, that that would have been an aspect of the tempering, and we would have accepted it, that it was not being negative to Bethan’s case, but just as a matter of protocol, a matter of routine, that that was part of their job to do well beforehand, I think well before the operation, not the day before, but well before, when we were in a spirit receptive to receive that information.’[502]

430 Paul Bradley suggested that, as a point of reference, all post-operative counselling and support procedures should include an invitation in writing to return and meet the clinicians.[503] He said that a parent, traumatised after the death of a child, might find it difficult to remember what was said at the time, whereas written information was something that they could return to and consider in the future.

431 Sharon Tarantino, mother of Corinna, told the Inquiry that she would have been upset if such matters as post-mortem and organ retention had been discussed before an operation and that she would not have found it helpful.[504]

432 She agreed that it would be useful to have some formal system whereby an arrangement could be made to come into the hospital to speak to a counsellor who would ask, amongst other things: ‘Is there anything you want to know which you do not know and feel we can help you with?’.[505]

433 Sharon Tarantino also agreed with the value of written information being that one has the opportunity to:

> ‘… take it, think about it and understand it when one had the time to get one’s mind around it.’[506]

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[502] T53 p. 38–9 Paul Bradley
[503] T53 p. 43 Paul Bradley
[504] T53 p. 74 Sharon Tarantino
[505] T53 p. 69 Sharon Tarantino
[506] T53 p. 76 Sharon Tarantino

434 Michelle Cummings suggested:

> 'I think parents do need as much information as they can personally take on board and I think if information is going to be given to parents, it needs to be in a form that can be understood and that misunderstandings are less likely to happen, and I think perhaps with that, you need consultation and I think that perhaps there needs to be clear guidelines so that parents know what to expect and what their options are. But I think in 1988 or 1987, for myself and Rob, these questions were not being asked. There was no reason in our eyes for them to be asked. We trust Mr Wisheart; we always have done. We trust Dr Jordan, and always did, so that was not a concept that we thought about at the time. We had a sick child and we needed help and these people offered to help her. I think that also is a major consideration for families.'[507]

435 Sheila Forsythe said that it would be helpful if the pre-operative conversations and estimates of risk and descriptions were put in writing:

> 'I think it would definitely help, because so many people take so many different things away with them. I know from our point of view, again, we had taken different views of what had been said. It is quite clear that those parents who were supported, who had a piece of paper with a diagram, seem to have been able to understand more.'[508]

436 Justine Eastwood suggested:

> 'Any information extra to what you have been told, if there is anywhere where parents can go to read up, to watch videos, anything. At that particular point, where you have been told your child has something wrong with them, you just want to absorb as much information as you possibly can, from any source, really.'[509]

437 Some of the parents suggested that they would want complete frankness from the clinicians, no matter how upsetting it was initially.

438 Michelle Cummings said:

> 'I think one of the things I feel is that it can be difficult if, as a parent, you obviously do not go into hospital wishing your child to die. You go into hospital because part of you feels that this is the right place to be and these people will help to make your child well, so that you can bring them home. With that, I think, goes an unrealistic expectation of what you think other people can do for your child, and that can be difficult, then, when you are actually taking on the information that is being given to you, because you can be selective, and you do not want to hear certain views. Mr Wisheart was extremely honest with us. He went into every risk factor, every

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[507] T95 p. 60–1 Michelle Cummings

[508] T95 p. 68 Sheila Forsythe

[509] T95 p. 70 Justine Eastwood

> possible thing that he, at the time, felt may go wrong or would go right. There were no angles that we had not covered. But there was still that element that I felt, "Yes, but I want to take her home, so, you know, you have to do it right, so what if this happens, what will you do if you cannot do that?" I did go into those questions with him and that can be very difficult, because how much information in that state can I actually credibly take on board and how much does that clinician — do they know how much to give me? And when you have reached saturation point, it is just going over your head. I think that is a very real problem.'[510]

439 Marie Edwards suggested that not all parents wanted as full an account:

> 'I think it goes through more on a judgment of the person feeding the information to the parent. The parent [*sic*] needs to be able to communicate clearly and decisively the needs of each individual parent. Some parents want to know, other parents wish, and choose not to. I feel strongly that each individual should be treated in that way, as an individual person.
>
> 'I feel the person should be able to have a feel of what that character is and what their needs are as a parent and to ask their wishes … Give them time to actually get their heads round the situation. You go into immense shock, almost a shutdown of knowing that your child is in hospital per se and never mind the severity of the operation, it is an operation, it is terrifying to any parent because you know there is a risk factor. It really … takes time for you to actually absorb and to digest before you can move on to asking why, how, when? So I feel it is up to the person that is delivering the information to be skilled enough to read the signs when it is time to give that parent enough space to be able to gather their thoughts, as it were … Be it 10 minutes, 15 minutes, 2 hours, that break can be immensely important. Just to allow the parents to realise what is going on. With me it was a terrible shock to hear that my daughter was not going to obtain an operation, yet she was going to die, was not given that choice, the chance of life. To me it terrified me but I can only speak from my experience and I feel any form of 5 or 10 minute break to allow that parent to understand and gather their thoughts and discuss it with their partners if they have a partner with them.'[511]

440 Justine Eastwood said that she did not think it was always appropriate to leave parents with hope:

> 'I think you need to know. It hurts. You do not want to be told your child is possibly not going to survive the operation, you want the surgeon to say "Everything is going to be fine, I am going to pull the child through." It hurts to hear it, but you need to know the truth. I do not want to be told everything is going to be jolly and fine. It is a fact of life.

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[510] T95 p. 79–80 Michelle Cummings

[511] T95 p. 134–5 Marie Edwards

> '… You do not want people to be cruel to you, but you need honesty in a situation like that. You just have to deal with it. You are in a situation that you cannot get out of; you have to deal with it.'[512]

441 Richard Lunniss, father of William, told the Inquiry that:

> '… you cannot trust people if you do not think they are being honest, even if they are being nice. Once you think that they might not say the thing as it is, then you can never believe quite — there is no working relationship from that point on.'[513]

442 Michelle Cummings told the Inquiry:

> 'I … have a concern … of what actually informed consent is and how do you sort of measure that? How do we, as parents, know exactly what our rights are in terms of informed consent? If you asked me, I feel that I was fully informed and I have no illusions of what I was told. I am quite, you know, firm on that. But if you asked another person who I feel perhaps was given the same information, their opinion and their analysis of what they were told was completely different. So I wondered whether part of the Inquiry would be to look at ways of perhaps providing guidelines for parents so that we actually know when we are going into hospital, before we go into hospital, exactly what we can expect, what our rights are, and exactly what informed consent is for us, what it means to us so that there can be no misunderstandings … I think it has to be for clinicians as well. It is no good telling the parents one thing if the clinicians do not know. It has to be something that everybody knows what the other person's role is. So otherwise, it will not work. But if the clinicians are in a position where they are uncertain what their position is regarding informed consent and they feel in good faith that they have acted and given the information over, but the parents' interpretation does not agree with that, then you have a problem. So if you have guidelines, perhaps, that both the parents and clinicians understand, perhaps it will help towards clarifying it.'[514]

443 John Mallone told the Inquiry that:

> 'I think consent for the operation has to be fully informed consent and if, as I hope will happen, surgeons are going to be made to say what their percentage success rates are, then that should be part of that informed consent[515]… I think the more channels of communication you use to inform one the better the information is going to be received, understood … a video … book, diagram, face-to-face contact, to reinforce one another. There is no ideal method, you need to have them all.'[516]

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[512] T95 p. 80 Justine Eastwood

[513] T95 p. 81 Richard Lunniss

[514] T95 p. 92–3 Michelle Cummings

[515] T95 p. 201–2 John Mallone

[516] T95 p. 203 John Mallone

> '… Doctors must be trained to communicate more openly and effectively with patients and those responsible for them, for example parents. There is a fine line between not wanting to worry people and being unduly optimistic to the point of misleading them … Doctors and others involved in patient care must also be more aware of the need to communicate effectively with one another. It should not be possible for a parent to be told that a child is going to die and then for this information to be flatly contradicted by another doctor.'[517]

444 The evidence set out in the Interim Report of the Inquiry[518] (as to the retention of organs and the giving of consent for post-mortems) has not been repeated here, but nonetheless forms part of the body of material upon which the Inquiry has drawn for its conclusions. Reference should be made to the Interim Report for a review of the evidence received by the Inquiry specifically in relation to informing parents of the need for a post-mortem examination and as to the information given concerning retention of their child's tissue and organs.

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[517] T95 p. 209 John Mallone

[518] The Inquiry's Interim Report *'Removal and retention of human material'*, May 2000

Chapter 18 – Medical and Clinical Audit

Introduction

1 The practices and systems in use for informing the Department of Health and Social Security (DHSS), Department of Social Security (DSS), Department of Health (DoH), National Health Service Management Executive (NHSME), National Health Service Executive (NHSE), the regional health authorities (RHAs) and district health authorities (DHAs) of the performance of units for which they had responsibilities are of such importance that they call for separate consideration.

2 In the first part of this chapter the development, over time, of ideas and practices of what has become known as audit is charted. A definition of audit is given at para 5 below.

3 The way in which these developments at a national level found reflection in the practices and systems applicable to the Bristol Royal Infirmary (BRI) and Bristol Royal Hospital for Sick Children (BRHSC) throughout the period of the Inquiry's Terms of Reference is set out in the second part of this chapter. (The collection of data by Dr Stephen Bolsin and others, with specific reference to paediatric cardiac surgery, is dealt with from Chapter 26, when the evidence as to the expression of concerns and the grounds for those expressions is set out.)

4 In the final part of this chapter we set out the extent to which there was audit of paediatric cardiac surgery in Bristol.

Audit: the national perspective

Defining audit

5 There are many definitions of audit, but the most widely cited in the UK during the period of the Inquiry's Terms of Reference was the definition given by the DoH in 1989:

> '… the systematic, critical analysis of the quality of medical care, including the procedures used for diagnosis and treatment, the use of resources, and the resulting outcome and quality of life for the patient.'[1]

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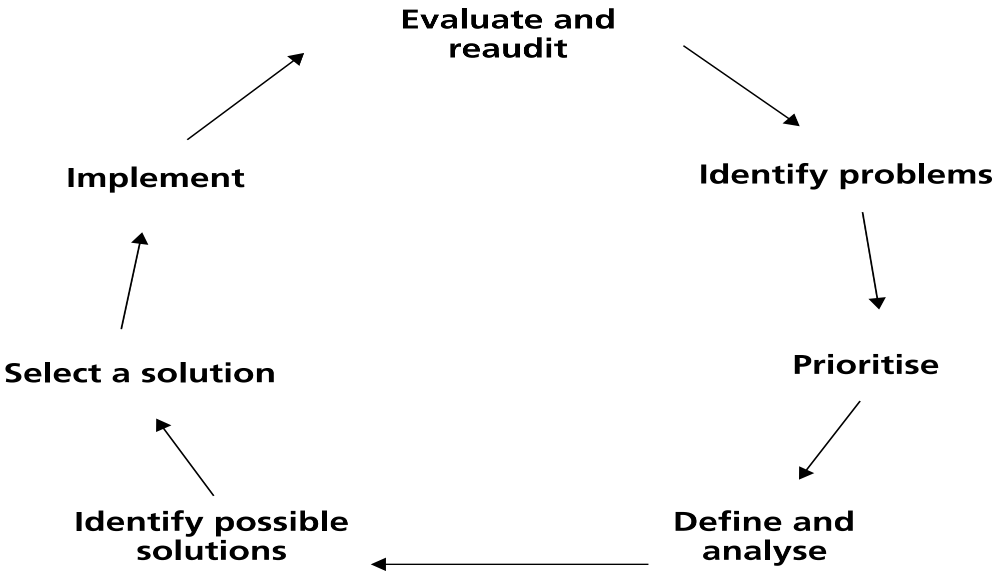
[1] HOME 0003 0127; DoH, *'Working for Patients: Working Paper 6'*. London: HMSO, 1989

The assessment and then the improvement of quality are widely regarded as forming a cycle of activity (see Figure 1 below) which together produce continuing improvements in quality.[2]

Figure 1: The audit cycle



6 The setting of standards against which to measure activities and performance was seen as a key aspect of audit. Miss Lesley Salmon, General Manager of Obstetrics, Gynaecology and ENT at the BRI from October 1994 to date, observed:

> 'The setting of standards is something that runs throughout the Health Service. In a sense, it is the first step in audit, in that if you were going to audit your performance, generally speaking you would be within a department or a service setting standards to then measure yourself against to ensure you were meeting the standards already set, whether they were clinical or non-clinical standards. Audit is then auditing your performance against the standard that has been set and it can be either one internally you have set or it can be something that compares you to other services, similar services, elsewhere.'[3]

7 This aspect of audit, the concern for measuring conduct against agreed standards, is not prominent in the 1989 definition set out in para 5, above. During oral evidence, Counsel to the Inquiry referred Sir Barry Jackson[4] to that definition in para 5, and compared it to the definition of audit set out in the Royal College of Surgeons of

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[2] Fowkes F. 'Medical audit cycle: a review of methods & research in clinical practice'. *'Medical education'* 1982; 16: 228–38. Illustration reproduced with the kind permission of Blackwell Science Ltd

[3] T31 p. 94 Miss Salmon

[4] WIT 0048 0001 Sir Barry Jackson, President of the Royal College of Surgeons of England, from July 1998 to date

England (RCSE) paper. The Royal College explicitly included the question of prescribed targets and standards, stating:

> 'Audit is the systematic appraisal of the implementation and outcome of any process in the context of prescribed targets and standards.'[5]

8 Sir Barry Jackson said:

> '… I think at the time these documents were written there was no clear understanding amongst everybody as to a uniform meaning of the term "audit". … I also know that in the minds of surgeons and other doctors, not just surgeons, throughout the country, there was enormous confusion as to what audit actually was and to how it should be used, and its importance. There is no doubt at all in my mind that the definition that you see on the screen currently is the correct definition of "audit", that is to say, it is a systematic appraisal or analysis, if you wish, of any particular process in the context of a prescribed standard which has been set, a comparison of what is actually being done against that standard or target which has previously been identified, and that should there be a disparity, then measures should be put into place to rectify the disparity, or alternatively, to change the standard or the target which might of course be incorrect. … I think that some of the confusion may have arisen between these three terms, "audit", "medical audit", and "clinical audit". I say no more than that because I think it was a very confused area. I think it is still confused to some extent in the minds of many, even today'.[6]

9 Sir Barry Jackson said that:

> 'The setting of the standards have created considerable problems in many areas, and in 1989/1991 those standards in most instances were not recognised; therefore, to all intents and purposes, they did not exist. This is where I think some of the confusion has arisen as to what one is meaning by "audit" because so often what was perceived as audit — and I have to say, going back to the HRC [Hospital Recognition Committee] and the SAC [Specialist Advisory Committee] visits … the audit that they were looking at was probably not audit in the true sense of the word; in other words, comparing against an accepted standard.'[7]

The development of definitions

10 Whilst an early definition of audit is set out above at para 5 above, the understanding of the term, and the meaning ascribed to it, varied and was developed across the period with which the Inquiry was concerned.

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[5] WIT 0048 0117 Sir Barry Jackson

[6] T28 p. 87 Sir Barry Jackson

[7] T28 p. 92 Sir Barry Jackson

11 Initial uncertainties about the meaning and scope of audit were captured in the first paragraph of the *'First Report of the Royal College of Anaesthetists' Audit Committee'*,[8] November 1989:

> 'What is Audit [?]
>
> 'Audit is derived from the Latin and means "hearing". In financial terms it derives from the practice of a landowner calling his steward to give an account of the use of the landlord's property. (Look at the parable of the talents, Matthew, 25, 14–30). *"The Economist's Pocket Accountant"* shows that the aim of a financial auditor is to present a true and fair view of the financial state of an organisation. Essentially the accounts should show how the organisation has used its resources in the preceding defined period.
>
> 'There seems to be no generally accepted definition as to what medical audit is. But the idea behind most schemes is that the participants can demonstrate to themselves and their colleagues (not only in medicine) the quality and quantity of the work that they are doing. This entails an account of the use of the resources and the outcome of the clinical practice, to demonstrate the limitations of the clinical service and the needs for improvements.'[9]

12 Dr Jane Ashwell, who was, at the relevant time, a Senior Medical Officer at the DoH, referred to the Inquiry's Issues List in her statement[10] and said:

> 'I think the way the word audit is being used in issue M [the Issues List] is actually rather different from the Audit I am talking about and which the DH [Department of Health] was introducing in the early 1990s. There were no systems — it was new and developing. Much of the research information on which to base audit was not available and much of my work was aimed at helping doctors to establish research such that robust guidelines could be produced to do audit against. You can't look at practice unless you establish a standard to compare it with. Audit was not a means of measuring outcomes but a way of comparing what doctors did as against what the research evidence indicated they should do. Some professional bodies did collect anonymised outcome data as did NCEPOD [National Confidential Enquiry into Perioperative Deaths] but it was not robust research that could link the outcome with causes nor was it, strictly speaking, audit.'

13 For clinicians, therefore, audit could form an aspect of research and scientific development. It was also a form of continuing professional education, in that it involved scrutiny of aspects of clinical practice and care.

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[8] The Committee was subsequently renamed the Quality of Practice Committee: see report of May 1991, WIT 0065 0595 Professor Strunin

[9] WIT 0065 0589 Professor Strunin. In the next report, May 1991, the definition in *'Working for Patients: Medical Audit'*, Working Paper No 6, was set out. See WIT 0065 0595

[10] WIT 0338 0003 Dr Ashwell

14 The Standing Medical Advisory Committee wrote:

> 'Since the technical competence to assess quality of medical care belongs to doctors, medical audit must be conducted by the medical profession as its success depends so much on medical knowledge. Medical audit needs to involve all doctors who should take corporate responsibility for it.
>
> 'Medical audit should lead to a better standard of patient care by better informed doctors. It must be an educational process, and this form of audit should not be used for disciplinary purposes.'[11]

15 Mr James Wisheart, consultant cardiac surgeon, saw audit as having:

> '… a place in terms of education and peer review…to be an activity conducted by doctors in the interests of their education …'[12]

Further,

> 'The initial view of audit was that it was an activity which was to be led professionally and undertaken professionally as a peer review, educational exercise.'[13]

Dr Trevor Thomas, consultant anaesthetist, and chairman of the United Bristol Hospitals NHS Trust (UBHT) Medical Audit Committee said that medical audit, was:

> '… a system which was being used as an educational system …'[14]

Mr Janardan Dhasmana, consultant cardiac surgeon, stated:

> 'The audit of one's own data was always considered essential in maintenance of professional standard and in improving performance.'[15]

16 Counsel to the Inquiry asked Dr Sally Masey, consultant anaesthetist at the BRI since 1984, what she thought the purpose of audit was. She replied:

> 'The purpose of audit in the broadest sense is to have a mechanism to look at our practice in order to improve the quality of care in the broadest sense.'[16]

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[11] *'The Quality of Care'*, report of the Standing Medical Advisory Committee, DoH, 1990, p. 16
[12] T41 p. 82 Mr Wisheart
[13] WIT 0120 0384 Mr Wisheart
[14] T62 p. 99 Dr Thomas
[15] WIT 0084 0026 Mr Dhasmana
[16] T74 p. 22 Dr Masey

17 Mrs Margaret Maisey, employed at the UBHT from 1986 to 1997 as a General Manager (South and later Central Unit), Director of Operations and Director of Nursing, stated that:

> 'The term [audit] has had a rather equivocal meaning during my recent employment within the NHS. To some it has meant an educational process, a structure for reviewing the process of health care, rather than the outcomes of that care. To yet others, it merely borrowed the word from accountancy to refer to the stocktaking process when applied to various aspects of the health care system.'[17]

18 Mrs Maisey demonstrated the use of 'audit' to describe aspects of managerial activity, by giving the example of a 'lifting equipment audit' that was instituted in 1992 by Janet Maher, then General Manager UBHT, and was an information-gathering exercise about the facilities for lifting, moving and handling patients. The results of this 'audit', according to Mrs Maisey, were very helpful and a minimal lifting policy was introduced, but:

> 'There is no way in which such management activity can be called "clinical audit" as I understand the term to be used when applied to clinical situations today.'[18]

She continued:

> 'I recall that the various advices and circulars from the centre, the College and others, over a number of years defined audit differently at different times. The view of what it might be, how it might be implemented and applied to one's own area of responsibility, changed with time.'[19]

19 Dr Ian Baker, Consultant in Public Health Medicine with the Bristol and District Health Authority (B&DHA), said:

> '… I think health authorities were interested in audit in so far as it was a way of considering the heading "Quality" in contracting terms, and I think those of us in public health medicine had a professional interest in this tool, providing information on quality.'[20]

20 When Dr Baker was asked what obstacles stood in the way of the development of audit, he said:

> 'I think the main one was the feeling that audit was going to become some form of inspectorial management tool of professional practice. I think, in general, the medical profession, and possibly others, closed ranks to some extent to take ownership of this process to try and accept it as something which was educational

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[17] WIT 0103 0072 Mrs Maisey
[18] WIT 0103 0072 Mrs Maisey
[19] WIT 0103 0072 – 0073 Mrs Maisey
[20] T36 p. 101 Dr Baker

> and related to training and practice in that way, rather than a more general approach to quality assessment.'[21]

21 The 1992 UBHT Medical Audit Committee (MAC) report stated:

> '… medical audit … must continue to be seen to be a confidential and independent educational process — not merely the inquisitional arm of purchasers under the auspices of the Regional Health Authority.'[22]

22 Equally, audit was seen as a potential tool to persuade managers that further resources were needed. For example, the Audit Committee of the Royal College of Anaethetists (RCA) listed amongst the 'good reasons' why audit should be performed:

> '… the need for information to identify strengths and weaknesses of the various services, to ensure effective training of junior staff and finally to ensure that the capital and recurrent expenditure associated with anaesthesia is used effectively, and increasingly, economically. Audit should be usable in demonstrating to colleagues and managers that resources are used well and that claims for additional moneys are well supported.'[23]

23 In May 1991, the RCA advised its members:

> 'Representatives of the employing authority have a legitimate interest in those aspects of audit which include resource management, staffing levels, list cancellations or overruns and the use of ITU and recovery facilities.'[24]

24 There was potential confusion as to the difference between expressions or activities such as 'quality assurance'and 'audit'. Sir Barry Jackson gave evidence that:

> '"Quality assurance" is a jargon phrase, which is widely in evidence at the moment.[25] I think it just refers to the broad field of quality in its entirety. Audit, I think, will be one aspect of a method of trying to ensure satisfactory quality, but there would be others such as the CME [Continuing Medical Education] and CPD [Continuing Professional Development], for example, … examinations and other aspects of ensuring quality.'[26]

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[21] T36 p. 103 Dr Baker

[22] UBHT 0032 0080; MAC report 1992

[23] WIT 0065 0589; *'First Report of the Audit Committee'*, November 1989

[24] WIT 0065 0598; *'Report of the Quality of Practice Committee'*, May 1991

[25] WIT 0307 0018; Dr Kieran Morgan, Director of Public Health, Avon Health Authority commented on Mr Jackson's evidence that the phrase 'quality assurance' was jargon. He said: 'The term "quality assurance" is not a jargon phrase. It very clearly refers to the obligation of providers of services to demonstrate to those who receive the service that that service is of high quality'

[26] T28 p. 89 Sir Barry Jackson

25 Dr Kieran Morgan, Director of Public Health Avon Health Authority (Avon HA), took the view that there were standards or benchmarks in relation to structures and processes even though there were none in relation to outcomes of care. He stated:

> 'Much of the monitoring we were trying to introduce was about following the introduction and development of structures and processes and, of course, this is something that the UBHT felt was not a concern of the Health Authority and wholly the responsibility of the Trust (see the note of the clinical audit review meeting of the UBHT in November 1992).'[27]

26 In a paper commissioned by the Inquiry entitled *'Medical and Clinical Audit in the NHS'*, audit is explained as follows:

> 'To health professionals, audit offers a systematic framework for investigating and assessing their work and for introducing and monitoring improvements. The process of carrying out an audit involves a characteristic sequence of events which includes:
>
> - 'defining standards, criteria, targets or protocols for good practice against which performance can be compared;
> - 'gathering systematic and objective evidence about performance;
> - 'comparing results against standards and/or among peers;
> - 'identifying deficiencies and taking action to remedy them; and
> - 'monitoring the effects of this action ie. "closing the audit loop".
>
> 'Audit is regarded as a cyclical activity, on the assumption that reviews of this sort should be carried out continuously.'[28]

27 Dr Kieran Walshe, Senior Research Fellow in the Health Services Management Centre at the University of Birmingham, recognised there were various interpretations of the term 'audit':

> 'I think the definition offered in the Inquiry's paper is a helpful one … I think the definition you have offered in this paper is in some ways more helpful [than the Department of Health's 1989 definition referred to in para 5] because it makes it clear the process involves both gathering information about the quality of practice and performance, identifying problems and opportunities for improvement and then taking action to remedy those problems or difficulties, to bring about change. There are ways in which you can make differentiations — and the paper referred to distinguishes between medical audit, clinical audit and organisational audit and

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[27] WIT 0307 0015 Dr Morgan

[28] INQ 0011 0009; *'Medical and Clinical Audit in the NHS'*

> quality assurance and TQM [Total Quality Management] and CQI [Continuous Quality Improvement]. There are lots of definitional discussions you can have. What brings all those definitions all together is that they are all about systematically attempting to identify problems with the quality of care, and then taking action to understand their causes and bring about changes that make improvement in the quality of care take place.'[29]

The national scene: a brief history of audit[30]

Key events

28 Prior to 1980, explicit concerns about quality appears to have been largely absent from the thinking and policy documents of the NHS.

29 The medical profession was expected to be the regulator of the quality of clinical care, and had been since the Medical Act 1858 established the General Medical Council (GMC) to regulate the medical profession on behalf of the state. This legitimated the profession's claims to autonomy and its right to self-regulation. When, in 1948, the NHS was created, the regulation of the medical profession was left largely in the hands of the profession through the GMC (and, in matters of training, the Royal Colleges).

30 Audit as a notion and a practice was conceived as being wholly associated with the activities of the medical profession until relatively recently. However, to the extent that it is concerned with quality of care, widely understood, it is inevitably concerned also with the conduct of all the other carers involved in the care of patients.

31 The *'Historical Perspective'* to the formal introduction of the obligation to undertake audit within the NHS was summarised by the Standing Medical Advisory Committee in 1990.[31]

> 'The idea of medical audit is not new: indeed, reference to it can be found in the Charter of the Royal College of Physicians of 1518 which states that one of the College's functions is to uphold the standards of medicine "both for their own honour and public benefit". Examples of medical audit which are currently taking place [in 1990] include the Confidential Enquiry into Maternal Deaths, which began in 1952 and is run jointly by the Department of Health and the Royal College of Obstetricians and Gynaecologists. The Royal College of General Practitioners was involved early on in medical audit in general practice. Much of the work of the Birmingham Research Unit in the 1950s and 1960s was concerned with designing the tools for audit. In pathology the National External Quality Assessment Scheme (NEQAS) was started in 1969 and encompasses all commonly used numerical investigations in pathology. It is a voluntary scheme open to NHS and private

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[29] T62 p. 5 Dr Walshe

[30] The distinction between medical and clinical audit and the shift in policy from the former to the latter is discussed at paras 59–66 onwards. Medical audit carried out by doctors and the audit of nursing care by nursing staff was realised to be less instructive than the multidisciplinary approach to the examination of overall care of the patient that became known as 'clinical audit'

[31] *'The Quality of Care'*, report of the Standing Medical Advisory Committee, DoH, 1990, p. 7–8

> services. The Royal College of Physicians conducted a survey in 1980 of causes of death in medical wards of all patients under the age of 50. The Association of Anaesthetists and the Association of Surgeons together carried out an enquiry into perioperative deaths in three Regions (CEPOD); this was extended into a national confidential enquiry at the beginning of 1989. The Health Advisory Service, which was established in 1976, is an example of multidisciplinary audit; it carries out reviews of hospitals and community health services provided for the elderly and the mentally ill and makes recommendations for the improvement of care.

'The Department of Health's health service indicators include measures of activity, and some of outcome … These provide some indication of the quality of medical care. The health service indicators also include a set of data which compares death rates by region and district for certified causes of death from conditions considered 'potentially avoidable'… The incidence of potentially avoidable deaths (that is those from conditions amenable to treatment) has been analysed for each Health Authority and shows large variations between Health Authorities even after adjustment for social factors. All these may provide some indication of the quality of medical care.'

32 Dr Morgan stated:

> 'Recognisable medical audit has taken place throughout the Health Service for many years but a systematic approach to engaging all clinicians became evident in the NHS only in the late 1980s.'[32]

33 Prior to 1980 explicit concerns about quality appear to have been largely absent from the thinking and policy documents of the DoH.[33] Dr Graham Winyard[34] considered that the DoH's relatively limited involvement in the field of audit and outcome assessment at the time reflected the then established division of responsibility for standards of professional practice, which were set by the GMC and the medical Royal Colleges:

> '… through general and specialist examinations, the inspection of training posts and involvement in consultant appointment committees. However, the prime responsibility for a doctor's ongoing standard of professional practice lay with that individual and was seen very much as a matter for him or her. General peer pressure was undoubtedly important in maintaining overall standards but could prove much less effective when an individual was, for whatever reason, resistant to criticism.'[35]

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[32] WIT 0307 0011 Dr Morgan

[33] INQ 0011 0007; *'Medical and Clinical Audit in the NHS'*

[34] Dr Graham Winyard was the Medical Director of the NHS Executive and Deputy Chief Medical Officer from 1993 to 1998

[35] WIT 0331 0002 Dr Winyard

34 Thus, the evidence indicated that prior to 1989 there was a varied and patchy pattern of audit. Dr Walshe elaborated:

> '… in most hospitals you would have found a small number of clinical professionals, particularly doctors, who were gathering data about their own practice, who were, if you like, audit enthusiasts and who were engaging in a process of clinical audit for themselves. You would have found, I think, in most parts of most organisations, relatively little activity. There would have been some traditional mortality and morbidity meetings or death and complication meetings going on, at which problems to do with the quality of care perhaps got reviewed, but you could not have said that in I think almost any health care organisation at that time in the NHS there was a systematic program of quality assurance or quality improvement in place. You would also have found some important national initiatives which were focused on particular areas of care and were important in those areas but were somewhat isolated in that they did not have a wider remit or impact. Examples would be the Confidential Enquiry into Maternal Deaths and the National Confidential Enquiry into Peri-operative Deaths, work done by the Royal College of General Practitioners on standards for general practice, and things like that. So there were important initiatives, but there was no system that covered even a large minority of the care being provided.'[36]

35 Attitudes began to change within the medical profession itself. For example, some parts of the medical profession gained extensive experience of quality assessment exercises set up by bodies such as the Royal Colleges, notably into anaesthetics and obstetrics, as well as confidential enquiries established on a national basis to study maternal, infant and peri-operative deaths.[37]

36 Formal arrangements for audit were in their infancy throughout the NHS during the 1980s. Progress was limited because no additional resources were allocated for audit whether for the supra regional services or in the NHS generally. It was only with the introduction of the NHS reforms in the 1990s that funding was made available for the specific purpose of introducing audit.[38]

37 The publication of the DoH's White Paper *'Working for Patients'*[39] in January 1989, set out plans for the creation of the internal market. Together with the '*Working for Patients: Medical Audit Working Paper 6'*, it also set out plans for a comprehensive system of medical audit, covering both primary healthcare and the hospital and community health sector. The Government made it clear that all health-care providers in the NHS in England should develop medical audit programmes that involved all medical staff in critical examination of the quality of care and practice. Subsequently, the DoH broadened this programme to provide some funding for an audit programme in Nursing and Therapy as well. Uni-professional audit was proposed at that time; that

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[36] T62 p. 13–14 Dr Walshe

[37] INQ 0011 0008; *'Medical and Clinical Audit in the NHS'*

[38] WIT 0049 0021 Dr Halliday

[39] HAA 0165 0145; *'Working for Patients'*

is to say medical audit for doctors, nursing audit for nurses and their own audit for the Professions Allied to Medicine (PAMs).

38 *'Working for Patients'* sets out the fundamental principles, 'to which the Government is committed', as follows:

> '(a) Every doctor should participate in regular systematic medical audit.
>
> '(b) The system should be medically led, with a local medical audit advisory committee chaired by a senior clinician.
>
> '(c) The overall form of audit should be agreed locally between profession and management, which itself needs to know that an effective system of medical audit is in place and that the work of each medical team is reviewed at regular and frequent intervals to be agreed locally.
>
> '(d) The results of medical audit in respect of individual patients and doctors must remain confidential at all times. However, the general results need to be made available to local management so that they may be able to satisfy themselves that appropriate remedial action is taken where audit results reveal problems.
>
> '(e) Where necessary management must be able to initiate an independent audit. This may take the form of external peer review or a joint professional and managerial appraisal of a particular service.'[40]

39 It was Dr Winyard's opinion that the proposals in the working paper recognised that audit:

> '… needed to be owned by the medical profession if it were to be effective in stimulating genuine peer review and changing clinical practice where that was indicated. They sought to strike a balance between this and the wider and equally legitimate interests in the quality of care by ensuring confidentiality for the audit process itself, while insisting that the "general results" of audit were made available to management.'[41]

40 The DoH's policy at the outset was that medical audit should be primarily the concern of providers, rather than district health authorities or other purchasers. As the NHS reforms took effect, structures and audit activities would therefore need to be based at a provider level:

> 'Health authorities are responsible for establishing a medical advisory structure. With the separation of the purchaser/provider functions, medical audit will become

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[40] HOME 0003 0130; *'Working for Patients'*

[41] WIT 0331 0004 Dr Winyard

> a provider unit based activity and it will be to unit managers that regular reports of the general results of audit are addressed.'[42]

41 The benefits of the audit programme were expected to be profound and wide ranging. An internal discussion paper in the DoH stated:

> 'Medical audit should trigger changes in practice within specialties, across specialties, across provider units and across boundaries including those between primary, secondary and tertiary care. The findings of medical audit should encourage comparison and challenge working practices throughout the NHS … This should result in optimal delivery of effective and appropriate care by the right professionals, in the right combination, in the right setting and at the right time.'[43]

42 Dr Walshe identified three elements which in his opinion were the catalyst for these audit reforms in 1989, a year that many witnesses regarded as marking the introduction of audit as a formal process:

> 'I think there are three things that had happened. One was the rise of general management during the 1980s and the arrival of individuals, some clinically qualified, some not clinically qualified, but individuals who had general management responsibility and authority for healthcare services, and had more of a remit and a legitimate right to ask questions about the quality of care. Second was the rise of concerns about quality of performance across public services, and indeed private services. It was a theme in Government in the 1980s and a focus on the role of managers and managerialism and a concern about the power of the professions running across education and health and social services, and other sectors. I guess I would also point to the fairly positive experience of those initiatives I have described going on in the 1980s, seen as examples of good practice that perhaps we should be trying to emulate and roll out on a wider scale. I do not think I could point to one particular event or set of circumstances which led the Government then to say "we have to have systems of medical audit". It was a combination of things.'[44]

43 The aims and objectives of the DoH's audit programme from 1989 to 1993 are set out in Figure 2, below.

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[42] HAA 0164 0025; HC(91)2. *'Medical Audit in the Hospital and Community Health Services'*

[43] INQ 0011 0012; NHS Management Executive. *'Steering the Audit Programme'* (Internal Discussion Paper), 1991

[44] T62 p. 15 Dr Walshe

Figure 2: Aims and objectives set by the Department of Health for its audit programme[45]

1989	1992	1993
'To enhance the quality of care given to patients in the NHS.' 'To provide the necessary reassurance to doctors, patients and managers that the best quality service is being achieved within the resources available.' '[To develop] a proper organisational framework for the introduction of systematic medical audit in each Health Authority and Family Practitioner Committee.' 'Every doctor should participate in regular systematic medical audit.' 'The system [of audit] should be medically led, with a local medical audit advisory committee chaired by a senior clinician.' 'The overall form of audit should be agreed locally between the profession and management, which itself needs to know that an effective system of medical audit is in place and that the work of each medical team is reviewed at regular and frequent intervals to be agreed locally.' 'The results of medical audit in respect of individual patients and doctors must remain confidential at all times. However, the general results need to be made available to local management so that they may be able to satisfy themselves that appropriate action is taken where results reval problems.' 'Where necessary management must be able to initiate an independent audit. This may take the form of external peer review or a joint professional and managerial appraisal of a particular service.'	'Medical audit should be shown to lead to change in quality of care and health outcome.' 'Medical audit should be fully embedded throughout the NHS.' 'Medical audit should be an integral part of undergraduate, postgraduate and continuing education in all specialties.' 'National audits investigating important areas using approved methodologies and producing valuable and generalisable findings should continue to be supported centrally.' 'Audit should be seen as a process of setting standards and comparing practice against standards in order to achieve change.' 'Healthcare commissioning for populations should be informed by both national audit findings and also by the findings of local medical audit.'	'[Audit should] be professionally led.' '[Audit should] be seen as an educational process.' '[Audit should] form part of routine clinical practice.' '[Audit should] be based on the setting of standards.' '[Audit should] generate results that can be used to improve outcome of quality care.' '[Audit should] involve management in both the process and outcome of audit.' '[Audit should] be confidential at the individual patient/clinician level.' '[Audit should] be informed by the views of patients/clients.'

44 In order to meet these objectives, the Department of Health allocated almost £221 million to facilitate the development and implementation of medical audit (later clinical audit) programmes in every health care provider in England, and to support central initiatives such as audit projects and programmes at the medical Royal Colleges. The provider units received £28 million, allocated for funding the newly created medical audit committees in the first two years (1989 and 1990). This rose to £48.8 million in 1991/92, the year in which the committees began to function fully.[46]

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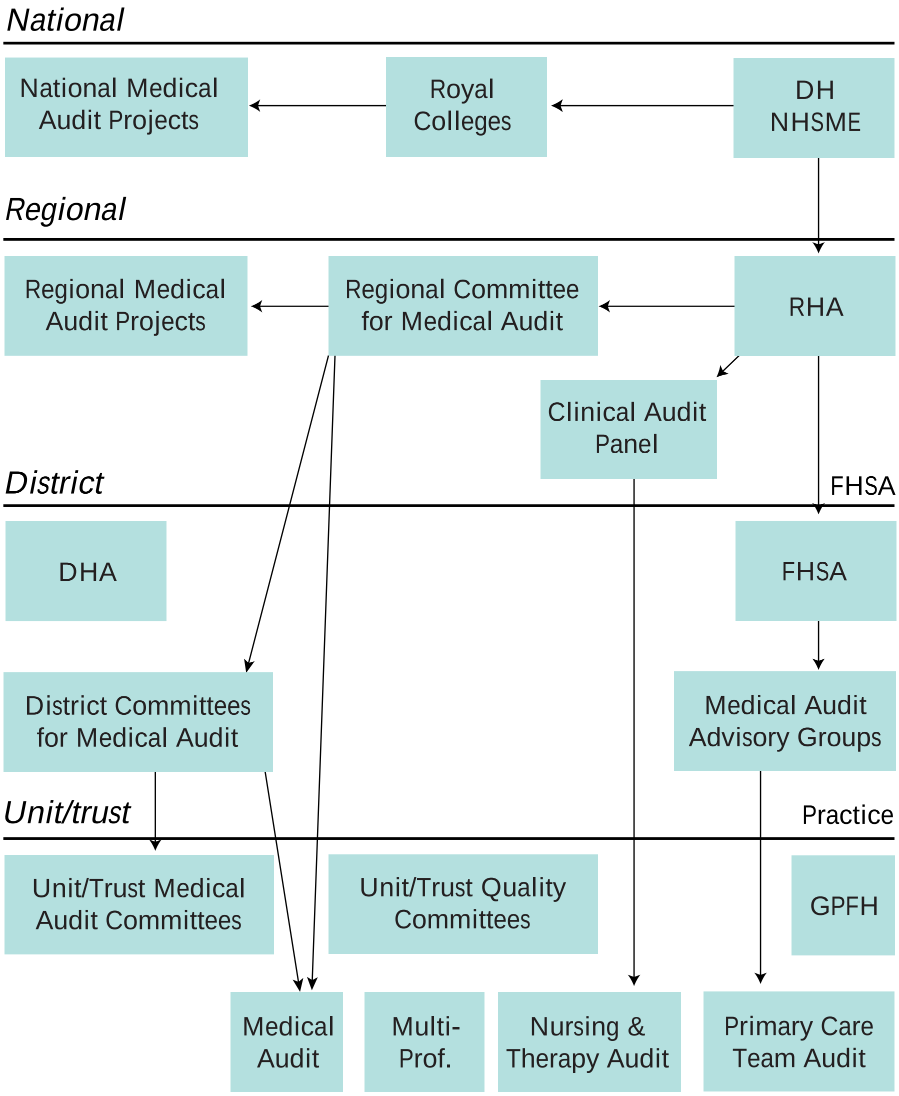
[45] *'Evaluating Audit: Provider audit in England: A review of twenty-nine programmes'* 1995 CASPE Research. Illustration reproduced with the kind permission of CASPE Research

[46] INQ 0011 0012; *'Medical and Clinical Audit in the NHS'*

45 A separately funded Nursing and Therapy audit programme was also introduced, from 1991 onwards. It received £2.3 million in 1991/92.[47]

46 Figure 3 shows the flow of funds for clinical audit between 1990 and 1994.

Figure 3: Flow of funds for medical and later clinical audit 1990–94[48]



Key

DH	Department of Health
DHA	District Health Authority
FHSA	Family Health Service Authority
GPFH	General Practitioner Fund Holders
NHSME	National Health Service Management Executive
RHA	Regional Health Authority

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[47] INQ 0011 0013; *'Medical and Clinical Audit in the NHS'*

[48] Reproduced with permission from the author. *'Evaluating clinical audit: past lessons, future directions'*, edited by Kieran Walshe, International Concerns and Symposium Series 212. Proceedings of a conference organised by the Royal Society of Medicine and CASPE Research, London, 27 April 1995

Reactions to the Government's proposals

47 Medical reaction to the White Paper proposals as a whole were generally negative. The reactions are set out as follows:

- concern that the proposals failed to address the chronic under funding of the NHS;
- doubts about the need for such a major reorganisation of the system;
- scepticism about whether patients would benefit from the changes;[49]
- doubts about whether there would be adequate time for audit and whether confidentiality could be maintained;
- suspicion about the possible covert use of the policy as a diversionary device to deflect attention from insufficient resources;
- concerns about a shortage of skills, lack of interest, lack of adequate data and information systems, lack of willingness to focus on key issues such as appropriateness of treatment, reluctance among consultants to judge their peers and risk of attribution of blame to junior staff; and
- the view that, to the extent that audit remained a private activity internal to the medical profession, the need for greater public accountability would remain unmet.[50]

48 The Inquiry's expert on audit agreed that the reaction from members of the medical profession to the White Paper as a whole was generally very negative but:

> '… the reaction to the ideas for audit from the Royal Colleges and others speaking on behalf of the medical profession was strikingly positive.'[51]

Thus, although medical audit was promoted by the DoH and, formally, initially led by the RHA, it was also actively promoted by the Royal Colleges. In the case of the RCSE, guidelines on audit were published in 1989 that were revised and updated in 1995.[52] The Colleges in their publications reiterated the principle that medical audit was educational, confidential and non-judgmental.[53]

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[49] INQ 0011 0013; *'Medical and Clinical Audit in the NHS'*

[50] INQ 0011 0014; *'Medical and Clinical Audit in the NHS'*

[51] INQ 0011 0013; *'Medical and Clinical Audit in the NHS'*

[52] WIT 0048 0119 Sir Barry Jackson. *'The Royal College of Surgeons of England – Guidelines to Clinical Audit in Surgical Practice, March 1989'* RCSE 0001 0051 (revised June 1995)

[53] INQ 0011 0013; *'Medical and Clinical Audit in the NHS'*

49 In turn, the DoH took care to emphasise the positive aspects of medical audit, compared to existing quality control mechanisms such as the GMC's disciplinary procedures and the law. The various documents relating to medical audit avoided such terms as 'mandatory' or 'compulsory' and there was no mention of penalties for those who resisted.

50 Further, the endorsement of 'medical' audit was not supported by all:

> 'At a time of increasing recognition of the importance of a team approach in clinical work, the emphasis on uni-professional audit was criticised, by the Director of the Royal College of Nursing among others, as inappropriate and potentially divisive.'[54]

51 The commentators with a management perspective went one step further and challenged the appropriateness of segregating audit from other management initiatives relating to quality, such as resource management. The Director of the Institute of Health Service Managers argued for the integration of professional audit into a much wider model of co-operative working.

52 Doubts about the wisdom of a policy focusing on the methodology rather than the purposes of clinical quality assurance were also expressed. For example, there were concerns that:

- audit would become an end in itself;
- topics chosen would be chosen because they were easy or interesting or data already existed;
- aspects of practice might be neglected entirely because they were not susceptible to audit;
- important problems might be dealt with ineffectually through audit when they could be dealt with more satisfactorily in some other way;
- the weakness of the evidence that audit could be beneficial to patients and the known difficulty of completing the audit cycle effectively.[55]

53 Following the publication of *'Working for Patients'* new enterprises that could be called 'a healthcare quality industry', emerged, leading to a great expansion of activity. Several quality management systems began to be introduced into healthcare in the UK, including for example the King's Fund *'Organisational Audit'*, BS5750, which was developed as a pilot for organisational accreditation within the UK.[56]

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[54] INQ 0011 0014; *'Medical and Clinical Audit in the NHS'*

[55] INQ 0111 0015; Inquiry Paper

[56] See *'The Reality of Practitioner-Based Quality Improvement'*, National Institute for Nursing, 1995, WIT 0042 0444 Mrs Jenkins, for an account of the development of tools for quality assurance

Systems of Total Quality Management were also developed. In 1990, the Royal College of Nursing (RCN) launched its workbook on the Dynamic Standard Setting System or DySSSy.[57]

Creation of the NHS market

54 On 1 April 1991 the *'Working for Patients'* reforms came into operation.[58]

55 Although the legal framework for a hospital trust established by the NHS and Community Care Act 1990, empowered the Secretary of State, by Order, to establish bodies 'to assume responsibility … for the ownership or management of hospitals … or to provide and manage hospitals',[59] there was nothing in that Act setting out the duties of trust directors in respect of quality or safety. In particular, no guidance on responsibility for standards of safety or quality was given to trust directors.

56 In July 1991, the then Prime Minister, John Major, launched the Citizen's Charter, aimed at promoting good quality services in the public sector. In October 1991, the *'Patient's Charter'* was launched by the DoH.

57 The Charter was described in its foreword as:

> '… a central part of the Government's programme to improve and modernise the delivery of the service to the public whilst continuing to reaffirm the fundamental principles of the NHS.'[60]

One 'right' that was newly established by the Charter was 'to be given detailed information on local health services, including quality standards and maximum waiting times.'[61] The local health authority was to publish annual reports detailing how it was performing against national and local charter standards.

However, the National Charter standards were not legally enforceable. They were described in the Charter as:

> '… not legal rights but major and specific standards which the Government looks to the NHS to achieve, as circumstances and resources allow.'[62]

58 The Government and other bodies undertook further work on the development of audit tools. A series of frameworks were developed centrally for different audit tools. In nursing, a *'Framework of Audit for Nursing Services'* was published by the NHSME. It described an eight-stage approach to nursing audit, broadly consistent with the quality assurance cycle described in DySSSy, but using significantly different terminology.[63]

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[57] See further below at para 117

[58] See Chapter 2 for an introduction to these reforms

[59] NHS and Community Care Act 1990, Section 5

[60] HOME 0001 0003; *'The Patient's Charter'*

[61] HOME 0001 0006; *'The Patient's Charter'*

[62] HOME 0001 0004; *'The Patient's Charter'*

[63] *'The Reality of Practitioner-Based Quality Improvement'*, National Institute for Nursing, 1995, WIT 0042 0444

The introduction of clinical audit

59 By 1993, policy had shifted to recognise that separate medical audit by doctors of medical care and nursing audit by nurses of nursing care was sub-optimal. For audit to be effective, the totality of patient care needed to be studied. All members of a team delivering a particular service should together audit the work that the team was undertaking. This multidisciplinary approach was given the name 'clinical audit'.[64]

60 In November 1992 the first meeting of the Department of Health's new Clinical Outcomes Group (COG) was held. The group was chaired jointly by the Chief Medical and Chief Nursing Officers, and aimed to give strategic direction to the development of clinical audit. It advised upon the development of methodologies to identify and achieve improved outcomes.[65]

61 On 23 April 1993 the NHSME sent out a letter[66] that noted the central development of the clinical audit programme. A policy statement setting out the main strands of the clinical audit strategy had been commissioned by COG and was soon to be published. Whilst funding for medical and nursing and therapy audit was still to be separately identified in 1993/94, an additional allocation of £3.2 million had been made to facilitate the development of multi-professional clinical audit. In 1993/94, Regions were asked to promote the use of the clinical audit programme as part of the purchaser's role in contracting.

62 The letter explained that the NHSME needed to be assured that the appropriate mechanisms and procedures were in place to underpin the development of clinical audit. It required the regional general managers to set out their proposals for achieving this aim in the letters submitting the 1992/93 annual reports.

63 Annexed to the letter was a paper, *'Audit and the Purchaser/Provider Interaction'*,[67] prepared by a working group of the Regional Medical Audit Coordinators Committee and Conference of Colleges Audit Group.[68] The paper was an aid to discussion of clinical audit. It set out the key features of clinical audit, which it was hoped would lead to improvements to the care of patients within five years:

- 'Audit will be largely multidisciplinary (clinical) audit and part of hospital-wide quality management programmes.
- 'Audit will be informed by purchaser/provider and public/patient as well as professional (college) priorities.
- 'The findings of audit will inform service development and purchasing.

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[64] UBHT 0273 0278; (EL(93) 59)NHSME circular, WIT 0108 0047 Dr Roylance, WIT 0120 0378 Mr Wisheart

[65] *'Clinical Audit: Meeting and Improving Standards in Healthcare'*, DoH, 1993, p. 10

[66] UBHT 0028 0014; EL(93)34 NHSME circular

[67] UBHT 0028 0017

[68] Dr Ian Baker, then Consultant in Public Health Medicine at the B&DHA, was a member of the Working Group. He was a representative of the Faculty of Public Health Medicine on the Academy of Royal Colleges Committee on Medical Audit WIT 0074 0037

- 'Audit will be an integrated part of routine activity and continuing professional education.
- 'Audit will increasingly demonstrate its effectiveness and cost effectiveness to provider, purchaser and the public.
- 'Audit will increasingly focus upon outcomes and their relationships to the processes of care.
- 'Audit will be a shared process bridging primary and secondary care sectors.'[69]

64 Dr Walshe told the Inquiry about the shift from medical to clinical audit during 1991 to 1995. Counsel to the Inquiry asked Dr Walshe whether clinical audit replaced medical audit or whether it was common to find the two operating in tandem. He replied:

> 'It generally replaced and it was part of the wider shift towards for example more managerial involvement, that there was this move towards a more multi-professional approach to audit and quality improvement. The department had established, back in 1990, a separate nursing and therapies audit programme run by a separate part of the Department of Health, part run by the Chief Medical Officer's section and part by the Chief Nursing Officer's section. In 1993 they recognised, as did others, that that division did not make sense and they brought the two together and encouraged Trusts to bring the systems together. What usually emerged within a Trust was a Clinical Audit Committee with a more multi-professional membership, although the membership of those committees tended to be quite medically dominated.'[70]

65 In July 1993 the DoH published a policy document, *'Clinical Audit — Meeting and Improving Standards in Healthcare'*. It set out a strategy for moving towards multi-professional clinical-audit, with an emphasis on clear definitions, and quality and outcome of care. This document stated:

> 'A key component of demonstrating quality of clinical care is identifying the benefit of care in terms of improved health, patient satisfaction and reassurance and improved quality of life, i.e. clinical outcome. Clinical outcome usually reflects the consequence of the collective efforts of a number of professionals, consequently while it was necessary, initially, to set up the audit programme on a uni-professional basis, there is now a need to move to a more integrated approach to audit.
>
> 'Therefore while uni-professional audit will continue to be essential, where a mix of professionals are involved in the care of patients, multi-professional audit has

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[69] HAA 0009 0089; *'Audit and the purchaser provider inter-action'*

[70] T62 p. 51 Dr Thomas

> already become established e.g. Accident & Emergency, Psychiatry and Medicine for the Elderly, as audit on any other basis would have been of limited value.'[71]

Further guidance was subsequently given by the DoH publication *'The Evolution of Clinical Audit'*.[72] It stated that items which would indicate that audit is developing successfully are that it is:

- 'undertaken by multi-professional healthcare teams;
- 'focused on the patient;
- 'performed within a culture of continuing evaluation and improvement of clinical effectiveness focusing on patient outcomes.

> 'The first two aspects are closely related. By making the patient central to the audit process, the professions that need to be involved in the audit will automatically be identified. (There is however still a role for uni-professional audit, where professions can clearly identify their own singular contribution.)'[73]

66 Dr Walshe considered that after the introduction of clinical audit there was no longer a role for a medically orientated form of audit except in some situations:

> 'I think it depended on the specialty, the area and the quality issues that you were addressing, but I think most people would agree that most quality problems do not belong to an individual profession. When you start to examine why a particular problem or difficulty exists, it quickly rolls out, given the complexity of the process of care, into the territory of other professional groups. So clinical audit seemed much better fitted to dealing with the very multi-professional nature of most areas. Clearly there are some specialties who tend to work much less multi-professionally than others, and there was no purpose in having a multi-professional process if the issue simply … affected the anaesthetists. But the default, I think, was meant to be that these processes should be multi-professional, because most of the time that was what was needed.'[74]

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[71] *'Clinical Audit: Meeting and Improving Standards in Healthcare'*, DoH 1993

[72] Circulated under cover of EL(94)20, 28.2.94; HAA 0009 0026. The letter noted that the guidance was prepared by a working group of Regional Audit Co-ordinators and endorsed by COG

[73] *'The Evolution of Clinical Audit'*, DoH 1994c

[74] T62 p. 52–3 Dr Walshe

Changes in funding 1994/95

67 Funding for the national audit programme to 1994/95 was provided as follows:

Table 1: Audit funding allocations[1]

	Medical HCHS[2] (£m)	Primary care (£m)	Nursing/Therapy (£m)	Total (£m)
1989–91	28.0	5.0	–	33.0
1991–92	48.8	12.5	2.3	63.6
1992–93	42.1	12.5	7.2	61.8
1993–94	41.9	12.2	8.2	62.3
Totals	160.8	42.2	17.7	220.7

1. *'Clinical Audit: Meeting and Improving Standards in Healthcare'*, DoH, 1993
2. 'Hospital and Community Health Services'

NB. £3.2 million was provided in 1993/94 to 'pump prime' multi-professional clinical audit

68 On 23 April 1993 the NHSME issued EL(93)34 entitled '*Clinical audit in HCHS: allocation of funds 1993/94'*. This stated that:

> 'Funding for clinical audit from 1994/95 will be included in overall allocations to Regions. Regions will be expected to maintain and develop clinical audit and will be held accountable in this area; specific criteria on which performance will be measured after 1993/94 will be agreed at a later date.'[75]

Thus, the ring-fenced funding allocation for audit was to cease in 1994/95.[76]

69 In the following year, on 28 February 1994, the NHSME issued EL(94)20 entitled '*Clinical Audit: 1994/95 and beyond'*. This contained further advice about the changes in funding arrangements that were to take place in the coming year. It attached guidance upon the funding of audit through the contracting process that had been developed by a working group commissioned by COG. Whilst the advice might come too late for full implementation by many purchasers/providers in the current purchasing round, it was hoped it would assist in the future. The guidance noted that:

> 'From April 1994 funding for HCHS [Hospital and Community Health Services] clinical audit will be included in Regional Health Authorities (RHAs) recurrent funding on a resident population share basis. These monies will be the sum of monies previously set aside for medical and nursing and therapy audit with one major adjustment. Allocations to regions for medical audit purposes, previously calculated on a whole time consultant equivalent basis, will now be allocated on the basis of resident population.

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[75] UBHT 0028 0014; *'Clinical Audit in HCHS'*

[76] UBHT 0028 0018; *'Clinical Audit in HCHS'*

> 'The cessation of ring fencing allows funding to become recurrent, allowing longer term plans for audit to be developed at provider and DHA level. It also allows audit to address more adequately questions of healthcare needs and healthcare effectiveness and to become fully integrated in the mainstream business of provider units/trusts/primary care and health purchasing authorities.[77] The transition of funding should be undertaken in such a way as to enhance the early steps in the evolution from medical to clinical audit.'[78]

The guidance also noted that the recommended approach included:

> '… an agreed contract between the DHA and each service provider for clinical audit, specified in terms of facilities and including some form of indicative workload agreement.'[79]

The role and responsibilities of each group were also set out in the directive. RHAs were to be:

> '… accountable from 94/95 for the maintenance and development of clinical audit. The new NHSME Regional Offices will have a performance monitoring role for both purchasers and providers in the future.'[80]

DHAs and FHSAs were told that their plans:

> '… should indicate the purchasing authority's long term vision for audit and incorporate priorities which have been jointly agreed between purchaser and provider.'[81]

Units and trusts were to:

> '… develop appropriate structures and processes to achieve effective clinical audit.'[82]

70 Thus, in the financial year 1994/95 the funding responsibility for audit moved from RHAs to the purchasing DHAs. Funding for audit became part of the contract between the purchaser and the provider. Furthermore, funding for medical, nursing and therapy audit was no longer separately allocated by the DoH; instead one allocation for clinical audit was made. Figure 7 shows the organisation of clinical audit after April 1994:

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[77] This paper uses the terms DHA and FHSA but recognises the move towards unincorporated associations of DHAs and FHSAs in some regions which will undertake the functions described pending changes in legislation

[78] HAA 0009 0029; *'Clinical Audit; 1994/5 and beyond'*

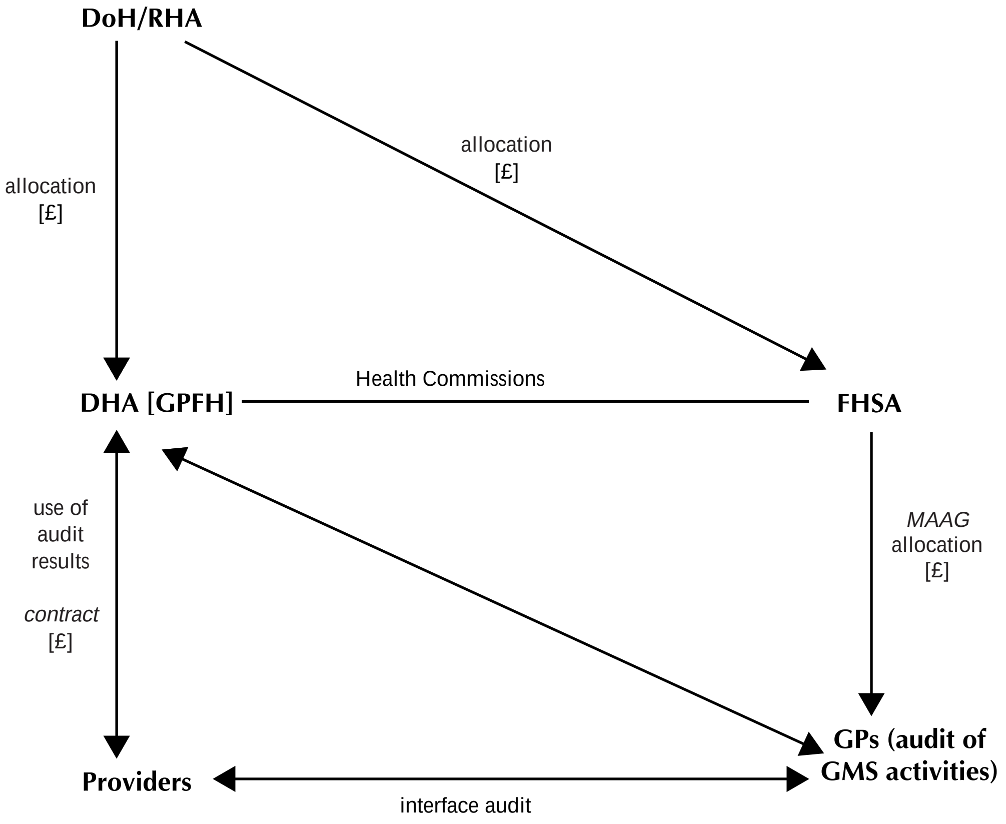
[79] HAA 0009 0030; *'Clinical Audit; 1994/5 and beyond'*

[80] HAA 0009 0031; *'Clinical Audit; 1994/5 and beyond'*

[81] HAA 0009 0032; *'Clinical Audit; 1994/5 and beyond'*

[82] HAA 0009 0033; *'Clinical Audit; 1994/5 and beyond'*

Figure 4: The organisation of clinical audit (after April 1994)1



Key

DHA	District Health Authority	GPs	General Practitioners
DoH	Department of Health	GPFH	General Practitioner Fund Holders
FHSA	Family Health Service Authority	MAAG	Medical Audit Advisory Groups
GMS	General Medical Services	RHA	Regional Health Authority

1. Reproduced with the kind permission of the author, Exworthy M. *'Purchasing Clinical Audit. A study in the South West Region'*, University of Southampton, July 1999

Clinical effectiveness

71 Towards the end of the period of the Inquiry's Terms of Reference, the focus of the Government's guidance shifted away from the organisation and monitoring of audit to considerations of effectiveness. An effective clinical audit programme was defined as one which involved balanced topic selection, employed adequate audit processes, secured implementation of audit results and was comprehensive (involving all aspects of healthcare).[83]

72 National policy guidance had shown an increasing emphasis on the improvement of clinical effectiveness since 1993, as shown in Figure 5:

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[83] INQ 0011 0013; *'NHS Executive: The New Health Authorities and the Clinical Audit Initiative: Outline of Planned Monitoring Arrangements'* (EL(95)103) Leeds: DoH NHS Executive 1995

Figure 5: National policy guidance on improving clinical effectiveness[84]

Dec 1993
EL(93)115. The first EL to make explicit reference to clinical effectiveness, it set out the range of initiatives in train to provide information on effectiveness, and recommended guidelines in seven specific clinical areas. Health authorities were asked to report on their progress in using these guidelines in contracting. [1]

July 1994
EL(94)55. Priorities and planning guidance for the NHS for 1995/96. Medium term priority G called on health authorities to '… Invest an increasing proportion of resources in interventions which are known to be effective … reduce investment in interventions shown to be less effective'.[2]

Sept 1994
EL(94)74. Provided an update on the sources of information on clinical effectiveness that were available, but did not ask health authorities and trusts to take specific action. [3]

June 1995
EL(95)68. Priorities and planning guidance for the NHS for 1996/7. Medium term priority C was to 'improve the cost effectiveness of services throughout the NHS, and thereby secure the greatest health gain from the resources available, through formulating decisions on the basis of appropriate evidence about clinical effectiveness'. It called for health authorities to show they had 'strategies to secure sustained and comprehensive improvements in clinical effectiveness'and significant shifts in investment on the basis of effectiveness.[4]

Dec 1995
EL(95)105. Provided a further update on the importance of clinical effectiveness and the growing range of sources of information. Attached a list of interventions being researched and said they should not be used in routine care at present.[5]

1. HAA 0164 0173 – 0182 Guidance EL(90)115
2. HAA 0164 0199 – 0221 Guidance EL(94)55
3. HAA 0169 0136 – 0154 Guidance EL(94)74
4. HAA 0164 0139 – 0144 Guidance EL(95)68
5. HAA 0164 0275 – 0280 Guidance EL(95)105

73 By 1996 audit programmes were no longer seen as the central mechanism for improving the quality of care, as they had been in 1989, but rather as a part of the broader work on improving clinical effectiveness.[85]

The setting of standards

74 Central to the concept of audit, as defined at para 5 above, was the idea that standards of clinical care should first be set; then performance assessed, and possible improvements in practice identified and implemented.

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[84] Reproduced with the kind permission of the authors Walshe K and Ham C, *'Acting on the evidence: progress in the NHS'*, Health Services Management Centre, Birmingham: The NHS Confederation, 1997

[85] INQ 0011 0013

75 Dr Winyard stated:

> 'In the middle and late 80s there was developing interest in more direct and locally based medical audit in which individuals and groups of clinicians would define the standards that they wish to achieve, compare their actual practice with those standards, and institute remedial action where the standards were not being achieved, re-auditing performance subsequently to ensure that the remedial actions had been successful. This process became known as the Audit Cycle and forms the basis of all subsequent medical and clinical audit. In the year before the publication of *"Working for Patients"*, the Department funded a number of the Medical Royal Colleges to develop medical audit projects on this basis. The then Chief Medical Officer also secured the endorsement of all College Presidents that such activity should be an integral part of routine clinical practice. However, at that stage medical audit was very much a minority activity pursued by enthusiasts.'[86]

Increasing pressure developed for doctors' clinical activity to be included in NHS initiatives concerning quality. For example, evidence emerged about unexplained variations in practice related to length of stay, hospital admission rates and variations in outcome. A number of arguments about hospital clinical competence were well publicised. There was an increase in the willingness of pressure groups to publicise information about substandard services.[87]

76 Professor Sir George Alberti, President Royal College of Physicians (RCP), pointed to the difficulty of measuring quality of care and outcome of care and said that comparative information evidencing national standards did not start to emerge until after 1990.[88]

77 Counsel to the Inquiry referred Sir Graham Hart, NHS Management Board Director of Operations from 1985 to 1989 and from March 1992 to 1997 Permanent Secretary at the DoH,[89] to the 1983 *'NHS Management Inquiry Report'* in the following exchange:

> 'Q. In the Griffiths report — we will just have a look at some of the general comments which he made … This comes from Griffiths, it is page 10 of what is acknowledged to be a short but effective report. In paragraph 2, under his general observations, he describes the NHS not having a profit motive but being enormously concerned with the control of expenditure: "Surprisingly, however, it still lacks a real continuous evaluation of its performance against criteria such as those set out above … Rarely are precise management objectives set. There is little measurement of health output. Clinical evaluation of particular practices is by no means common and economic evaluation of those practices extremely rare."

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[86] WIT 0331 0003 Dr Winyard, Medical Director of the NHS Executive and Deputy Chief Medical Officer from 1993 to 1998

[87] INQ 0011 0008; *'Medical and Clinical Audit in the NHS'*

[88] T9 p. 43 Professor Sir George Alberti

[89] WIT 0040 0001 Sir Graham Hart

> ‘Leaving aside the economic and leaving aside the question of output, the number of operations done, clinical evaluation of particular practices is by no means common.
>
> ‘In this paragraph as a whole, what Griffiths appears to be observing, and the implication is, complaining about, is that the NHS had no proper measurement of the quality of the care it was providing in general terms.
>
> ‘First of all, from your own perspective, was he probably right about that, at the time?’
>
> ‘A. Yes. I mean, I would say, I think, what he was saying was that there was no system, if you like. Some of these things happened, but they did not happen in an organised and systematic way. I think that is true. He was spot-on, there.’[90]

78 The opinion of Professor Sir Kenneth Calman, Chief Medical Officer (CMO) for England 1991–1998[91] on the issue was explored in the following exchange:

> ‘Q. … Sir Graham Hart … has told us that, throughout the period of particular concern to this Inquiry, there was no proper measurement of the quality of care which was available within the NHS, looking at the question of the delivery of care by hospitals.
>
> ‘Is that broadly your view?’
>
> ‘A. No, I do not think that would be my view, because for really a very long time, the outcome of the health care has been part of the responsibilities of individual doctors and indeed trusts and before that, hospital boards. It would be impossible to manage a system without knowing what the outcome was. That was done in a variety of different ways over the years, but I think in terms of the outcomes of healthcare, there are difficulties in measuring sometimes the outcome of health care. Mortality is a very relevant way to measure, but once you move into other areas like quality of life, for example, it becomes more difficult to measure, but in terms of the outcome of healthcare, 30-day mortality, wound infection rates have been recorded and reported for a very long time.’[92]

79 Sir Barry Jackson said that the:

> ‘… setting of the standards have created considerable problems in many areas, and in 1989/1991 those standards in most instances were not recognised; therefore to all intents and purposes, they did not exist.’[93]

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[90] T52 p. 34 Sir Graham Hart

[91] WIT 0336 0001 Professor Sir Kenneth Calman

[92] T66 p. 5 Professor Sir Kenneth Calman

[93] T28 p. 92 Sir Barry Jackson

80 Dr John Roylance, Chief Executive of UBHT 1991–1995, was asked about a paediatric cardiology report of March 1992, set out upon the MAC standard form. The 'audit' topic reviewed was paediatric cardiac surgical mortality for 1991. The document contained comparisons with previous years.[94] Dr Roylance gave evidence that he regarded this kind of exercise not as audit but as a review of recent outcomes.[95]

81 Looking at the same document, Sir Barry Jackson agreed with this emphasis upon the centrality of standard-setting:

> 'In the strict meaning of the term, I would agree with Dr Roylance, as I said earlier, because there is no standard set there with which to compare the mortality other than previous years, but there is no acceptance written there that the previous years' figures are the standard to which they were judging the current years' standard.'[96]

82 Sir Barry Jackson further gave evidence that if the standard used was in the form of national indicators of outcomes, drawn, for example, from the cardiothoracic surgeons' register, this was not audit in the formal sense, unless:

> '… it has been defined and agreed initially that that is the standard to which one is aspiring …'[97]

83 Dr Kieran Morgan stated:

> 'I believe Mr Jackson is correct when he has asserted that clinical audit is strictly concerned with setting standards and then auditing activity against those standards. However, there are many preliminaries to a clinical team reaching the stage where they can set standards in an authoritative way and then measure their activity correctly. It is part of the quality assurance concept for providers and commissioners of services to observe that this process is taking place.'[98]

84 Dr Morgan further commented on Dr Roylance's evidence:[99]

> 'Dr Roylance's view in his statement is that true clinical audit was happening rather infrequently and, of course, this depends on the definition of audit. The early definition spoke of systematic, critical appraisal of clinical activity and includes case note review by peers, etc. This kind of activity was not uncommon throughout the Trusts, including the UBHT. However, if one uses a more modern definition of clinical audit – the explicit setting of standards and vigorous measurement of activity to assess the extent to which its standards have been met – then Dr Roylance is right.'[100]

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[94] UBHT 0061 0161; paediatric cardiology report 1992

[95] T25 p. 42 Dr Roylance. He also made the point that audit as he understood it was not only about measuring morbidity and mortality rates for surgical procedures and the like, but also included, for example, the monitoring of the effectiveness of equipment

[96] T28 p. 91 Sir Barry Jackson

[97] T28 p. 91 Sir Barry Jackson

[98] WIT 0307 0018 Dr Morgan

[99] T25 p. 36 Dr Morgan

[100] WIT 0307 0014 Dr Morgan

The nature of audit

85 In 1990 the Standing Medical Advisory Committee (SMAC) wrote:[101]

> ‘The essential nature of medical audit is a frank discussion between doctors, on a regular basis and without fear of criticism, of the quality of care provided as judged against agreed standards … It should lead to action where practice has not matched the agreed standards so that the quality of medical care is improved. The principles of medical audit can be compared with those of feed back loop control in which the expected standard of care is defined in whatever terms are agreed to be appropriate, reality is compared with the defined standard and practice is changed in the light of this comparison. This is referred to as the “audit cycle”.
>
> ‘Although sharing similar objectives with medical audit in respect of medical education and training, the “grand round” or “interesting case” type of clinical meeting does not meet the requirements of medical audit. Medical audit is a systematic structured procedure with the express purpose of improving the quality of medical care. Wherever possible it should be quantified.
>
> ‘Medical care can be considered in terms of structure, process or outcome. Structure is concerned with the amount and type of resources available, for example the condition of buildings, the number of beds available and staffing levels. These are easy to measure but are not necessarily good indicators of the quality of care provided. Process relates to the amount and type of activity expended in the care of a patient. Unless resources are severely limited process has more significance than structure and in many circumstances it is the only measure available. The most relevant indicator of quality of care is outcome. … Examples of outcome measures include mortality, such as perinatal mortality and perioperative deaths, residual disability, relief of symptoms and patient satisfaction …’

Types of audit

86 In 1990, SMAC wrote:

> ‘There are two main approaches to the practice of medical audit. They are (i) retrospective internal audit within a specialty, hospital, general practice or district community in which records are used to review past events, and (ii) concurrent audit which is a continuous assessment of patient management. In both types of audit results are compared with agreed standards, which may be implicit or explicit, protocols or criteria. We feel that retrospective internal audit is likely to be the most appropriate approach for the introduction of medical audit but these approaches to audit are not mutually exclusive.

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[101] *‘The Quality of Care’*, report of the Standing Medical Advisory Committee, DoH, 1990, paras 4.1–4.3

> ‘Ideally the basis of audit should be outcome but in practice it is often not. Usually audit of “process” is carried out on the assumption that good process gives rise to good outcome. The subject of audit may include administrative processes (such as medical records, referral and discharge letters), clinical processes (use of drugs, investigations and procedures), clinical condition (classified by diagnostic category) or outcome (return to work, ambulation or unexpected death).
>
> ‘Medical audit is now increasingly recognised as a component of medical practice and therefore all doctors should be expected to take part. The main components in the process are:
>
> - ‘identification of subject matter to be assessed
> - ‘establishment of suitable criteria agreed locally against which to judge performance. Criteria should be based on the best published figures where available or on criteria provided by the Royal Colleges or other appropriate group if such criteria exist
> - ‘identification and analysis of any problems
> - ‘refining the above criteria in the light of experience
> - ‘formulation of recommendations and follow-up action
>
> ‘Follow-up action is an absolutely essential feature of medical audit without which the justification for medical audit is lost. Medical audit should lead to changes in the organisation and availability of services, clinical policy and clinical practice with consequent improvement in the quality of medical care as measured by appropriate indicators.’[102]

87 Further, as a national policy upon the introduction of audit developed, guides to the process of audit began to be published.[103]

88 The Quality of Practice Committee of the RCA noted:[104]

> ‘Almost any medical activity may be usefully subjected to audit. Included under this heading are:
>
> ‘Record keeping
>
> ‘Workload and staffing
>
> ‘Morbidity and mortality

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[102] *‘The Quality of Care’*, report of the Standing Medical Advisory Committee, DoH, 1990, paras 7.1–7.2.1

[103] See, e.g., Shaw C. *‘Medical Audit – a Handbook’*, London: King’s Fund, 1989

[104] WIT 0065 0596 Professor Strunin, May 1991

> ‘Provision and use of specific services (e.g. operating theatre time, ITU, pain services, etc.)
>
> ‘Education and training.’

89 Dr Baker, in his evidence, noted the debate between the UBHT and the District on the role of measures of process and of outcome. The UBHT wished to concentrate on measures of outcome.[105] He observed:

> ‘By the end of 1995 there was recognition within the medical literature and amongst professional and health service organisations that audit carried out productively to benefit patients was an exacting task, no less so than any other quantified approach to the measurement of quality or resolution of uncertainties. The National Centre for Clinical Audit published *“Good Practice in Clinical Audit”* in 1996 which summarised in particular the difficulties of audit of clinical outcome and encouraged audit of processes of care in relation to explicit criteria. Auditing clinical outcomes requires essentially that cause and effect are well understood in relation to the contributory components of healthcare and their actual relationship to variations in outcomes. In most instances of healthcare this relationship is not well understood.’[106]

The effectiveness of the national audit programme

90 The Inquiry received evidence upon the successes and failures of the Government’s introduction of medical and, subsequently, clinical audit.

91 The Inquiry was also referred[107] to a number of research studies that had been undertaken to assess the impact and effectiveness of the national audit programme.[108]

92 The case study of the implementation of audit in general medicine in four hospitals undertaken in 1991/92 on behalf of the King’s Fund[109] found that:

- ‘audit programmes were formulated by local clinicians on an ad hoc basis and managers had little role in shaping the audit process
- ‘overall attendance at audit meetings averaged two-thirds to three-quarters of all those designated as part of the general medicine audit group

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[105] See para 246

[106] WIT 0074 0040 Dr Baker

[107] Walshe K and Ham C. *‘Acting on the evidence: progress in the NHS’*, NHS Confederation, 1997

[108] These included: Buttery, Walshe, Coles, Bennett. *‘Evaluating Medical Audit: The development of audit – Findings of a national survey of healthcare provider units in England’*, CASPE Research, 1994; Morrell C, Harvey G, Kitson A. *‘The Reality of Practitioner-Based Quality Improvement: A Review of the Use of the Dynamic Standard Setting System in the NHS of the 1990s’*, National Institute for Nursing, 1995; Willmot, Foster, Walshe, Coles. *‘Evaluating Audit: A review of audit activity in the nursing and therapy professions – findings of a national survey’*, CASPE Research, 1995; Buttery, Walshe, et al. *‘Evaluating Audit: Provider Audit in England: A review of twenty-nine programmes*, CASPE Research, 1995; National Audit Office. *‘Clinical Audit in England’*, 7.12.95. Further evaluative studies were assessed in the Inquiry paper on *‘Medical and Clinical Audit in the NHS’*, INQ 0011 0016

[109] Kerrison S, Packwood T, Buxton M. *‘Medical Audit: Taking Stock*. London: King’s Fund, 1993; T62 p. 3 Dr Walshe

- ‘in audit meetings, doctors did not act as peers but rather as consultants and juniors in a hierarchical relationship
- ‘there was very little planning and the entire audit cycle was usually collapsed in a single meeting
- ‘there was often uncertainty about what should happen as a result of audit or who was responsible for taking any action
- ‘audit activities concentrated on the technical aspects of inpatient care
- ‘there was very little use of hospital-wide information technology systems and, in almost all cases, the sample sizes used were small
- ‘most criteria were developed locally with little reference to external guidelines’.

93 The Clinical Accountability Service Planning and Evaluation (CASPE)[110] study of the impact of the medical audit programme[111] surveyed provider units towards the end of 1993. It found:

- ‘Less than a third (29%) of audit programmes were directed by a clinical audit committee, many (31%) had some combination of medical and other audit committees, but 39% had solely a committee for medical audit. The membership of audit committees of all types was dominated by medical staff, particularly from acute specialties. Virtually all audit committees were chaired by a consultant.
- ‘The development of medical audit has been well resourced, almost wholly from centrally ringfenced funding … Most of the resource has been used to establish and staff audit departments to provide information systems and technology.
- ‘It is difficult to assess the effectiveness of resource usage from a survey such as this. Almost all providers had some form of audit department or audit staff. Many audit staff were educated to degree level and a substantial minority held some clinical professional qualification. There was considerable variation between provider units in the titles, grading, qualifications and apparent responsibilities of audit staff.
- ‘The audit process was well established in almost all healthcare provider units, with about 95% of specialties holding some form of audit meetings. However, it was unusual for other clinical professionals (apart from doctors) and for managers to be involved in these review meetings. While much audit activity

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[110] CASPE is an organisation that undertakes research into audit mechanisms for a variety of organisations, including the DoH; T62 p. 4 Dr Walshe

[111] Buttery, Walshe, Coles, Bennett. *‘Evaluating Medical Audit: The development of audit – Findings of a national survey of healthcare provider units in England’*, CASPE Research, 1994

revolved around traditional case note reviews and mortality and morbidity reviews, the survey found a growing use of more systematic and explicit approaches to quality measurement.

- 'Audit has caused or facilitated change in a wide range of areas, although the extent to which audit has resulted in meaningful change was not clear. In some instances it seems to have influenced clinical practice and management and encouraged the development of written guidelines and protocols. It has also affected the organisation and management of healthcare services, by stimulating organisational change and enabling some service developments and expansion. Moreover, audit was reported to have contributed to changing the culture of healthcare providers, developing a greater sense of clinical accountability, openness, interprofessional understanding and sensitivity to patients' needs.'[112]

The primary barriers to the development of audit, according to the study, may be summarised as follows:[113]

- 'The pressure of competing programmes of structural change and other priorities that made it difficult for clinicians and managers to allocate the time and effort needed to establish an effective audit programme.

- 'Weak links between the medical audit programme and the provider unit in which they were based. In many healthcare providers, medical audit was organisationally, functionally and philosophically quite separate from the service or business of the provider unit itself. This separation in part reflected the way in which the medical audit programme was directed and managed centrally. The emphasis placed on clinical leadership, the linking of audit to professional education, the deliberately limited role of managers, and the ring-fenced funding mechanism used to allocate resources all tended to foster a certain distance and detachment between audit programmes and provider clinical and managerial structures. However, many items of data from the survey seemed to indicate that this situation was changing, and that provider unit Boards and senior managers were becoming more involved in audit.

- 'Limited investment in the teaching and development of appropriate skills. The potential training needs of clinicians did not seem to have been fully recognised or addressed by many providers. In contrast, a substantial proportion of funds had been invested in information technology systems, with uncertain benefits. In fact, because patient records were far more important as a source of audit data, it might be argued that investment should have been directed to towards improving the reliability and accessibility of those records rather than towards new computer systems.

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[112] Buttery, Walshe, Coles, Bennett. *'Evaluating Medical Audit: The development of audit – Findings of a national survey of healthcare provider units in England'*, CASPE Research, 1994, p. 1–2

[113] Buttery, Walshe, Coles, Bennett. *'Evaluating Medical Audit: The development of audit – Findings of a national survey of healthcare provider units in England'*, CASPE Research, 1994, p. 101–7

- ‘The management of audit programmes was poor; many of those involved in establishing and directing audit programmes probably had little previous experience in programme or project management. As a result, the planning of audit programmes was inadequate. Monitoring and reporting arrangements were generally better, but were usually focused on monitoring the process of audit – such as meetings or data collection – rather than the impact of audit on the quality of care. “Moreover, when monitoring or reporting show that particular specialties or departments are not performing as they are expected or required to, most providers have few mechanisms for taking action or intervening to address these deficiencies in the audit process.”

- ‘The choice of audit topics was generally motivated by individuals’ interests or enthusiasms. By choosing the focus of audit projects more carefully, substantial improvements in the resulting yield of changes in practice might be achieved.

- ‘Much audit continued to tread familiar ground, using long-established approaches such as case-note review and mortality and morbidity review. “However, a substantial proportion of providers have begun to use more systematically organised and explicit methods – chiefly the auditing of care against explicit standards or criteria. Since many specialties were already holding regular meetings to review selected cases or to discuss complications in the past, it could be suggested that some relabelling of these existing activities as audit has taken place. It also appears from the survey, that there is now a substantial volume of new activity which is quite different from the more traditional meetings of the past.”’

94 The CASPE study also found that by the end of 1993, clinical, as opposed to medical, audit was not well established:

> ‘It seems that medical audit has become a part of the fabric of practice for almost all medical staff. It would be difficult to find many doctors in the HCHS [Hospital and Community Health Services] whose working life has not been touched in some way by audit over the last four years. While this does not mean that medical staff are all committed to audit, or involved in assessing the quality of their own practice, it is a considerable achievement. Among other clinical professions – such as nurses, therapists, pharmacists, scientists and others – participation is probably much lower. This is not necessarily because members of those professions have not wanted to be involved – they may well exhibit the same spectrum of opinion as medical staff; from enthusiasm to disinterest in audit. Rather, it is because the medical audit programme was led by doctors and was focused on securing the involvement of medical staff – the involvement of other professional groups has often not been welcomed or encouraged. Indeed, enabling these much larger and more numerous professional groups to take part in clinical audit in the future presents some real challenges.’[114]

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[114] Buttery, Walshe, Coles, Bennett. *‘Evaluating Medical Audit: The development of audit – Findings of a national survey of healthcare provider units in England’*, CASPE Research, 1994, p. 105

95 The study noted that: '… for the many clinicians who were participating in audit for the first time, the prospect of sharing potentially sensitive information with colleagues from other disciplines was not appealing, especially at first.'

96 '*Evaluating Audit: Provider Audit in England: A review of twenty-nine programmes'* [115] set out seven 'critical success factors' for clinical audit programmes. These were:

> '**Clinical Leadership** This seemed to be the most important single determinant of an audit programme's success.
>
> '**Vision, strategy, objectives and planning** Providers with successful audit programmes had an explicit vision of what the audit programme was there to do, which had been communicated to everyone and was kept to consistently.
>
> '**Audit staff and support** Successful audit programmes had good audit staff who were recognised as an expert resources for advice and support and valued as important members of the team.
>
> '**Structures and systems** Many audit programmes faltered because they lacked basic structures and systems, e.g. for managing the workload, prioritising, timetabling, monitoring and reporting.
>
> '**Training and education** Few providers had recognised the need for training in audit skills which, despite their professional background, many clinicians did not already possess.
>
> '**Understanding and involvement** As well as good communication, training and leadership, successful participation in audit programmes also depended on resources, time and appropriate incentives and sanctions.
>
> '**Organisational environment** Well-managed providers with good personal and professional relationships among staff and with purchasers were able to establish better audit programmes. Dysfunctional organisations with a history of internal and external conflict and dissent found establishing audit more difficult. Thus the organisations likely to be most in need of audit and quality improvement were probably the least able to make it happen.'

97 In oral evidence to the Inquiry, Dr Walshe criticised the professional guidance from the DoH on the earlier approach of medical audit:

> 'I think it would be true to say that the Department's proposals for medical audit in the NHS at that point in time could be criticised with hindsight as not being particularly directive, not if you like mandating a particular process, not requiring

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[115] Buttery, Walshe, Coles, Bennett. *'Evaluating Medical Audit: The development of audit – Findings of a national survey of healthcare provider units in England'*, CASPE Research, 1994

> the organisations to undertake audit in a particular way and for also perhaps not putting in place particularly strong incentives or requirements for people to engage in this process.'[116]

98 Professor Sir George Alberti told the Inquiry[117] that it appeared that the DoH's focus was more on throughput and waiting lists than on outcome or quality of care and that the lack of guidance given in the area of audit was a reflection of this:

> 'They were not interested in results; they were interested in as many people passing through the system as possible for as low a cost as possible … commercial considerations did seem to enter into it rather strongly.'[118]

99 Dr Ernest Armstrong, the Secretary of the British Medical Association (BMA) from 1993 to date, took the view that audit, be it medical or clinical, had not been successful thus far. He said that evidence showed:

> '… clinical audit has not actually delivered the results that early enthusiasts, and I include myself amongst those, might have expected. We still have a long way to go to change the culture to allow doctors to take part in an open and responsive way in a supportive managerial structure that will ensure that we are not in a punishment mode; that when we find things not as they should be, we do not punish them [*sic*]; we have to put them right.'[119]

100 He said that the evidence also showed that the BMA had encouraged doctors:

> '… to take part in medical audit, in clinical audit, to discuss with peers, not only with medical peers but actually recognising that this involves discussing with peers in the wider health care team, the outcomes of their work, in a situation where, of course, as you would expect, people who do not have a problem turn up and people who do have a problem do not, and do not take part.
>
> 'The question is, how does one encourage people to learn that by taking part they can only benefit, that this is not a threatening or censorious procedure, it is a learning exercise for everyone: one in which the aim is to generate support for something which is not as good or not at the standard that it was supposed to be and to generate a method of putting it right so that the next time you audit it, it is where it is supposed to be?
>
> 'That is very difficult and it is particularly difficult if doctors think that by talking frankly and fully and openly with their colleagues about just why they are not at the standard, the outside standard, however it is measured, that they ought to be, the result is going to be some kind of disciplinary action … and then one, I think,

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[116] T62 p. 6 Dr Walshe

[117] T9 p. 42 Professor Sir George Alberti

[118] T9 p. 42 Professor Sir George Alberti

[119] T20 p. 90–2 Dr Armstrong

> should be able to understand the reluctance of doctors to take part and the need for the BMA in doing as I said earlier this morning, its role of describing what leading edge looks like and where people ought to be in advocating doctors to move closer to the leading edge.'[120]

The constraints (if any) placed on confidentiality and/or the assurance of anonymity[121]

101 The implementation of audit in the late 1980s and early 1990s and, in particular, the development of information technology systems to support it created an accessible collection of data relating to the performance of individual clinicians. The perception was that this information was capable of misinterpretation and was potentially damaging both to individual clinicians and to public confidence in the healthcare system.[122]

102 Clinicians were concerned that data collected could be disclosed to patients or to patients' representatives in court actions for clinical negligence. They were also concerned about disclosure to non-professionals or managers, who might misuse it for 'whatever purpose'.[123]

103 In 1990, SMAC wrote:[124]

> 'Concern has been expressed that any record of the discussions of a medical audit meeting could be subject to legal subpoena. It is important that doctors should not feel that they are under a greater threat of litigation because of their involvement in medical audit. Confidentiality is essential. We recommend therefore that the documentation of audit meetings are [*sic*] provided in an appropriately anonymised form so that the general conclusions of the meeting and recommended action are recorded while the cases used in the discussion are not in any way identifiable.'

104 In May 1991, the Quality of Practice Committee of the Royal College of Anaesthetists advised:

> 'In common with other Colleges and Faculties, the College of Anaesthetists has considered the medico-legal consequences of audit. When data are collected centrally every attempt is made to render its [*sic*] origin unidentifiable and to destroy secondary records as soon as possible.

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[120] T20 p. 90–1 Dr Armstrong

[121] In this section the term 'confidentiality' refers to the basis on which information may be made available which identifies individuals caring for a patient; that is, confidentiality in the context of data that refers to individual clinicians and clinical teams. Confidentiality, in the sense of protecting patients from being identified, was not a contentious issue in the Inquiry although it was an exercise that needed to be carried out to enable the use of data for audit. Dr Walshe confirmed that anonymising patient details was not a bar 'to producing effective medical or clinical audit'

[122] WIT 0323 0031 Dr Thomas

[123] T62 p. 19 Dr Kieran Walshe; T14 p. 104 Professor Strunin

[124] *'The Quality of Care'*, report of the Standing Medical Advisory Committee, DoH, 1990, para 8.5.2, p. 20

> 'Nevertheless, it is the responsibility of all clinicians to keep records of events which involve patients, and it is an offence to alter or destroy such records. The College has been led to understand that all primary records (case notes, anaesthetic records, etc.) are ultimately accessible to patients' relatives and their legal representatives. Secondary data extracted from such records can be rendered anonymous and destroyed.
>
> 'This should not deter clinicians from their responsibilities for performing audit, although it should cause great care to be taken when an opinion is given and recorded as to the cause of any untoward event which may be discussed under the heading of morbidity and mortality.'[125]

105 Although in Dr Walshe's and Sir Barry Jackson's opinion concerns about confidentiality appeared to have waned over time,[126] these concerns were prevalent at the time of the formal introduction of audit in 1990 and, in the opinion of Mr Wisheart, until around 1995.[127]

106 Dr Thomas told the Inquiry that in response to these initial concerns, guidelines and protocols on confidentiality were contained in DoH Working Paper No 6[128] and the 1991 recommendations were contained in the RHA's protocol on confidentiality.[129]

107 Dr Roylance believed that this document, '*Confidentiality of Clinical Audit Information',* was in response

> '… to the concerns of many doctors about the potential access to audit information by managers and it was agreed in Bristol that any requests for audit information, whether from managers or from purchasers, should be channelled through the appropriate Clinical Director.'[130]

108 Dr Walshe told the Inquiry:

> '… Data about individual clinicians would stay within the team and the Clinical Director, so that the Clinical Director had a key role there. That did not mean that if that Clinical Director had concerns about a particular individual, they would not then be able to raise those concerns, and indeed, they would have a duty to raise those concerns with those higher up in the organisation. But it was our kind of pragmatic response to try and find a middle way between the concerns of clinicians and the effectiveness of having an effective audit process.'[131]

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[125] WIT 0065 0599 Professor Strunin

[126] T62 p. 20 Dr Walshe; T28 p. 96 Sir Barry Jackson

[127] T41 p. 86 Mr Wisheart

[128] UBHT 0052 0306; DoH Working Paper No 6

[129] WIT 0323 0027 Dr Thomas; T62 p. 121 Dr Thomas

[130] WIT 0108 0046 Dr Roylance

[131] T62 p. 25 Dr Walshe

International comparisons

109 Dr Walshe described the state of audit in the United States as at 1989. He said:

> '… the United States has had systems for the external accreditation or inspection of hospitals in some form or other since the 1980s, in fairly vigorous form certainly since the 1960s and it first mandated quality assurance, introduced federal legislation that required it effectively in I think 1973. So we would have found a very long history of this kind of work, and lots of efforts with different approaches to attempting to measure quality, different kinds of measures and different ways of structuring and doing this, so a great deal of experience … Every hospital we visited then and indeed now, would have had a well-developed internal quality assurance programme with staff, structures, processors and things like that in place. They would also have had programmes for risk management and utilisation review, looking at the use of resources, and then we would have also found a number of external programmes, payers for healthcare, examining the quality of healthcare provided by hospitals and healthcare providers. I think it would be right to say you would also have found far from a consensus about how useful that very substantial investment had been in bringing about quality improvement and in fact from the late 1980s, the US healthcare system began to move away from its traditional approaches to quality assurance and to embrace what is sometimes called "whole system" approaches to continuous quality improvement and TQM, and that movement in the US has continued.'[132]

110 Dr Walshe said that it would not necessarily be possible to implement the USA model in the UK. First, the system of quality assurance or audit within the USA was largely imposed externally or was required by regulatory systems, and secondly, there was a lack of consensus as to the benefits that had been produced by those approaches.[133]

111 The other difference noted by Dr Walshe was that, in the USA, audit had been required by federal legislation and by payers of healthcare. There were also cultural differences between the way that the US healthcare organisations had traditionally been run compared with British NHS trusts or healthcare organisations. Dr Walshe pointed to the

> '... big differences in the employment status of doctors and the degree of medical involvement in the management of those organisations, and big cultural differences that effect the transference of an organisational approach to quality improvement from their context to ours.'[134]

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[132] T62 p. 9–10 Dr Walshe

[133] T62 p. 10 Dr Walshe

[134] T62 p. 11 Dr Walshe

112 Dr Walshe was asked whether the legal position in the UK, whereby audit data does not attract public interest immunity or any other form of confidentiality within civil litigation, differed from the stance taken in other countries. He told the Inquiry that it did:

> 'In the United States, something like 47 or 48 of the states have legislation which gives some kind of qualified immunity or privilege to information that health care providers collect for quality assurance purposes. Not all states have that, but the great majority do. Some people pointed to that as an example and said clearly that is needed to allow audit or quality improvement to be established. That has to be seen in the light of levels of litigation for medical negligence which are an order of magnitude higher at least in the US, so a very different situation.
>
> 'Interestingly, more recently, I think I am right, Australia has introduced some legislation which gives some qualified privilege to information that providers there collect for the purposes of quality improvement.'[135]

He was further asked whether it was possible to assess whether the provision of such immunity made any difference to the effectiveness of the audit process, and replied:

> 'I do not think we can really answer that question. You could argue in practical terms. It clearly has not been necessary in Canada, it has not been necessary in other European countries and it does not seem to have been necessary here, but we cannot prove the counterfactual, had we had that legislation, things would be different today.'[136]

Nursing audit

The national context

113 In its written statement to the Inquiry, the Royal College of Nursing (RCN) stated:

> 'The RCN has a long history of supporting developments in the field of nursing quality and audit in the United Kingdom. A dedicated quality and audit unit, the Dynamic Quality Improvement Programme, has focused on developing work, including the following:
>
> - 'Developing a philosophy and framework for nursing quality evaluation
> - 'Developing systems for quality evaluation in healthcare
> - 'Developing specialist guidelines and standards
> - 'Undertaking research and development.'[137]

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[135] T62 p. 22 Dr Walshe

[136] T62 p. 22 Dr Walshe

[137] WIT 0042 0005; statement of the RCN, submitted by Christine Hancock (former General Secretary)

114 The RCN also provides support, and a forum, for nurses who have concerns about their practice and their profession. As its submission stated:

> 'The RCN provides support for nurses who wish to raise their concerns about the standards of nursing care and other professional issues. The RCN's structure to support nurses who raise concerns about professional practice and standards of care is through the local RCN Branches where concerns can be raised with local management and, if necessary, the Community Health Council and local Members of Parliament and local media. Nurses can also raise their concerns through Forums that can raise the issues at national conferences and also are able to lobby and influence nationally.'[138]

115 The RCN gave evidence to the effect that the nursing profession was progressive in its attitude to standards and audit. The RCN conducted research into these areas in the late 1980s:

> 'Drawing on the specialist knowledge of the membership groups within the RCN, an initial programme of work to develop national standards for particular specialty areas was undertaken during the late 1980s and early 1990s. This resulted in the production of standards for a whole range of specialist subjects, including paediatric nursing, school nursing, radiology nursing, cancer nursing, nursing in older people, and gynaecological nursing.
>
> 'The idea behind these types of specialist documents was that local practitioners could use them as a guide for developing standards within their own clinical area. More recently, however, the focus has moved towards developing evidence-based national guidelines for specific clinical topics, for example, the management of venous leg ulcers, the assessment of pain in children and the assessment and prevention of pressure ulcers. A shift from developing specialist standards of practice to more focused guidelines has been a response to the growing emphasis on evidence-based healthcare, and is aiming at ensuring that national guidance is based on the best available knowledge to promote quality improvement in practice.'[139]

116 The view of the RCN was that:

> 'Changes in managerial structures in the last decade may have had the unintended consequence of weakening the system for identification, monitoring and investigation of untoward incidents. Clinicians (both doctors and nurses) may be inclined to keep matters in their own hands and to resent enquiries by managers. This position may arise out of perceptions of managerial indifference, clinical

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[138] WIT 0042 0028 RCN (Christine Hancock)

[139] WIT 0042 0005 – 0006 RCN (Christine Hancock)

> freedom, unwillingness to admit problems, or even the reluctance to face the death of a patient.
>
> ‘ The organisational culture has a part to play in the reporting of untoward incidents. A combination of high stress levels, clinical inadequacies and punitive, authoritarian culture may provide a background in which not only do mistakes occur but energy is spent on damage limitation rather than open enquiry with a view to future prevention. The RCN has long argued for independent counselling to be provided for NHS staff.’[140]

The Dynamic Standard Setting System (DySSSy)

117 The Inquiry was given details of the work of the RCN in promoting the ‘Dynamic Standard Setting System’ (DySSSy). This was developed by the RCN to enable health-care practitioners to define quality of care locally. The DySSSy involves a group of practitioners, assisted by a trained facilitator, moving around a cycle of describing, measuring and taking action, within a philosophy of continuous improvement in care.[141] It was described as follows in the National Institute for Nursing Report No 124, 1995:

> ‘The Dynamic Standard Setting System depicts both a philosophy and a methodology for developing quality patient care. In terms of philosophy it makes explicit its definition of quality care and most importantly, identifies the organisational culture and values necessary for quality of care to improve and flourish.
>
> ‘The framework for local standard setting was first outlined in 1989 in a publication entitled *“A Framework for Quality”* (Kitson 1989), which outlined a method for setting standards, but located it very clearly within a framework for quality assurance in health care for an entire organisation. The framework also clearly stated the need for a collaborative approach to setting objectives, stressing the importance of interprofessional negotiation.
>
> ‘In 1990 the Dynamic Standard Setting System was launched as a formal workbook, based on the experience of three years of running workshops. It comprised an introductory text and accompanying overhead projector originals (RCN 1990). The workbook focused largely on the mechanics of the system of local standard setting, expounding the quality cycle in some detail. It also described the need for trained facilitators to enable groups of practitioners to move around the cycle, improving care to patients.
>
> ‘The principles underpinning DySSSy were that all activities had to be patient or client focussed. Every standard set should clearly state what level of excellence of

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[140] WIT 0042 0027 RCN (Christine Hancock)

[141] WIT 0042 0451; RCN (Christine Hancock), referring to: *‘The Reality of Practitioner-Based Quality Improvement: A Review of the Use of the Dynamic Standard Setting System in the NHS of the 1990s’,* National Institute for Nursing, Report No 124, 1995

> care a client could expect to receive, relating the standards to client experience rather than diagnostic label or issues of care management.
>
> ‘In addition, DySSSy located the responsibility for the setting, monitoring and improving of standards with practitioners directly involved in client care. Staff must own and control the process of quality improvement, and be fully involved. Finally, standards have to be achievable and all quality improvement activities must recognise the contribution of the entire clinical team.

‘The cycle of quality improvement

‘Improvement

> ‘The Dynamic Standard Setting System is based on a cycle of describing, measuring and taking action, resulting in the continuous improvement of care …
>
> ‘In the describing phase a group of practitioners are helped by a trained facilitator to select their topic for quality improvement, devise a standard statement which reflects the overall intention of the exercise, and identify the elements or criteria necessary for implementation. … These elements can relate to the resources required, the activities undertaken by staff and the anticipated results of the intervention in terms of patients’ experiences. Donabedian (1966) classified these as structure, process and outcome.
>
> ‘Once criteria have been identified, refined and organised, the standard statement is reviewed and edited if necessary. In order to measure practice against the standard, an audit form is then devised by the group from the structure, process and outcome criteria. … A sample is identified, together with data collection methods, a time frame for the collection of data and the individuals responsible ... Implementation and audit dates are then negotiated by the group in consultation with the wider team. …
>
> ‘The final phase of the cycle involves action planning. Data are summarised and brought back to the group to interpret the findings … and decide on what action (if any) is needed. Actions are prioritised and individuals given responsibility for seeing that plans are carried out in an agreed period of time and a date for re-audit negotiated. …
>
> ‘DySSSy shares many common characteristics with other methods for clinical audit and quality improvement. What distinguishes DySSSy from other systems is its unique combination of the following features:
>
> ‘(i) it is clinically as opposed to managerially led, though it must be supported by the organisation;

> ‘(ii)it is locally based, emphasising the full participation of practitioners in all three phases of the cycle;
>
> ‘(iii)it uses small group processes within the local quality improvement team to ensure commitment to developing practice;
>
> ‘(iv)there is a clearly identified facilitator role, guiding and supporting local groups; the facilitator role is undertaken by a skilled and trained member of the team;
>
> ‘(v) it involves the generation of explicit standards, with criteria for implementation developed for structure, process and outcome.’[142]

Comparing DySSSy and Medical Audit[143]

DySSSy	**Medical Audit**
Standards are broad statements of what is to be achieved.	Standards are targets or degrees of compliance.
Structure process and outcome criteria are identified for each standard statement.	Structure, process, outcome is used to classify the topic for audit.
Audit objective is defined after standard and criteria are identified.	Audit objective formulated from the identified topic.
Audit criteria are developed from criteria for the standard. Methods of data collection are developed from the audit criteria.	Methods for audit are chosen from the audit objective, criteria comprise a statement of what is to be measured.
Role of the group facilitator is made explicit.	Role of audit support staff is made explicit.
DySSSy is marketed as a problem-solving approach to quality improvement.	Medical audit is marketed as an educational tool.

118 The overall assessment of the use of DySSSy by the National Institute for Nursing’s Report was that:

> ‘Improvements in patient care were described in all the sites visited, with DySSSy appearing to act as a catalyst. Time to commit to local quality improvement projects was commonly raised as a difficulty…
>
> ‘The lack of information on audit contained within the original DySSSy information was raised as a problem in some places. The involvement of patients in DySSSy has varied, with all standards described as patient centred, although patients were rarely involved.

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[142] WIT 0042 0460 – 0464; RCN (Christine Hancock), referring to: *‘The Reality of Practitioner-Based Quality Improvement: A Review of the Use of the Dynamic Standard Setting System in the NHS of the 1990s’,* National Institute for Nursing, Report No 124, 1995

[143] WIT 0042 0465 Christine Hancock; *‘The Reality of Practitioner-Based Quality Improvement: A Review of the Use of the Dynamic Standard Setting System in the NHS of the 1990s’,* National Institute for Nursing, Report No 124, 1995

> ‘The data suggest that the personality, skills and attributes of the key facilitator are highly influential in the development of a practitioner-led quality programme …
>
> ‘The lack of training and education in principles and systems for quality improvement and skills in group work and facilitation was raised as a barrier to further development in many areas. The problems appeared to centre around funding for the training itself, and releasing staff from clinical duties. The importance of integrating quality and audit into basic and post-basic education was also highlighted.
>
> ‘Some of those interviewed felt that the biggest benefit of the purchaser-provider split was that quality issues had been introduced in areas where they had not previously featured. In addition, application for Trust status had helped some organisations draw existing initiatives together into a coherent strategy. This had given DySSSy and local quality improvement initiatives a much higher profile.
>
> ‘DySSSy appeared to have been most useful in developing patient care in areas where it had become integrated with other issues related to quality …
>
> ‘A fragmented approach to quality strategy persisted in a large proportion of sites visited. An integrated approach appeared to require not only clear leadership, but also the full commitment of the management team in establishing systems and structures to support the many initiatives.
>
> ‘DySSSy was being used successfully as a model for multi-professional clinical audit in a few of the sites visited. In other areas it appears that misunderstandings and tribal boundaries between professions persisted, hindering the development of genuinely multi-professional audit.
>
> ‘… whilst DySSSy continues to provide a useful framework for practitioner-led quality improvement, additional work is necessary to develop the model further for use with multi-professional teams. Mechanisms for involving service users in quality improvement also need continued work.
>
> ‘Time for quality improvement activities remains a major issue and needs addressing at all levels, by dissemination of innovation at a national level, by recognition of the resource implications at strategic level, and by good planning and prioritising of work locally.
>
> ‘In addition, it is recommended that to maximise the potential of practitioner-led quality improvement initiatives, they must be firmly integrated within the strategic work of the Trust or provider unit.’[144]

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[144] WIT 0042 0451 – 0452 Christine Hancock; *‘The Reality of Practitioner-Based Quality Improvement: A Review of the Use of the Dynamic Standard Setting System in the NHS of the 1990s’,* National Institute for Nursing, Report No 124, 1995

Evaluation of the nursing and therapy audit programmes

119 The Inquiry was referred by Mrs Jenkins of the RCN to *'A review of audit activity in the nursing and therapy professions: Findings of a national survey'*, a study conducted by CASPE in the second half of 1994 on behalf of the DoH.

120 The findings were as follows:

> 'The resources available for nursing and therapy audit were almost wholly obtained from centrally ringfenced monies, only 16% coming from other sources, much of that (7%) coming from provider units.
>
> 'Over 70% of the funds available were used to meet staff costs, with information technology using 10% of the resources. Training and dissemination accounted for very little expenditure and were considered to be under resourced. The management of resources seemed to have been effective in most cases …
>
> 'The audit activities surveyed were each led by a named individual. There was a diversity in profession and status of those leading these activities although most were led by directors at board level or by service managers …
>
> 'Whilst the majority of activities were led by nurses, when considered in proportion to the size of the profession, the distribution of leadership across professional groups was reasonably equitable. … Audit leadership was commonly only one aspect of these people's work with the majority spending less than ten hours per week on it, which in most cases was not funded by earmarked audit monies but was a cost borne by the provider unit. … This direct involvement of clinical staff in undertaking audit contrasts with the medical audit programme, where much data collection and analysis was undertaken by central support staff, and may have encouraged a greater integration of audit into routine clinical practice. Most of the audit activities within the nursing and therapy audit programme were multi-professional by nature, with about half involving four or more professions. Only 13% of activities were uniprofessional.
>
> 'The programme achieved a reasonably equitable distribution of activity across different types of provider units and, although not intended at the outset, also included the primary healthcare sector through the involvement of practice nurses in audit. The audit projects funded by the programme tended to look at specific areas in healthcare of particular concern to individual professionals. Not surprisingly, many of the projects focused on areas that had been suggested in national and regional documents. They tended to be selected either because they were of particular interest or concern to healthcare staff, or because there was known variation in clinical practice, they consumed a lot of resources or were considered to be of high risk to patients. Initiatives focused more on establishing the infrastructure for audit and included activities such as identification of audit topics, setting up an audit committee and facilitator role, awareness raising and dissemination as well as undertaking specific audits. The main aim of initiatives

> was recognised, by participants, as encouraging the establishment of audit throughout the unit. There was fairly widespread dissemination of information about activity, within and outside the host units. Written reports were distributed and nearly 70% of activities were reported at externally organised seminars or workshops. There were some difficulties in meeting all the aims set by the audit activities and finishing within set timescales. These were often due to the very limited resources available, but also to a lack of organisational and planning experience in audit.
>
> 'Eighty-three percent of audit activities funded through this programme were claimed to have brought about change. Audit initiatives were felt to have succeeded in raising the level of knowledge and awareness about audit and to have made some contribution to bringing about changes in clinical management and in the quality of communication with patients and other clinicians. It was thought, with rather greater frequency, that projects had also brought about change in these latter two areas and also in the quality of record keeping and patient documentation. However, very few (7% compared to 40%) felt that projects had brought about a change in knowledge or awareness across the organisation. The scale of resources available to audit activities appear to be important in determining its success. Small projects, for example those receiving less than £10,000, had less chance of success than larger activities.
>
> 'The nursing and therapy audit programme was established in order to encourage the development of a framework for audit for the nursing profession and professions allied to medicine within every provider unit. A high proportion of projects funded by the programme had succeeded in encouraging healthcare professionals to undertake further audit projects, but only 15% had led to the development of a more permanent infrastructure for audit within the provider unit. This was not surprising since, by their nature, projects tended to be finite and discrete in their objectives, unlike the wider ranging initiatives that were funded. Indeed, in contrast to projects, 80% of audit initiatives continued, either with or without financial support, after the initial period of funding expired, thus leaving an infrastructure in place to support continuing audit activity.'

The study concluded that:

> '… the nursing and therapy audit programme has been relatively successful in promoting the development of audit, particularly when the modest level of funding available to it is taken into account. It has resulted in a diverse range of both uniprofessional and multiprofessional audit activities, covering all aspects of healthcare; has succeeded in reaching many different professional groups; has resulted in changes in practice, service management and in culture and attitudes; and on the whole has had a lasting effect within provider units. Indeed, its achievements bear comparison with those of the much more generously funded medical audit programme.

> ‘Some problems were commonly encountered by those undertaking nursing and therapy audit activities. Problems encountered as a result of the low level of resources could have been addressed by host provider units if they had decided to commit additional resources to these activities, thus acknowledging that they were an important element of the provider’s business. This might have gone some way towards addressing another issue identified – that of a certain lack of commitment and enthusiasm for audit and its achievements, by those not directly involved in the activity.
>
> ‘Recommendations
>
> ‘Although many nurses and therapists have become involved in audit over the last four years, because of the size of the professions concerned there remain very many clinicians who have had little or no contact with audit activity. As a result, there is still a considerable need to generate awareness of audit, interest and enthusiasm. In order to achieve this, additional support and education is required to provide healthcare professionals with the skills they need to undertake audit, and to enable them to participate in audit activities. This education and support should ideally come from within existing provider audit departments, and should aim to demonstrate to healthcare professionals that audit has the capacity to improve the quality of the care they provide.’[145]

The role of the coroner

121 Thus far, evidence relating to the NHS has been set out. Other individuals and institutions are also concerned with deaths or critical incidents in hospital: for instance, the coroner, the registrar of deaths and the Home Office. The Health and Safety Executive also has a role, but principally as regards the health of healthcare workers and potential accidents to them or others within hospital. In this section we set out the principal evidence received relating to the coroner, the registrar of deaths and the Home Office, as possible monitors of health outcomes from outside the NHS.

The coroner

122 Coroners are required by Rule 54 of the Coroners Rules 1984[146] to maintain an indexed register of all deaths reported to them, with prescribed details.[147]

123 A number of witnesses commented to the Inquiry on whether the coroner’s court is an appropriate means of enabling audit or for identifying local or national trends in mortality.

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[145] WIT 0042 0252 – 0265 Mrs Jenkins

[146] 1984 SI No 552 (as amended by the Coroners (Amendment) Rules; 1985 SI No 1414)

[147] The form of the register appears at *‘Schedule 3, 1984 Rules’* and requires the following to be recorded: date on which the death is reported to the coroner, full name and address, age and sex of the deceased, cause of death, whether the case was disposed of, Pink Form A or Pink Form B or whether an inquest was held, and the verdict at inquest if any

124 Professor Roderick MacSween, the then President of the Royal College of Pathologists, stated that the coroner's court could act as a '… useful unofficial forum for audit …'[148] and that if certain patterns of death emerged in a particular hospital or at the hands of a particular clinician the coroner could comment upon these and draw them to the attention of the appropriate authorities.

125 Mr Robert Clifford, Head of the Coroners Section of the Animals, Bye-laws and Coroners' Unit of the Home Office, told the Inquiry that the system of inquests was designed to look at individual deaths and that there was no requirement on a coroner to look across a range of deaths in a way that would enable trends to be discerned. He identified a number of matters which made such spotting of trends difficult, including: the limited records of previous cases which the coroner is required to maintain; some cases would be dealt with not by the coroner but by a deputy or assistant deputy; there was no one with responsibility to maintain and analyse a database of all the information that came out of individual inquests; such information would in any event exclude deaths that had not been reported to the coroner; and each coroner's jurisdiction is limited to bodies lying within his district.[149]

126 Professor Jeremy Berry, Professor of Paediatric Pathology, stated:

> 'The statutory role of the Coroner is limited to determining the cause of death, and does not extend to monitoring the adequacy of surgical or other services. The pathologist may mention minor deficiencies in treatment in his or her report, but it is generally only major errors that might lead to an inquest (e.g. mis-matched blood transfusion, major equipment failure, or some surgical disaster). The Coroner's system is therefore best suited to recognising individual or repeated gross deviations from normal medical practice … It is not intended to carry out long term monitoring of individual specialised clinical services, which is the function of clinical audit.'[150]

127 The Inquiry heard from Professor Michael Green, Consultant Pathologist to the Home Office and Emeritus Professor of Forensic Pathology, University of Sheffield, that he was aware of only two episodes in the last ten years when the coroners' post-mortem examination system had identified a particular surgeon in a particular specialty within surgery as having a high mortality rate.[151]

128 The Coroners' Society memorandum, *'Coroners and the Investigation of Deaths',* prepared by Mr Michael Burgess, Honorary Secretary of the Coroners' Society of England and Wales and HM Coroner for Surrey, states that: 'The limited nature of the inquest may make it difficult to examine anything other than the circumstances of the single death before the coroner at that time'.[152]

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[148] WIT 0054 0033 Professor MacSween

[149] T42 p. 129–30 Mr Clifford

[150] WIT 0204 0005 – 0006 Professor Berry

[151] T42 p. 101 Professor Green

[152] WIT 0039 0027 Mr Burgess

Records kept by the Home Office

129 Under Section 28 of the Coroners Act 1988 the coroner is required to make an annual return to the Home Secretary giving prescribed details in relation to inquests.[153] The return requires coroners to state the number of verdicts recorded in relation to male and female deaths. It does not require, for example, the age of the deceased or place of death.

130 The Home Office publishes statistical bulletins based on the information contained in the returns, none of which relates to particular identifiable cases.[154]

131 The Inquiry heard from Mr Clifford that the Home Office requirement for statistics relating to the coroners' service was limited and was mainly related to information about case load and did not extend to the circumstances of individual deaths. The Home Office, according to Mr Clifford, does not seek nor receive detailed information regarding post mortems and inquests with a view to analysing, monitoring or acting on the data. It is not a function of the Home Office, Mr Clifford stated, to obtain and use such information beyond ensuring as far as possible that coroners are aware of and observe any requests they may receive to help collect data for other agencies. The Home Office has no involvement in national data in relation to paediatric cardiac surgery.[155]

132 Mr Clifford stated further that, whilst coroners may make reports in the interests of preventing the recurrence of fatalities, such reports are sent to the person or authority which may have power to take action and are not routinely sent or copied to the Home Office.[156]

133 Mr Clifford stated that, since 1993, the Home Office has sought information in coroners' annual returns regarding the length of time taken to complete certain key tasks.[157]

Reports sent to other organisations

134 Although the principle of the 'rider to the verdict' has been abolished,[158] Rule 43 of the Coroners Rules 1984 provides that a coroner who believes that action should be taken to prevent the recurrence of fatalities similar to that in respect of which the inquest is being held, may report the matter in writing to the person or authority who may have power to take such action.

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[153] A copy of the return *'Deaths Reported to Coroners'* was provided to the Inquiry by Mr Clifford at WIT 0043 0091 – 0094

[154] See, for example, Home Office Statistical Bulletin Issue 11/98, 23 April 1998 at WIT 0043 0095 – 0109 Mr Clifford

[155] WIT 0043 0003 Mr Clifford

[156] WIT 0043 0004 Mr Clifford

[157] WIT 0043 0004 Mr Clifford

[158] By the Coroners (Amendment) Rules 1980

135 In certain specified cases, not relevant to paediatric cardiac surgery, the coroner is obliged to report to the Secretary of State.[159]

'Unnatural death' and 'death by natural causes'

136 The extent to which the coroners' system may provide a useful forum for audit in part depends on the interpretation that individual coroners (and others) place on the terms 'unnatural death' and 'death by natural causes' as verdicts open to the coroner.

137 The Inquiry heard from Mr Donald Hawkins[160] that:

> 'During the period 1974 to 1991 I took the view that deaths following operations to correct medical conditions were deaths arising from natural causes and as such only referable to the coroner if the cause of death was unknown, or unknown without a hospital post mortem examination. However, I did require to be notified of deaths that actually occurred on the operating table. When such a death was so referred and the cause of death was known and was natural I dealt with the matter by way of Form A without a post mortem examination.'[161]

138 Mr Paul Forrest, Coroner for Avon who succeeded Mr Hawkins, stated:[162]

> 'You will be aware … that the switch[163] deaths reported to me from 1992 onwards were, following post mortem examination, recorded and registered as deaths from natural causes.'

139 The terms 'unnatural death' and 'death by natural causes', are not defined by statute even though provisions such as Regulation 41(1)(d) of the Registration of Births and Deaths Regulations 1987, and Section 8(1) of the Coroners Act 1988 use the term 'unnatural' in relation to the requirement to investigate a death further.

140 *R v Price* interpreted 'unnatural' as 'a reasonable suspicion that there may have been something peculiar about the death; that it may have been due to other causes than common illness'[164]. A commentator described it as a death which was 'wholly or in part caused, or accelerated, by any act, intervention or omission other than a properly executed measure intended to prolong life.'[165]

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[159] Where a coroner holds an inquest into the death of a person who is proved to have been killed on a railway or to have died in consequence of injuries received on a railway, he must provide details including the cause of death to the Secretary of State, Coroners Act 1988, s11(8). The coroner is required to send notice to the Secretary of State of any inquest into a death following an accident occurring within Greater London or the City of London where it is alleged that the accident was due to the nature or character of a road or road surface or a defect in the design or construction of a vehicle, Coroners Act 1988, s18(1)

[160] HM Coroner for Avon from April 1978 to April 1992

[161] WIT 0348 0002 Mr Hawkins

[162] WIT 0039 0017; letter to the Inquiry dated 31 March 1999

[163] See Chapter 3 for an explanation of this term

[164] *R v Price* (1884) 12 QBD 247

[165] 'Natural and unnatural deaths': Herbert H Pilling, *'Medicine, Science & the Law'*, April 1967

141 In *R v Poplar Coroner ex parte Thomas*[166] the deceased suffered an asthma attack which, had an ambulance arrived sooner, she had a real possibility of surviving. In the event she arrived some 40 minutes later at hospital and could not be revived. The Court of Appeal decided that asthma was a natural cause of death, and that the death was not made 'unnatural' by the late arrival of the ambulance.

142 *'Jervis on Coroners'*[167] suggests that the proper view in that case would have been that the deceased died of 'untreated' asthma, and that if the treatment given seriously departed from the norms for the time, it would be sensible to conclude that this was an 'unnatural' cause of death.

143 In *R v Birmingham Coroner ex parte Benton*[168] it was decided that where a patient was suffering from a potentially fatal condition and the medical intervention (even if wrong) merely failed to prevent the death, then the proper verdict was 'death from natural causes', as it was the underlying condition which had caused the death. If the patient was not suffering from a life-threatening condition but the treatment given for whatever reason caused the death, the proper verdict was accident or misadventure, unless there was a question of unlawful killing.[169]

144 The memorandum *'Coroners and the Investigation of Deaths'* describes the verdict of death by natural causes at Appendix C:

> 'A death is considered to have arisen from Natural Causes if the evidence shows that it is probable (that is, more likely than not) that the cause of death was the result of a naturally occurring disease process running its [full] course.
>
> 'The word "natural" should be given its "usual meaning".'[170]

145 The memorandum then refers to Leckey and Greer, *'Coroners' Law and Practice in Northern Ireland'*: 'It is the *underlying cause of death* rather than the terminal event which is the test as to whether the death is from unnatural causes and therefore properly referable to the Coroner'.[171]

146 In evidence Mr Burgess, in commenting on the decision-making process in respect of a death of someone with a life-threatening condition, who has died during or following surgery, told the Inquiry:

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[166] [1993] QB 610

[167] Sweet and Maxwell, 11th edition at paras 8–20, p. 137

[168] [1997] 8 Med LR 362

[169] With specific reference to death during or after surgery, the determining factor according to the case law, therefore, appears to be whether the deceased would have died from the medical condition in any event, regardless of whether the surgery accelerated the death, rather than the standard of care received, or whether the medical condition could have been survived with appropriate treatment

[170] WIT 0039 0031 Mr Burgess

[171] WIT 0030 0031 Mr Burgess (emphasis in original)

> ‘What he [the coroner] is trying to do is maybe simplify what is probably quite a complex and difficult situation: was the death hastened by or brought about by the surgery, or was it that the death arose regardless of the surgery? I think it is often a debate that can quite properly result in well-held beliefs which are totally opposite.’[172]

Records kept by the Registrar of Births, Marriages and Deaths, and the Office for National Statistics

147 The registrar for each sub-district[173] receives reports of all deaths occurring in his sub-district for entry into the register. As with the coroner, his records relate to deaths occurring within his jurisdiction. The registrars would not for example receive reports of deaths occurring following surgery at a hospital lying within his sub-district if the deaths occurred after discharge from the hospital, and in another sub-district.

148 The reports the registrar receives will be from various sources: either the medical practitioner who attended the deceased during the last illness[174] (the medical certificate), or from the coroner. As noted above, the report from the coroner to the registrar may be on Pink Form 100A where the cause of death will be that certified by the deceased’s doctor, or on Pink Form 100B where the cause of death will be that disclosed by the pathologist. After an inquest the coroner reports on Form 99,[175] providing the registrar with the particulars required to be registered: the date and place of death, name and surname, sex, date and place of birth and occupation and usual address of the deceased.

149 The registrar delivers certified quarterly returns of all entries in his register to the superintendent registrar who, four times a year, sends copies to the Registrar General.[176] The Registrar General’s office, the General Register Office, forms part of the Office for National Statistics[177] and is responsible for the central archive of all registrations of births, marriages and deaths that have occurred in England and Wales since 1 July 1837.

150 The Registrar General annually provides the Chancellor of the Exchequer with a general abstract of the entries for the preceding year, including the number of deaths, which is then laid before both Houses of Parliament.[178]

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[172] T43 p. 19 Mr Burgess

[173] England and Wales are divided into districts and sub-districts for the purposes of registration, by the Registration Service Act 1953, s5(1) as amended

[174] Births and Deaths Registration Act 1953 s22(1)

[175] Coroners Act 1988 s11(7)

[176] Births and Deaths Registration Act 1953 s27

[177] Formed on 1 April 1996 by the merger of the Central Statistical Office of the Chancellor of the Exchequer, and the Office for Population Censuses and Surveys

[178] Registration Service Act 1953 s19

The South West Region and audit

1988–1990 The Regional Hospital Medical Advisory Committee (RHMAC)

151 In 1988, the Regional Medical Advisory Committee (RHMAC) took the responsibility at regional level for promoting the introduction of medical audit.[179] It produced its first report in June 1989. The account set out in this section therefore deals first with the role of the Region in the introduction of audit, before addressing the topics of the District and the UBHT.

152 In January 1989, the Government's White Paper '*Working for Patients; Medical Audit Working Paper 6*'[180] expressed the desire that within two years all hospitals would participate in audit. Funding was announced for the development of medical audit in all healthcare providers, with funds to be distributed by the RHAs.

153 The *'Working Paper 6'* stated that arrangements to support medical audit would need to be made at regional level, through a professionally led 'Audit Advisory Committee'. It further stated that the committee's role was to:

> '… organise audit of the smaller specialties on a regional basis in order to facilitate peer review and to maintain the confidentiality of results.
>
> '… arrange for clinicians to undertake the external peer review of particular problem services in Districts.
>
> '… advise on and support the development of audit across the Region.
>
> 'While this committee will need to be supported and serviced by the RHA, it should be clearly seen as working on behalf of the District committees, enabling them to discharge their responsibility for ensuring that suitable comprehensive audit covers all services. Membership of the Regional committee will need to be determined locally to include a representative of each District committee, chosen to ensure that the main specialty interests are all covered. Whether the remit and membership of this committee should also cover the needs of primary care requires consideration.'[181]

154 The RHMAC was given responsibility for the centrally allocated funds and for reporting on progress to the DoH.

155 At this time it was the prevailing view amongst those seeking to introduce audit programmes that audit was essentially a professional educational activity and that the profession should lead its development. In his written evidence to the Inquiry, Mr David McCoy, Chairman of the RHMAC 1990–1994, stated:

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[179] UBHT 0068 0006; notes to the 1989 RHMAC guidelines

[180] HOME 0003 0124; *'Working for Patients; Medical Audit Working Paper 6'*

[181] HOME 0003 0133; ibid.

> 'Clinical Audit and its importance were recognised, but these were relatively early days and we were concerned with establishing the mechanism of audit. It was understood that the results would remain confidential.'[182]

He also stated:

> 'The picture of audit at its inception was resented by some, and completely clouded by uncertainty of patient confidentiality, and the legal situation, with the risk of action for defamation as the result of published results.'[183]

156 The RHMAC did not delegate the development of audit to a sub-committee as it regarded audit as central to its own professional advisory function. In June 1989, it issued regional guidelines entitled *'The Regional Approach to Medical Audit'*.[184]

157 The RHMAC's report stated that 'There is no need for a separate audit committee to be set up at regional level.'[185] It outlined the programme of work that had already been started. It spoke of the need for district audit committees to advise and implement medical audit procedures.[186] The report further stated that staff in each hospital or group of hospitals should formally agree to accept corporate responsibility for the quality of medical care and the general implementation of audit.[187]

158 The report accepted that audit was essentially a professional and educational activity and that the profession should lead its development. It stated that:

> 'Health authorities and managers are held responsible for the overall running of the hospital service, but they are not competent to make judgments on the technical quality of medical care. They must therefore entrust this function to the medical staff, with an agreed level of feedback and assurance that professional self-review does exist and is effective in improving patient care.'[188]

159 It further advised that:

> 'Clinicians should be provided with the resources required for medical audit. At least one session of any full time consultant's programme may be ascribed to education activities, including medical audit. This should be acknowledged in a formal allocation of sessional time … Current, accurate patient-based data should be available to doctors for medical audit in each specialty. These should include local, diagnostic, operation and mortality listings as well as national data, such as performance indicators for "avoidance of deaths".

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[182] WIT 0436 0002 Mr McCoy

[183] WIT 0436 0002 Mr McCoy

[184] UBHT 0068 0001; *'The Regional Approach to Medical Audit'*

[185] UBHT 0068 0004; *'The Regional Approach to Medical Audit'*

[186] UBHT 0068 0005; *'The Regional Approach to Medical Audit'*

[187] UBHT 0068 0006; *'The Regional Approach to Medical Audit'*

[188] UBHT 0068 0011; *'The Regional Approach to Medical Audit'*

> ‘Clerical and computer support should be available to doctors in order to minimise the investment of clinical time in medical audit.’[189]

160 The RHMAC’s programme included the appointment of two senior lecturers to the Bristol University Department of Public Health to assist the Committee: Dr Charles Shaw (clinical audit) and Dr D Pheby (clinical computing).[190] The Regional Medical Officer (RMO) was to set their objectives and to meet them regularly to review their progress.

161 Dr Shaw was appointed in January 1989 to a part-time post. Dr Shaw’s appointment was also as an advisor to the District Audit Committees, when these were set up. He was responsible on behalf of the RHMAC for preparing the annual audit reports to the DoH to account for how the central funds had been spent. These reports were approved by the RHMAC before submission.[191]

162 Dr Thomas Hargreaves, a member of the RHMAC from 1987 until January 1991,[192] stated in his written evidence to the Inquiry that:

> ‘… the key issues addressed at local level were: 1) Audit committees had been set up in each district 2) Reorganising support staff into groups supporting clinical unit 3) Introducing audit assistants 4) Training support staff to abstract and code clinical data 5) introducing the clinical workstation/medical data index 6) Improving library facilities.’[193]

163 Medical audit had already commenced prior to the 1989 White Paper. The structures and procedures being put in place were consistent with the directions later to be contained in HC(91)2, *‘Medical Audit in the Hospital and Community Health Services’.* Dr Shaw stated:

> ‘As in other regions at that time, local audit committees were consultant-led, predominantly medical, and with little direct management involvement. The philosophy was to encourage and support doctors to participate in increasingly systematic evaluation of their own work, to the benefit of patients and of their own professional development.’[194]

Dr Baker stated that, at this stage:

> ‘… The development of audit locally and nationally was slow in general, individual enthusiasts for audit stood out by exception e.g. radiologists, anaesthetists, surgeons. Funds were spent on audit assistants but co-ordination of the development of audit was difficult at all levels and output was limited. Preparation

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[189] UBHT 0068 0012; *‘The Regional Approach to Medical Audit’*

[190] WIT 0399 0002 Dr Alistair Mason, former Regional Medical Officer

[191] UBHT 0068 0006; *‘The Regional Approach to Medical Audit’*

[192] WIT 0434 0001 Dr Hargreaves

[193] WIT 0434 0003 Dr Hargreaves

[194] WIT 0437 0001 Dr Shaw

> for the purchaser/provider split and the establishment of NHS Trusts strained the task further.'[195]

Dr Baker told the Inquiry that one of the main obstacles standing in the way of audit

> '… was the feeling that audit was going to become some form of inspectorial management tool of professional practice. I think, in general, the medical profession, and possibly others, closed ranks to some extent to take ownership of this process to try and accept it as something which was educational and related to training and practice in that way, rather than a more general approach to quality assessment.'[196]

164 Dr Shaw stated that:

> 'The Regional Hospital Medical Advisory Committee assumed responsibility for medical audit in 1989, before it became a general requirement in the NHS. Before audit moved from "medical to clinical", committee structures and chairmen were established by the profession and they generally reported to medical staff committees; part of the transition [from medical to clinical audit] was to redesign structures to become accountable to trust boards, such as through the medical directors, and thus to chief executives.'[197]

165 Dr Marianne Pitman[198] saw the role of Region in the audit system as ensuring' … that there was an audit system which was appropriate to each specialty.' [199] She could not say who would select the topics to be audited, because some of the topics were agreed District-wide rather than Region-wide. She told the Inquiry: 'I was not totally involved with the auditing system; I just knew that we had some that were labelled "regional audits"and some which were labelled "hospital audits".' [200]

166 Miss Catherine Hawkins, Chief Executive of the SWRHA from 1984 to 1992, stated in her written evidence to the Inquiry that:

> 'The RHMAC produced the SWRHA first series of service strategic statements in November 1989. This covered 6 specialist services including cardiac services. This report was a strategic statement with input from a variety of cardiologists and cardiac surgeons Region wide. This committee did not identify problems at the BRI unit.
>
> 'Item 20 of that report recommends "that the Bristol Centre, while it is the only Unit in the South West[,] be fully utilised by the Districts in the Region and that the London Hospitals only be used to take excess demand". During 1986 the RMO

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[195] WIT 0074 0037 Dr Baker

[196] T36 p. 103 Dr Baker

[197] WIT 0437 0012 Dr Shaw

[198] T58 p. 4; Dr Pitman worked for the SWRHA throughout the period 1984–1995

[199] T58 p. 85 Dr Pitman

[200] T58 p. 85 Dr Pitman

> identified that basic statistics appeared to show less good outcomes from surgery at the BRI than other acute units.'[201]

167 Audit is addressed in the Cardiac Services section of the 1989 Service Strategic Statement where it says:

> '… There is a continuing need to monitor the outcome of established treatments.'[202]

168 In 1990 the RMO assigned a doctor on his staff to the task of promoting the processes of audit in the BRI as the first Acute Unit and then to follow through to all the other Acute Units.[203]

169 In September 1990 the RHMAC published a further document, *'Hospital Audit Update 1990'*[204] summarising the progress to that date.

170 After trust status was introduced in 1991, the BRI moved out of RHA supervision to become part of a trust, the UBHT, and as such was under direct DoH monitoring. According to Miss Hawkins, the residual role of Region in the financing and supervision of audit was from then on only on the basis of devolved responsibility from the DoH. Audit would apply equally to all the units in the geographical area, whether they were trusts or non-trusts. Accordingly, to avoid unnecessary complication and duplication of work, responsibility for audit with respect to the trusts was devolved on to the RHA. [205]

171 This meant that the responsibility of the Region to monitor the quality of services after 1991 changed:

> 'There was a shift of emphasis on monitoring which would move away from the providing of the service to the purchasing of the service, because we would be working through the purchasing DHAs, whereas the performance monitoring of the provider was the DHSS[206] if they were a Trust.'[207]

172 Nonetheless, according to Dr Morgan: 'Throughout the period 1991–1994, the Regional Health Authority maintained a relationship with NHS trusts quite independently of purchaser Health Authorities.'[208]

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[201] WIT 0091 0001 Miss Hawkins
[202] WIT 0091 0016 Miss Hawkins
[203] WIT 0091 0003 Miss Hawkins
[204] HAA 0036 011
[205] T56 p. 115–16 Miss Hawkins and WIT 0091 0005 Miss Hawkins
[206] Or DoH. In July 1988 the DHSS was split into two departments: the Department of Health and the Department of Social Security
[207] T56 p. 125 Miss Hawkins
[208] WIT 0307 0004 Dr Morgan

173 According to Dr Shaw:

> 'The initial clarity of the medical audit programme and its regional structure was reduced by the transition to multi-disciplinary clinical audit (from 1992), the growing independence of the new trusts, devolution of budgets to purchasers, the reduced role of the RHA, and thus the waning influence of the RHMAC.'[209]

The Bristol Clinical Audit Unit

174 The Bristol Clinical Audit Unit (BCAU) was established in late 1992. Dr Shaw summarised the function of the Unit as follows:

> 'The Clinical Audit Unit, on behalf of RHMAC, advised hospital and community units on the preparation of the centrally required annual audit reports, analysed these for compliance with criteria for funding, and included summaries in the composite report from SWRHA to the DoH. These reports, both local and regional, aimed to disseminate effective methods and practical lessons, as well as to account for past expenditure in order to release funding for the following year.'[210]

175 The BCAU was comprised of a director, Dr Shaw, and a manager, together with representatives from the Regional GP Audit Advisory Committee and the Local Hospital Audit Committees. The BCAU contributed discussion documents on methods and resources for audit; training programmes; and, for the smaller specialties, direct support for audit projects.[211] The BCAU tried to promote effective audit through training workshops and direct co-ordination of selected specialty projects. It convened a Region-wide meeting in 1992 of doctors and nurses in paediatrics, surgery and anaesthesia to discuss the recent report of the National Confidential Enquiry into Peri-operative Deaths (NCEPOD) relating to surgery on children. The NCEPOD report developed some general principles and audit measures, for example the availability of paediatric staff and accommodation, accessibility of specialised units and the extent of surgery on children without specialised training. It also showed the weakness of routine hospital data systems for regional monitoring of surgery.[212]

176 The funding and plan of work for the BCAU and for Dr Shaw was agreed annually with the RHMAC and the RMO. Progress and any deviations from the programme were reported to the monthly meetings of the RHMAC.

177 Dr Shaw stated in his written evidence to the Inquiry that:

> '… Late in 1992, RHMAC adopted the collective chairmen of local hospital audit committees (LHAC) as a regional subcommittee to advise on transition from medical to clinical audit. Also the research and development directorate began to take on the role of advising the RHA on the funding and organisation of audit, in

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[209] WIT 0437 0002 Dr Shaw

[210] WIT 0437 0003 Dr Shaw

[211] WIT 0437 0002 Dr Shaw

[212] WIT 0437 0002 Dr Shaw

place of the RMO and RHMAC, and increasing emphasis was put on local management of clinical audit.'[213]

178 In 1993, in preparation for the devolution of audit funding to purchasing authorities instead of directly from the RHA to the provider units, the Audit Unit drafted specifications for effective audit which were to become the basis of future three-way contracts between the Regional Health Authority, purchasers and providers.[214] Under the aegis of the RHMAC and with the agreement of the hospital audit chairman, the same principles guided a series of self-assessments and external validations by a Regional Audit Team. These assessments were aimed to assist the local development of audit, to assess local progress with respect to structure, process and outcome of audit, and to help define contract specifications for 1993/94 funding.[215]

179 The Regional Audit Team was set up to try to encourage the development of audit. Its purpose was to try to develop a source of expertise at Regional level, which would be available to the Districts '… so we were not all inventing the wheel simultaneously.'[216]

180 Up to and including March 1993, the reporting requirements for audit were as stipulated in HC(91)2.[217] The purpose of the report was to account for the funding provided and to report on the progress made. Dr Shaw was responsible, as advisor to the RHMAC, for collating District audit reports to an agreed timetable and structure, and compiling the regional annual report. This report was presented to the RHMAC for approval, and was then distributed to the DoH, the Regional General Manager (RGM) and to the DHA and Trust managers and clinicians within the Region.[218]

181 Dr Shaw wrote:[219] 'During 1993, the reorganisation of the health service (in terms of regional authority and the purchaser/provider split) and of audit shifted the mechanics and accountability. The 1993/94 regional annual report *"Meeting and improving standards of healthcare"* was the first to address "clinical" rather than "medical" audit and to follow the format defined in EL(93)34[220] and 59.'[221]

182 Dr Shaw reported that the final Regional annual report of 1993/94 made no reference to the involvement of or approval by the RHMAC, except that a copy was sent to the chairman of the Committee. But it did declare that it was produced on behalf of the SWRHA.[222]

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[213] WIT 0437 0002 Dr Shaw

[214] The draft contracts were included in the 1992/93 Regional Annual Report, for application in 1993/94; WIT 0437 0013 Dr Shaw

[215] WIT 0437 0002 Dr Shaw

[216] T25 p. 46–7 Dr Roylance

[217] HAA 0164 0023; circular HC(91)2

[218] WIT 0437 0012 Dr Shaw

[219] WIT 0437 0013 Dr Shaw

[220] HAA 0164 0434; circular EL(93)34

[221] HAA 0164 0164; circular EL(93)59

[222] WIT 0437 0013 Dr Shaw. The three-way contracts between the RHA, purchaser and provider, introduced in 1993/94, required the provider units' reports to be sent to the Regional Director of Research and Development, Professor S Frankel; Dr Shaw was not involved in producing the 1993/94 regional annual report

183 According to Dr Morgan: 'There was remarkably little contact between the activities of this [Bristol Clinical Audit]Unit and local District Health Authorities – the relationship appears to have been almost entirely directly with Trust audit mechanisms.'[223]

Effectiveness of the regional audit programme

184 Miss Hawkins was asked by Leading Counsel to the Inquiry whether she, at the level of the Region, had access to what she regarded as full data on the performance of cardiac surgery at the BRI in the period up to 1992–1993. She replied:

> 'Not to my knowledge. Up until the time audit was properly accepted by medical staff, data was not openly and willingly shared. It was particularly difficult around the time of contracting when they had what they called "commercial confidentialities". At regional level, it was extremely difficult to have very specific surgeon/data aligned to one individual. Normally, if data came up, it was in a block scenario so you did not know who was accountable quite for what, so you could have a surgical specialty with subspecialties.
>
> 'It is one of the reasons why – the government did have a push for audit and why we did designate an individual person from Region to actually begin to develop the audit processes within hospitals which would also give us access, as audits came forward, to make good comparisons across regions and on a national basis. But the collection of data was not as it is now.'[224]

185 A letter dated 3 June 1992 from the Deputy Regional Director of Finance concerning medical audit allocations for 1992–1993 stated: '… The fragmentation of funding arrangements and the consequent lack of clarity over the responsibilities of the regional medical audit advisor, local audit committees and the DHAs has led to some confusion.'[225]

186 Miss Hawkins told the Inquiry that this was a reflection of the situation of audit in the early 1990s:

> '… because funding was coming from a variety of sources and each unit either had no audit procedures in operation, or committees, and the one that did had different approaches and there was no common agreement at that stage on how audit should be conducted.'[226]

187 At this stage the medical staff themselves were supposed to be responsible for audit. Miss Hawkins agreed that due to the suspicion and sensitivity from the profession, the prevailing idea during the 1980s was that the most appropriate level from which initiatives on audit should come would be from the RHA. The RHMAC gained the

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[223] WIT 0307 0012 Dr Morgan

[224] T56 p. 14 Miss Hawkins

[225] UBHT 0026 0083; letter from the Deputy Regional Director of Finance to chief executives, 3 June 1992

[226] T56 p. 113 Miss Hawkins

confidence of the consultant staff, and they felt that under the auspices of the RHMAC they would not be made vulnerable.[227]

188 Also influential was the introduction of the audit promoter, Dr Shaw, to assist local units and consultants to develop the process.[228]

189 According to Dr Morgan, RHAs worked directly with the trusts to develop medical audit, allocate funds and monitor progress: 'There was then little contact between the South West Regional Health Authority and Bristol and District Health Authority about these initiatives.'[229]

190 From the financial year 1994/95, the funding arrangement changed and the funding which the Regions had formerly separately identified became part of the general allocation of funding to the DHAs. From then on the districts ensured that audit was part of the standards and processes which they monitored as part of their contracting arrangements, rather than being a matter separately supervised by the RHAs.[230]

191 In preparation for this shift in role, a Regional Working Group had been established in December 1993, chaired by Dr Baker. The Group reported in February 1994.[231]

Audit at district and unit level

Introduction

192 Between 1984 and April 1991, the administration and management of the BRI and the BRHSC were the responsibility of the B&WDHA. Thereafter, they became the responsibility of the UBHT. This chapter gives an account of the evidence charting the development of audit at district level until April 1991, and thereafter at the UBHT. It makes reference, from time to time, to cardiac services and, more specifically, to paediatric cardiac surgical services, while seeking to focus on the more general picture.

193 The systems and practice of the audit of paediatric cardiac surgery have to be seen in the context of systems, practice and policy relating to audit at the level of the unit, which is the subject of this part of the chapter, and, indeed, against the national and regional background which was set out earlier in the chapter.

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[227] T56 p. 113–14 Miss Hawkins

[228] T56 p. 114 Miss Hawkins

[229] WIT 0307 0007 Dr Morgan

[230] T36 p. 101–2 Dr Baker

[231] WIT 0074 0038 Dr Baker

1985–1988 The B&WDHA Performance Assessment Committee

194 In 1985 the B&WDHA formed the Performance Assessment Committee (PAC). The Inquiry was told that the PAC was made up of lay members of the B&WDHA.[232] It was not an audit committee but, by means of examining 'work-related figures', concerned itself mainly with the task of ensuring that the hospitals in the Area functioned as efficiently as possible.[233]

195 Dr Trevor Thomas, Chair of the Medical Audit Committee (MAC) 1991–1993, told the Inquiry that the PAC had, on occasion, been less than tactful in its treatment of information and medical staff. Subsequently, this had adversely affected the introduction of medical audit at Bristol in 1990.[234]

196 One of the functions of the PAC was to monitor the care of patients. To this end it received statistical information from a Medical Information Working Group (MIWG). The MIWG consisted of both clinicians and managers. It seems to have been a sub-group of the PAC and assisted it by interpreting technical and medical information. The Inquiry was told that it was formed following misinterpretations of information and consequent misunderstandings between the PAC and members of the medical staff of the United Bristol Hospitals.[235]

197 Most of the data considered by the MIWG and the PAC was of a general nature, relating principally to bed usage, operating theatre usage, patient throughput and bed occupancy.The PAC received figures such as how many patients each consultant saw and the numbers of operations performed. As regards mortality, the data related only to general mortality statistics.[236]

198 The MIWG was not considered to be a medical or clinical audit committee:

> 'The nature and paucity of the available data, and its relative age, coupled with the cumbersome way in which it had to be assessed, manipulated and reported, through a regional system known as "Centrelink" was not conducive to its being used for audit purposes. This was widely recognised.'[237]

199 In February 1986, B&WDHA agreed that its District Medical Officer (DMO) should 'continue to assess clinical performance in an extended but carefully selected number of specialties'.[238] The difficulties of such assessment were acknowledged in the

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[232] T62 p. 71 Dr Thomas

[233] T62 p. 70 Dr Thomas. He does not define in which sense 'efficiently' is used, but the context is that of workload

[234] T62 p. 68 Dr Thomas

[235] WIT 0323 0003 Dr Thomas

[236] WIT 0323 0003 Dr Thomas

[237] WIT 0377 0016 Mr Alan Carter, former Director of Information Technology and Assistant Director of Operations, UBHT

[238] WIT 0038 0022 Ms Charlwood, Chief Executive Avon Health Authority 1994 to present

Authority's *'Strategy for Neonatal Care 1986–1994'*, adopted in May 1986, which pointed out that:

> 'No separate routinely available information is recorded for the outcomes of neonatal care in relation to neonatal surgery both cardiac and non-cardiac.'[239]

200 In June 1986 the SWRHA required DHAs to provide performance indicators and key indicators. In the view of Pamela Charlwood:[240] '… none was narrow enough to isolate paediatric cardiac surgery and none was concerned with surgical outcomes.'[241]

201 In 1986, the PAC reviewed four of the services provided in Bristol. Paediatric cardiac services was not one of them.

202 Ms Charlwood also told the Inquiry that, in April 1987, the PAC decided that a sub-committee of itself, together with the District General Manager (DGM), should conduct Unit reviews in September or October each year.

203 Consequently, in September 1987, the PAC appointed a Review Group, which reviewed the Central Unit (including the BRI and BRHSC) in October 1987. This Review Group reported to B&WDHA in November 1987.[242] It did not identify paediatric cardiac surgery as an area of concern.

204 Ms Charlwood informed the Inquiry that in August 1988 the MIWG reported that a steering group had been set up under the Chairmanship of Dr Thomas to oversee implementation of 'Medisgrps', a clinical management information system. It was designed to take into account the severity of the patient's condition as it affected the actual outcome of care. It was hoped that it would be applied to data relating to adult cardiology and cardiac surgery. It appears that it was never developed beyond a pilot stage.

205 In September 1988 the MIWG considered cardiothoracic surgery. Ms Charlwood stated that the report '… stressed there were no comparative figures in the form of performance indicators but Mr Wisheart is minuted as having referred to the "national register of cardiac cases".'[243]

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[239] HAA 0128 0033; *'Strategy for Neonatal Care 1986–1994'*

[240] Current Chief Executive, Avon Health Authority (since 1994)

[241] WIT 0038 0022 – 0023 Ms Charlwood

[242] WIT 0038 0023 Ms Charlwood

[243] WIT 0038 0023 Ms Charlwood

206 In summarising developments during this period, Ms Charlwood stated:

> ‘By the end of 1988 the DHSS had announced an intention to place greater value on medical audit … Up to that point B&WDHA had
>
> ‘i) recognised the need to monitor performance in terms of outcomes for patients;
>
> ‘ii) acknowledged the impracticability of assessing all outcomes in all specialties;
>
> ‘iii) opted to monitor specific services each year;
>
> ‘iv) not seen or heard anything about paediatric cardiac surgery to warrant selecting it for scrutiny.’[244]

207 In October 1988 the PAC received the BRI/BRHSC 1987 *‘Paediatric Cardiology and Cardiac Surgery Annual Report on Paediatric Cardiology’*. Mortality rates were described as virtually identical to those obtained nationally as published in the UK Cardiac Surgical Register. The PAC’s minute (119/88) stated: ‘Members … noted that there were no national performance indicators’.[245]

The District Audit Committee

208 On 6 March 1989 in response to the audit plans set out in *‘Working for Patients’*,[246] the PAC asked the MIWG to consider establishing a Medical Audit Advisory Committee. The MIWG considered itself well placed to take the matter forward, and did so in the first instance.[247] The MIWG reported back on 24 April 1989 that its membership and terms of reference were an ideal starting point for an audit committee.[248]

209 Thus the MIWG evolved into the District Audit Committee (DAC). Its function was to oversee the development of a medical audit programme.[249]

210 Dr Thomas stated that:

> ‘The Medical Audit Committee was formed as a sub-committee of, and reported to, the Hospital Medical Committee (HMC). Its constitution was discussed by HMC in the autumn of 1990 and the committee met for the first time on 5 December 1990.[250] … The constitution was based on statements contained in the Working Paper 6 (Medical Audit) of the Government White Paper ‘Working for Patients’ … The main objective of the committee was to establish a formal audit function within

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[244] WIT 0038 0023 Ms Charlwood

[245] WIT 0038 0023 Ms Charlwood

[246] HAA 0165 0145; *‘Working for Patients’,* Department of Health, HMSO

[247] HAA 0141 0085; report of the PAC 6 March 1989

[248] HAA 0141 0078; report of the PAC 24 April 1989

[249] UBHT 0068 0001; ‘*The Regional Approach to Medical Audit*’, June 1989

[250] The constitution of the District Audit Committee: WIT 0323 0009 Dr Thomas

the UBHT.[251] It was formed at a time of great change when the United Bristol Hospitals were preparing their submission for trust status.'[252]

211 The terms of reference in the constitution of the DAC were:

'1. To promote Audit, mindful of national, Royal College and regional initiatives and guidelines.

'2. Facilitate the creation and working of audit groups within individual directorates or other groupings.

'3. Review the reports of the individual audit groups to ensure that effective Audit is being undertaken, within the limitations of suitable confidentiality of individual data.

'4. To notify the Steering Committee of the Hospital Medical Committee of any desirable or proposed changes in utilisation or practice.

'5. To advise local managers as to the adequacy or appropriateness of resources made available for the process of medical audit.

'6. To report annually to the Regional Audit Committee, within the limitations of suitable confidentiality of individual data.

'7. To draw the attention of medical staff to new audit initiatives and facilities that may from time to time occur.'[253]

The approach of the District to audit after April 1991

212 The role and responsibility of the District for audit altered after trust status was conferred on the UBHT and the purchaser-provider split began in 1991. DHAs no longer directly managed hospital units and so their role, necessarily, had to change. Circular HC(91)2,[254] issued in January 1991, required DHAs to ensure a system of medical audit was in place by 1 April 1991.

213 Once the trusts were established, the districts' involvement in audit was through the mechanism of service agreement contracts between DHAs and trusts, and was therefore indirect. These agreements set out audit requirements, and provided that audit information was to be reported to a representative of the purchaser, often the Director of Public Health Medicine.[255]

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[251] The Trust was due to be formed with effect from 1 April 1991

[252] WIT 0323 0004 Dr Thomas

[253] WIT 0323 0009 – 0010 Dr Thomas

[254] HAA 0164 0023; circular HC (91)2

[255] WIT 0108 0046 Dr Roylance

214 Each trust put its own arrangements for audit in place.[256] Thus, the DAC evolved into the Medical Audit Committee (MAC) of the UBHT,[257] and no further audit committee was set up within the District in 1991.

215 The B&DHA's approach to audit through the 'contracting' mechanism was formally agreed on the advice of its Director of Public Health, the lead officer for that area of work.[258] Dr Kieran Morgan, Director of Public Health at Avon Health Authority (Avon HA), stated: 'Immediately after the formal establishment of Bristol and District Health Authority,[259] it began developing approaches to improving clinical quality.'[260]

216 From 1992 to 1995 the B&DHA's approach was to have a quality specification indicating the District's approach to quality which was common to all services, and a separate specification as to the service to be provided for each speciality. The latter specified if there were any additional monitoring requirements for the given year.[261]

217 The B&DHA's specification regarding quality was linked to outcomes in the form of enhanced health, but the guidelines for contracting continued: 'We can also recognise that some measures which on the surface relate to process, rather than outcome, can themselves influence outcome. User involvement is an example of this.'[262]

218 The B&DHA did not have the capacity to monitor all aspects of service quality itself and therefore relied on each trust to report on selected aspects of service delivery according to a quality monitoring schedule which formed part of the service agreement each year.[263]

219 A Medical Audit and Clinical Standards and Outcome Measurement (MACSOM) Working Group was established by the B&DHA in 1993, under the chairmanship of Dr R Kammerling, a public health physician. According to Dr Baker: 'The Committee sought to develop formal relationships with Medical Directors and Chairs of Trusts' Audit Committees for the contracting and funding of audit.'[264]

220 The aim was to agree not only firm contracting arrangements and sound audit processes, but also a limited number of areas for audit which would be recognised as of mutual concern and the findings of which would be supplied to the purchaser. Both process and outcome indicators of clinical quality were regarded by the District as relevant, but Dr Baker stated: 'Dr Morgan advised that UBHT were adamant that they

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[256] T36 p. 100 Dr Baker

[257] See below, para 302

[258] WIT 0159 0038 Ms Evans

[259] In October 1991, in succession to the B&WDHA

[260] WIT 0307 0005 Dr Morgan

[261] WIT 0159 0027 Ms Evans. See, for example, the list of incorporated Schedules in the B&DHA's 1993/94 Service Agreement, WIT 0159 0047 Ms Evans

[262] HAA 0156 0142

[263] WIT 0159 0027 Ms Evans

[264] WIT 0074 0038 Dr Baker

did not wish to generate and stick to clinical process standards and would wish to concentrate on outcome measures only.'[265]

221 In March 1995 Dr R Kammerling wrote a strategy for the Avon HA[266] on the further development of clinical audit. It contained a framework for assessing the development of clinical audit and was accompanied by Schedules of Agreed Audit Topics, agreed with the trusts. At that time, the Schedule agreed with the UBHT did not require an audit of paediatric cardiac services.[267]

The control of audit through the 'contracting' process

222 The minutes of a meeting of the B&WDHA on 16 July 1990 record that: 'Mr Dean Hart confirmed the Hospital Medical Committee's advice that only medically qualified personnel could negotiate, agree and implement contracts.'[268] Clinical directors, rather than general managers, were thus involved in the negotiation of contracts between the Trust and purchasing District.

223 1991–1992 was the first year in which 'contracts' or service agreements between purchasers and providers came into use nationally. The first contract between the newly formed UBHT and the District contained the provision that:

> 'The Providers will have Quality Assurance systems which include elements of quality control, identification of service deficiencies, and mechanisms for correcting and reviewing problems.'[269]

224 The contract also included performance monitoring requirements[270] and provisions relating to audit within the individual contract for each specialty. The contract for cardiac surgical services had separate sections on medical audit, nursing audit and paramedical/support services audit.

225 Medical audit was to:

> '… include audit of outcome, the medical process and the management process … the Cardiac Surgery Unit will set up an audit group to meet regularly and to provide the Bristol & Weston Health Authority with sufficient information for it to ensure that adequate audit is taking place.'[271]

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[265] WIT 0074 0038 Dr Baker

[266] The Avon Health Authority, recently formed

[267] WIT 0074 0039 Dr Baker. Arrangements for a multidisciplinary audit of paediatric cardiac services were subsequently made later in 1995, after the service had received adverse attention and publicity. Results for open and closed surgical procedures from May 1995–January 1996, undertaken by Mr Pawade, were received by Dr Baker, and agreed as a baseline of satisfactory activity

[268] UBHT 0249 0087; minutes of meeting of the B&WDHA 16 July 1990

[269] HAA 0011 0248; service agreement

[270] WIT 0159 0027 Ms Evans

[271] HAA 0010 0094; service agreement

226 In particular, the audit of outcomes was to include measures of 30-day mortality, one-year mortality and one-year symptomatic state. Ms Evans, the Contracts Manager of B&DHA from 1991–1995, expressed the view that those standards had most probably been discussed and agreed with the clinicians although she thought they were regarded as aspirational rather than actual standards to be attained.[272]

227 Before committing the Directorate to the service agreement, Mr Wisheart (as the surgeon who took the leading role on the Working Party which developed the service specification) wrote to Dr Roylance. His letter, of 13 March 1991, contains the following:

> ‘I have been asked to sign this document as the basis for the contract for provision of Cardiac Surgery Services for the year beginning 1st April 1991. As I participated in the discussion which led to the production of this document I am of course in agreement with what it is aiming to do. Lest my signature at the end of this document should be construed as my agreement to the contract for which I am responsible and accountable I must state the following reservations;
>
> ‘1. This service agreement contains no indication of the volume of work to be undertaken or agreed cost and payments …
>
> ‘3. We have agreed that the monitoring and reporting activities reported in Paragraph 18 to 21 should be provided. No resource or provision has been made to do this which may make it difficult or impossible to collect and report all of this data for the coming year.
>
> ‘4. Specific reservations … Paragraphs 15, 16 and 17 – the audit achievement [*sic*] are being established but may not necessarily operate fully from 1st April 1991.’[273]

228 Mr Wisheart gave his view of the concluded contract:

> ‘The early service agreements set out that quality measures, we will say of the management type, and a whole range of them, would be measured, and they were monitored and shared I think on a quarterly basis … Secondly, there was a requirement that audit, that is, medical clinical audit, would be carried out … I think initially the agreement was that they would be assured that it had been carried out, because that was generally the framework within which audit was carried out by clinicians and it was reported to the managers or the Board and they were assured that it had been carried out, rather than providing them with all the detailed information … The third element is the element of the additional agreed topics of audit. That agreement included, of course, the exchange of information because it was actually a collaborative exercise, in essence. So there was full and free exchange of information within that agreed topic.’[274]

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[272] T31 p. 36 Ms Evans

[273] HAA 0011 0254 – 0255; letter from Mr Wisheart to Dr Roylance dated 13 March 1991

[274] T41 p. 99–100 Mr Wisheart

229 The view of the District in relation to the same contract was given by Dr Baker:

> '… Initially, the first specification for contract in 1991/92 did carry a requirement for various aspects of the product of audit, including 30-day post-operative mortality. It was unspecified, but I think it was linked to other matters which suggested that we were thinking about adult activity. Then I think subsequently both in terms of our own reasoning and with advice that we received from others, we realised we had been over-ambitious in what we were asking for in that first contract. Subsequently, those aspects of quality were rephrased in various ways and moved in general terms more to a requirement for audit to be taking place rather than having the expectation that we could be provided with precise information on different aspects.'[275]

230 Dr Baker went on to say that subsequent contracts contained more general requirements that aimed to ensure that a suitable process of audit took place, rather than requiring specific indicators to be provided.[276]

231 The first contract provided that figures relating to outcomes in cardiac surgery should be provided to the DHA. They were to be provided directly to the purchaser, and were not passed through, nor did copies have to be sent to, the MAC. Dr Thomas explained that this was:

> '… because contracts were perceived as following a different route from audit and a sort of schism between the two was quite clear. In the Trust's mind and in I think the Audit Committee's mind as well, the contract negotiations would proceed and would only involve the Audit Committee if the Trust asked the Audit Committee to be a conduit for the passage of information from the directorate to the purchaser'.[277]
>
> 'At that time [1991] there was a clear undertaking being given by cardiac surgery to the purchaser that they would provide, to the purchaser direct, figures of mortality. As far as the Audit Committee were concerned, those figures were passed and we were not given any information that they were not passed. They did not go through the Audit Committee, much to our regret, because we believed that that should be a function of an Audit Committee. We were defeated on this matter by both the purchaser, by the directorate, by the management and so on and so forth.'[278]

232 A quality monitoring schedule having been introduced as part of the service agreement for each year, the 1992/93 B&DHA service agreement contained a 'Quality of Service' Schedule. A statement of 'Key quality objectives' was set out. Rights conferred by the *'Patient's Charter'* were noted and it was stated that providers were

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[275] T36 p. 109 Dr Baker

[276] T36 p. 110 Dr Baker

[277] T62 p. 140 Dr Thomas

[278] T62 p. 79 Dr Thomas

expected to meet patients' rights. Monitoring arrangements were set out. The obligations in the agreement concerning 'professional audit' were as follows:

> 'All Provider Units are required to develop medical/clinical audit programmes whose broad aims are to clarify and improve standards of patient care. These programmes should link with the Provider's overall approach to quality. Bristol & District Health Authority recognises that general features of professional audit will mean that:
>
> - 'Some audit activities will be highly confidential and will be confined to a small group of people. Others will operate under the general levels of confidentiality required by the NHS.
> - 'Some audit activities are best conducted on a multi-disciplinary basis.'

233 There then followed three specific topics for the provider units: hospital-acquired infections; unplanned re-admissions to hospital within four weeks; and pressure sores.[279] A report on audit programmes for medical nursing and Professions Allied to Medicine (PAMs) was required by the end of the year.[280] The agreement also contained a provision to hold a meeting during 1992/93 to review clinical audit.

234 The 1993/94 agreement recognised that there had not been just one meeting during 1992/93 to review audit, but a series of such meetings:

> 'During 1992/93 a series of meetings were held with Clinical Directors and Executives in each Trust to discuss progress with Clinical Audit. Bristol & District Health Authority intend to build on this constructive dialogue to develop our approach to clinical quality.'[281]

235 The agreement went on to state, under the heading 'Professional Audit,' (in recognition of the transition from medical to clinical audit):

> 'Bristol & District Health Authority acknowledge that Clinical Audit is primarily an educational process and must remain under professional control to achieve this goal. The clinical aspects of care are, however, no longer regarded as solely the province of clinicians and the need to develop clinical quality monitoring must be recognised.
>
> 'To ensure that this process has a measurable impact on patient care, it must expand beyond the medical profession to integrate work already taking place within the nursing and the paramedical professions.'[282]

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[279] HAA 0156 0152; service agreement

[280] HAA 0156 0179; service agreement

[281] HAA 0156 0331; service agreement

[282] HAA 0156 0340; service agreement

236 To ensure that audit was taking place, the agreement provided that clinical, nursing and paramedical audit reports were to be provided by trusts to the B&DHA in April 1994.[283]

237 This followed discussions which had taken place with trusts, as a result of which, Dr Morgan stated, the B&DHA had published its own set of principles in *'Medical Audit, Clinical Standards and Outcome Measurement'*[284] and agreed a programme[285] for monitoring clinical quality for 1993/94 onwards. He noted: '… At this time, the principle of [the] Health Authority being able to nominate certain priorities for audit was established for the first time alongside a requirement that each Trust provides a report on its full clinical audit programme on an annual basis.'[286]

238 In the 1994/95 contract, the section on clinical audit was far more detailed than that in previous years. It outlined the aims of audit and the role of the B&DHA, which included:

> '(a) to assure itself that clinical audit is being undertaken
>
> '(b) to facilitate the integration of audit into the routine monitoring process by encouraging audit on topics where it has a specific interest.'[287]

Further:

> 'B&DHA will not attempt to impose a model of audit or define the audit programme. It will, however, look for evidence of well supported audit activity of a high quality.'[288]

239 The annual audit report on the Trust was to be provided to the purchasers.[289]

240 As part of the 1994/95 agreement, the District agreed a Schedule for audit with the UBHT, which identified certain activities that were to be the subject of audit. Some of those activities related to adult cardiac services.

241 From the outset, the contracts with the B&DHA envisaged that clinical directors might seek the advice of the MAC if requested by purchasers to provide information about clinical activity. However, in practice, Dr Thomas told the Inquiry that he could not recall ever receiving requests for information from purchasers:

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[283] HAA 0156 0341; service agreement

[284] UBHT 0028 0155; *'Medical Audit, Clinical Standards and Outcome Measurement'*

[285] One topic was hospital mortality following operations for coronary artery bypass grafting

[286] WIT 0307 0005 – 0006 Dr Morgan

[287] HAA 0156 0429; service agreement

[288] HAA 0156 0430; service agreement

[289] HAA 0156 0430; service agreement. Evidence of the circulation of the UBHT's annual audit reports is to be found at paras 314–17, 364, 378 below onwards

> '… I am casting back in my memory to see whether I can recall any particular figures that came through the Audit Committee and the nearest example I can come to you with is that in, I think, early 1992, our general practitioner representative, Dr Whitfield, came to a meeting and said he felt that the Audit Committee should have a more proactive role.'[290]

242 Dr Black also stated that he could not recall any specific requests from the purchasers to audit any particular aspect of the UBHT's activity during his tenure as a member of the Committee.[291]

243 The contract mechanism thus provided for returns to be made to the B&DHA. The DHA Contracts Manager would receive the returns from the UBHT and either analyse them, or pass them on to colleagues, and then submit an overall comment to the Director in the DHA responsible for monitoring quality.[292]

244 The contractual regime created some difficulties for the provider trust. Ms Evans said that: 'One of the issues was that different purchasers would want to make different quality requirements of the same Trust, and one can imagine that with a Trust like UBHT with 43 purchasers, that would have been difficult.'[293]

245 By 1994/95, she reported, this was a general concern across RHAs throughout the country.[294]

Monitoring and review of performance by the District

246 Ms Evans said that the process within the DHA for dealing with issues relating to monitoring performance and quality 'varied according to the nature of the issue'.[295]

247 In the interim period between the formation of the UBHT in April 1991, and the formation of the Bristol and District Health Authority in October 1991, Dr Baker, then the DMO of the B&WDHA, engaged in discussions with clinicians including local cardiologists and cardiac surgeons, concerning the assessment of trends and attempts to develop outcome measures for adult cardiac surgery.[296]

248 In June 1991 he wrote to members of B&WDHA's Department of Public Health Medicine seeking ideas for items on audit for discussion with clinicians for the 1992/93 contracts. He stated that he had in mind the investigation of treatments that were effective, were applied to a substantial number of patients, and involved

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[290] T62 p. 82 Dr Thomas. Dr Michael Whitfield (Consultant Senior Lecturer in General Practice) produced a paper which suggested a role for the Audit Committee – UBHT 0026 0063

[291] WIT 0326 0004 Dr Black

[292] WIT 0159 0030 Ms Evans

[293] T31 p. 61 Ms Evans

[294] T31 p. 61 Ms Evans

[295] WIT 0159 0029 Ms Evans

[296] WIT 0038 0024 Ms Charlwood

considerable resources. The suggestions received in reply did not concern cardiac care.[297]

249 In December 1991 Dr Baker (by then Director of Public Health for the B&DHA) wrote to Dr Thomas, as Chairman of the MAC, expressing concern over the lack of progress in implementing medical audit.[298]

250 Each year, the B&DHA received feedback in respect of the performance of the provider trusts. Ms Evans stated that in relation to the UBHT the feedback[299] for the first year, 1991/92, drew attention to the fact that in order for the system to work, the Trust would need to take responsibility for setting its own quality assurance framework and for making sure it was reviewing its services against its own framework.[300]

251 The feedback had identified as a weakness that the UBHT did not appear to have an overall approach to quality, nor were there individuals with clear responsibility for it. Ms Evans commented:

> 'I think that in 1990/91/92, which this report is relating to, both the Trusts and ourselves as purchasers were feeling their way in this new world of different responsibilities for quality assurance … The UBHT later established a committee which was chaired by one of their non-executives … I think that one was aimed at looking at marketing issues and so on, but it was certainly a committee which sought out feedback about UBHT services. I was invited to that. I think latterly the Trust also developed a committee which was specifically about looking at quality. So it was an issue which I think they recognised and addressed over time, although, at this point, I think our comment was valid.'[301]

252 Ms Evans drew attention in her written statement[302] to instances in which problems identified in one set of monitoring returns had not subsequently been addressed or followed up. She told the Inquiry:

> 'I think we were very active in quality monitoring. I think probably that if one were to look at other district health authorities we were at least as active as others and probably more active than some. I think in my statement I was also trying to demonstrate that through the iterative process, we were identifying shortcomings and within the UBHT's directorates, they were trying to put them right. I think that is what one would expect to see in any cycle of quality monitoring, that you try and establish your standards and then check performance against them and if you feel they are not good enough, then you take corrective action and go back and re-audit them.'[303]

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[297] WIT 0074 0037 Dr Baker

[298] HAA 0034 0014

[299] HAA 0043 0011; Finance and Contracting Committee report

[300] WIT 0159 0030 Ms Evans

[301] T31 p. 69 Ms Evans

[302] WIT 0159 0190 Ms Evans

[303] T31 p. 74 Ms Evans

253 In 1992, meetings were arranged between the District and each trust within the District. The meeting with the UBHT took place on 11 November 1992.[304] Dr Morgan stated:

> 'At this meeting (A09796), the Chief Executive of the UBHT, John Roylance, explained that his Trust would not be keen on reporting on audit of process measures but would be happy to work on outcome measures with Bristol and District Health Authority. The Trust agreed to develop proposals for outcomes to be measured in a number of specialties and a list was provided in January 1993 (A09799). This list included adult cardiac surgery – "coronary artery bypass grafting, hospital mortality by pre-operative severity of disease".'[305]

254 A regional perspective of the extent to which the DHA monitored quality of outcome was provided by Ms Charlwood, referring to the period after 1992:

> '… the District Health Authorities do not appear to have used the vocabulary of safety in regard to quality, but they did include outcomes for patients as part of their consideration of quality issues.
>
> 'From the outset B&WDHA appears from its records to have tried to concern itself with qualitative issues, as distinct from quantitative issues such as the number of operations performed.
>
> 'However,
>
> '(i) the criteria for judging quality appear to have changed from time to time, often in response to changing priorities or emphases on the part of the Government (such as waiting lists and unit costs, or the introduction of the *'Patient's Charter'*);
>
> '(ii) the criteria chosen, and their indicators, were mostly of a general nature and on a large scale, so did not draw attention to concerns about surgical outcomes in a particular specialty at a particular hospital; and
>
> '(iii) much of the information that might otherwise have informed decisions about quality did not differentiate paediatric from other cardiac surgery.'[306]

255 She identified a development of the role from mid-1993:

> 'From April 1993 onwards, Health Authorities were given a more explicit role in promoting clinical audit, and funding audit through allocations and from 1995 through the "service agreements". In 1993, B&DHA discussed a joint strategy for clinical audit with UBHT (and the other local Trusts), and negotiated agreement of a

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[304] WIT 0307 0005 Dr Morgan

[305] WIT 0307 0005 Dr Morgan

[306] WIT 0038 0022 Ms Charlwood

> small number of areas for audit on the grounds of shared concerns. Paediatric cardiac activity was not identified by UBHT or the Health Authority as an area of shared concern. These agreements were monitored through review visits by Dr Morgan, the director of Public Health, and the Vice-Chairman of the Authority, Professor Gordon Stirrat, to the Trusts.'[307]

Involvement of the District in nursing audit

256 The reporting of nursing audit activities[308] became a requirement of the contract made with purchasers. Ms Evans told the Inquiry that the DHA saw:

> '… a number of reports which relate either to nursing audit and auditing aspects of the service for children, or to the patients' surveys which took place both in the cardiac surgery ward and in the Children's Hospital, and which sought parent and sometimes children's opinions on various aspects of the service. So there were a number of ways in which we tried to check that the trusts were being active in this area.'[309]

257 Ms Evans cited examples of audit undertaken by nursing staff. In 1992/93:

> 'The nursing staff in cardiac surgery were active … [in] defining nursing care standards and monitoring them. The 1992/1993 Report describes several of these including an audit of cardiac theatres using the National Association of Theatre Nurses audit documents.'[310]

258 Part of this audit referred to departmental organisation. It included the following:

> 'Standard 3 – "The department has an annual quality improvement programme". Although induction programmes had been devised, they were often not put into practice. It was felt that due to a shortage of experienced staff, new members of the nursing staff were often being trained in the practical skills without an all round induction to the entire work of the unit. Staff were not able to express a departmental statement of objectives or philosophy of care.'[311]

259 In the next year, 1993/94, Ms Evans stated that:

> '… the UBHT's monitoring reports begin to report a shift from uni-professional audit … to multi-professional "clinical" audit.'[312]

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[307] WIT 0038 0014 – 0015 Ms Charlwood

[308] For details of the approach of the UBHT to nursing audit, see below at para 379 onwards

[309] T31 p. 52 Ms Evans

[310] WIT 0159 0031 Ms Evans

[311] WIT 0159 0239 Ms Evans

[312] WIT 0159 0031 Ms Evans

260 In the *'UBHT Quality Monitoring Report'* for October 1993 to March 1994 it was noted that:

> 'The move towards multidisciplinary clinical audit described in the Nursing Audit report is welcomed. Discussions are taking place between United Bristol Healthcare Trust and Bristol and District Health Authority on areas for clinical audit in 1994/1995. It is important that nursing staff are involved in this process … It is good to see the positive action taking place as a result of nursing audit, in particular the recommendations from standard four: safety and the environment. The potential for confusion with both corporate standards and local directorate standards is noted.'[313]

261 Ms Evans stated that the report for 1994–1995:

> '… also described work in progress on audit across the nursing teams in the newly established directorate and appends the nursing standards specific to Ward 5 (which includes some standards relating to the care of children).'[314]

262 The report itself stated:

> 'Nursing standards and audit are well established and the emphasis now is to move closer to multidisciplinary audit.'[315]

Reporting of accidents/incidents

263 In 1955 the Ministry of Health issued a Circular, *'Reporting of Accidents in Hospitals'*.[316] The Inquiry was informed, in written evidence, by Mr John Gray, Manager, UBHT Legal Services since 1991, that this document was generally known within the NHS as *'Reporting Accidents and Untoward Occurences'*[317] and was always followed by the UBHT.

264 Before the change to general management, patients' incidents statements generated by nursing staff would normally be considered by a senior nurse before being passed to the hospital administrator. In more recent times there is initial consideration by the clinical nurse manager and a report made to the directorate manager or, in a larger directorate, to the assistant general manager of the directorate. Mr Gray indicated in his statement that 'there was no formal policy in the NHS during the relevant period as to which incident should be reported to the Chief Executive, or what specific action should be taken'.[318]

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[313] WIT 0159 0193 Ms Evans; *'UBHT Quality Monitoring Report'*
[314] WIT 0159 0032 Ms Evans
[315] WIT 0159 0185 Ms Evans
[316] WIT 0137 0032 Mr Gray
[317] WIT 0137 0026 Mr Gray
[318] WIT 0137 0026 – 0027 Mr Gray

265 Mr Gray went on that under the chief executiveship of Dr Roylance:

> 'It was a matter for the professional responsibility and judgment within Clinical Directorates as to what was drawn to the attention of the General Manager by the Assistant General Manager; or in turn by the General Manager exercising discretion as to what matters should be drawn to the attention of the Trust's Chief Nurse Advisor or Director of Operations; and in turn whether those matters needed to be drawn to the attention of Dr Roylance as the Chief Executive.'[319]

266 Mr Gray stated that:

> '… a formal analysis was not usually maintained, although a specific incident or series of incidents might prompt a retrospective analysis.'[320]

267 Mr Gray indicated that he could 'find no written policy relating to the period 1984–1995' on the reporting of accidents and untoward occurrences. Mr Gray's written evidence on the matter was drawn from his own knowledge and after consultation with Ian Barrington, Manager of Children's Services, and Rachel Ferris, Manager of Cardiac Services.

The BRI and the BRHSC pre-1991

268 Before April 1991, clinicians regarded audit as being part of medical practice. Audit activity was undertaken voluntarily by clinicians at specialty level.

269 Audit was:

> '… left to the individual practitioner …'[321]
>
> 'The systems of audit were consciously maintained but they functioned through the commitment and interest of the practitioners.'[322]
>
> 'Some doctors may have kept records of results … but it was certainly not systematic and it certainly did not involve all doctors or all specialties.'[323]

270 Dr Roylance stated that, in 1989:

> 'The guidance emanating from the profession at this time emphasised that it was for doctors to take corporate responsibility for clinical care in terms of outcome measurements, and it was for management to facilitate the conduct of audit and to respond to the conclusions from audit but not to involve themselves in the audit itself. Those conducting audit were required to identify any management action

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[319] WIT 0137 0027 Mr Gray

[320] WIT 0137 0028 Mr Gray

[321] WIT 0097 0322 Dr Joffe

[322] WIT 0120 0406 Mr Wisheart

[323] WIT 0523 0003 Mr Paul Barker, Administrator at the BRI from 1979 to 1985

> that was necessary as a result of an audit and then to inform management. Essentially, audit was seen as a professional activity which should be led by the profession.'[324]

271 'Audit', as defined for the Inquiry,[325] however, was not apparently taking place. Rather, the Inquiry heard evidence of changes in practice being introduced as the result of studying the relevant literature, attending and holding scientific meetings, visiting hospitals and keeping logbooks of operations.[326]

272 There was also some indication that comparisons of practice at the Bristol hospitals were being made with recognised benchmarks or standards. For instance, a comparison of the results for paediatric cardiac surgery at the BRI with national figures is documented in the BRHSC and BRI Annual Reports on Paediatric Cardiology and Cardiac Surgery for 1987,[327] 1988,[328] April 1989–March 1990.[329] The standards referred to related to mortality associated with a particular operation. There were differing views as to whether or not national mortality figures provided a reliable benchmark.

The BRI and the BRHSC after 1991

The involvement of management in audit

273 In April 1991 the creation of the UBHT and the separation of the functions of purchaser and provider meant that the Trust as provider had primary responsibility for the development and implementation of an audit programme within its hospitals. This responsibility was imposed as a term of the 'contracts' with the purchasers.[330] It was also a product of the need to account for the use of 'ring-fenced' funds that, until 1994/95, were allocated by the DoH and distributed locally specifically for the purpose of carrying out audit.[331]

274 The organisation and development of audit within the UBHT differed from that of the other trusts within the region, which were smaller. Consistent with the Trust's policy of decentralisation, the budget for audit and the responsibility for the employment of audit assistants was devolved to directorate level and from there to the specialties. The Trust adopted the philosophy that medical audit should be the responsibility of specialty divisions, or departments, and not necessarily the responsibility of individual directorates.[332]

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[324] WIT 0108 0043 – 0044 Dr Roylance

[325] See para 5

[326] WIT 0352 0025 Dr N Brian Williams, WIT 0084 0022, 0027, 0028, 0031 Mr Dhasmana

[327] UBHT 0055 0009; annual report 1987

[328] UBHT 0089 0023; annual report 1988

[329] UBHT 0055 0068; annual report 1989–1990

[330] HAA 0164 0023; circular HC (91) 2

[331] See above, para 68 onwards, for details of funding made available nationally

[332] UBHT 0273 0007; Medical Audit Committee report 1991. Dr Baker compared this devolved approach with that of other, smaller, local trusts: 'There was a contrast around audit … at UBHT … audit had found its way down to the individual clinical directorates and the individual clinical directorates determined the course of the development of audit largely, with the Audit Committee being I think a fairly low-key committee.' T36 p. 106 Dr Baker

275 Dr Thomas told the Inquiry that this approach was adopted following considerable debate:

> 'From my memory I think that all shades of opinion were voiced. People were, I think, worried or concerned about the prospect of audit being undertaken in a way which did not allow them to guide it or to be the owner, if you wish, of the process and the information.
>
> 'We looked at the Regional Health Authority's pronouncements and the Working Paper 6 for guidance and it seemed to us that if we were to reassure colleagues and actually persuade them to pursue audit and gain the benefits from it, that we had to actually allow them to build their own audit process within their specialty. That, we felt, would assuage their concerns quite considerably, but there is no question in my mind that concerns continued for the whole of my time as the Chairman of the Audit Committee, and there was a constant need to reassure people [individual clinicians] that confidentiality would be protected …'[333]

276 The NHS Working Paper No 6 had stated that:

> 'The [audit] system should be medically led, with the local medical audit advisory committee chaired by a senior clinician. The overall form of audit should be agreed locally between the profession and management …'.[334]

277 The Working Paper envisaged that management should be aware of audit results:

> '… the general results of [medical audit] need to be made available to local management so that they may be able to satisfy themselves that appropriate remedial action is taken when audit results reveal problems'.[335]

278 There was neither definition nor further explanation of what the phrase 'general results' meant.

279 The Working Paper also envisaged that management had a role in ensuring that effective systems of audit were in place:

> 'While the practice of medical audit is essentially a professional matter, management too has significant responsibility for seeing that resources are used in the most effective way, and will therefore need to ensure that an effective system of medical audit is in place.'[336]

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[333] T62 p. 67–8 Dr Thomas

[334] HOME 0003 0130; NHS Working Paper No 6

[335] HOME 0003 0130; NHS Working Paper No 6. See also the 1989 guidance from the Royal College of Surgeons, WIT 0048 0116 Sir Barry Jackson

[336] HOME 0003 0130; NHS working paper No 6

280 Furthermore, the draft Health Circular *'Medical Audit and the Hospital and Community Health Services'*[337] suggested that there was an obligation on the Audit Committee from the outset to provide regular reports to management as well as medical staff on the results of any audit being carried out:

> 'These may, for example, include:- a broad outline of the aggregate result, together with any national, regional or other comparisons available.'[338]

281 The NHS Management Executive's later report entitled *'Clinical Audit'* also described the Government's expectations of managers. On the one hand, the Government encouraged managers to be involved in audit and, on the other, they recognised that parts of audit were best left to the professions. The document stated:

> 'Managers need … to be actively involved in the audit process, this being particularly important as deficiencies revealed by audit relate more often to the running of the organisation than to poor quality professional practice. The more managers are involved in the audit process and its organisation the more likely they will be committed to securing the necessary improvements in care.
>
> 'For their part managers must recognise that some aspects of audit are best carried out in complete confidence by the professions concerned, thus ensuring that more sensitive issues are not avoided.'[339]

282 In relation to the role of the chief executives of trusts the report continued:

> 'The Chief Executives of provider units have overall responsibility for the quality of care provided for patients and must therefore have confidence in the local audit programme.'[340]

283 However, no evidence was put before the Inquiry of any formal indication as to what information was to be circulated to management. It was primarily for the clinicians to determine what information was passed up the chain in order to support a case for particular changes to be made within a hospital.[341]

284 Dr Morgan stated that it was fair to say that there were no clear guidelines about which audit results could be passed on to management within trusts and health authorities. He reported that in the early 1990s the clinicians were, in effect, in a position to choose what was reported to management and the health authorities. He stated in his written evidence to the Inquiry that this began to change later in the 1990s 'and is still evolving'.[342]

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[337] UBHT 0058 0134; draft health circular

[338] UBHT 0058 0138 – 0139

[339] UBHT 0271 0391; *'Clinical Audit',* NHS Management Executive, undated

[340] UBHT 0271 0391; *'Clinical Audit',* NHS Management Executive, undated

[341] T28 p. 102 Sir Barry Jackson, President of the Royal College of Surgeons of England

[342] WIT 0307 0019 Dr Morgan

285 Mr Graham Nix[343] also agreed that it was a matter for the clinicians involved in a particular area to keep abreast of their relative performance. He told the Inquiry that the senior management within the Trust kept abreast of relative performance for things such as waiting times and the outcomes of the Trust's services compared with others, but that there was no information on outcomes and no other 'top management' mechanism for monitoring relative performance of any particular specialty in the Trust.[344] Had there been such a mechanism, Mr Nix indicated that it would have fallen within the jurisdiction of the Deputy Chief Executive for clinical issues (Mr Wisheart),[345] since he (Mr Nix) was concerned only with financial and administrative matters.[346]

286 Dr Roylance stated that regular reports were made to the RHA for the purpose of demonstrating that audit was taking place, which subjects were being reviewed and what, if any, action was being taken to improve the quality of care. However, he went on, detailed results of audit were not communicated to the District or the RHA, because to have done so might have threatened the process and co-operation of clinicians.[347]

287 With respect to the role of management, he stated:

> '... the primary responsibility of management was to ensure that audit was being introduced and conducted and that the requisite resources were made available. It was clear from both Regional and national guidance that managers were not to be directly involved in audit and that the actual audit figures were to remain confidential to those providing the service, i.e. the clinicians. Indeed, it was thought that any attempt by the management to become directly involved in audit or the results of audit would seriously inhibit the development of the audit process. Instead, those conducting audit were responsible for identifying any areas which needed management intervention and then for informing management of what intervention was required. Implementation of the process of audit was overseen and monitored by a Trust Audit Committee which reported through the HMC to the District [Regional] Medical Officer.'[348]

288 Sir Barry Jackson told the Inquiry that the attitude within many hospitals, in the late 1980s and early 1990s, was that management should not be a party to audit. He said that there was widespread opinion that audit was a confidential matter between the clinicians concerned.[349]

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[343] T22 p. 124 Mr Nix, Deputy Chief Executive and Director of Finance, UBHT, since 1993
[344] T23 p. 24 Mr Nix
[345] A post created in 1993, according to Mr Nix T23 p. 97
[346] T23 p. 97 Mr Nix
[347] WIT 0108 0044 Dr Roylance
[348] WIT 0108 0019 Dr Roylance
[349] T28 p. 92 Sir Barry Jackson

Devolution of responsibility

289 Dr Roylance had a policy of devolving responsibilities for audit to the specialty level. This devolution was a consequence of the Trust's philosophy of decentralisation generally.[350] He stated:

> 'Audit took place on a specialty basis, with each specialty committee or division taking responsibility for deciding how audit was to be arranged and the resources required in terms of clinical time, clerical and secretarial support, information technology and training and education.'[351]

290 Referring to medical audit, which was subsequently superseded by clinical audit, Dr Roylance explained that it was controlled professionally rather than managerially:

> '… medical audit was introduced on the professional network from the Regional Medical Officer [RMO] and his Regional Hospital Medical Advisory Committee to the consultants within the staff, through the Medical Committee and their divisions; it was not through the management process; it did not come from the Regional General Managers.'[352]

291 This meant that audit was introduced directly to the consultants by the RMO, and it stayed at divisional level within the directorate when the clinical directorate structure was introduced and stabilised in the UBHT, and when medical audit was being changed to clinical audit.[353]

Views expressed on the devolutionary approach

292 Dr Thomas expressed the view that the devolutionary model worked well. It was, he told the Inquiry:

> '… a very logical way to proceed. It maintained the contact between like clinicians who had similar problems and could therefore explore them. One of the problems of audit was always how does a single-handed practitioner audit, and that was always difficult to do and had to be done on a cross-district or cross-region or whatever basis. So if you bring people together with a common area of interest, then that is perceived as concentrating your skills into a group that can improve its practice, can identify problems and so on and so forth.'[354]

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[350] T25 p. 49–50 Dr Roylance
[351] WIT 0108 0044 Dr Roylance
[352] T25 p. 24 Dr Roylance
[353] T25 p. 26 Dr Roylance
[354] T62 p. 112–13 Dr Thomas

293 Dr Baker referred to what he saw as both the strengths and weaknesses in the UBHT's approach:

> 'I suppose the counter-weakness … was that where one wanted co-ordination of competition for limited resources for audit assistants, some perhaps prioritisation of areas for audit, then there was not a ready mechanism for that taking place.
>
> 'The counter would be to say that in my experience of some audits with other Trusts, where the Audit Committee masterminded arrangements more so, at least from a purchaser point of view that could seem to be over-controlling and exclude to some extent our ability to make contact with clinicians to talk about audit areas.'[355]

294 Dr Walshe, as one of the Inquiry's Experts, told the Inquiry:

> '… I think it might be helpful to refer to some of the research and evaluation that we did here. One of the things that we looked at in our survey of all Trusts in 1993 was whether Trusts had devolved the process to directorates and devolved the resource as well to directorates, or whether they had a central function. I think we found from memory about ten percent of Trusts had chosen to devolve the process wholly or largely to directorates. The great majority had established some kind of central audit function, quite often with a link then to directorates, so individual audit staff would serve particular directorates, for example. In that report … we argued that the devolved model was not a good way to go, for a number of reasons: because it fragmented the resource across areas, it made it much more difficult to do anything across directorates; it was hard to monitor and there was some evidence from our survey that directorates did not necessarily use the resource for clinical audit as it was intended to be used, and it led to some very isolated audit and quality improvement staff. So we felt that a centrally led model, particularly in the early days of clinical audit, was much more appropriate.'[356]

295 Dr Walshe confirmed that Bristol was not one of the trusts involved in the research. However, he pointed out that:

> '… we looked at some very large acute Trusts and also some smaller acute Trusts. We looked at community Trusts and combined Trusts that combined medical health and acute services.'[357]

296 Dr Walshe acknowledged that he was:

> '... quite cautious about imposing a particular shape to the process on a Trust, because one of the things the research suggested was that it was very dependent on

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[355] T36 p. 107 Dr Baker

[356] T62 p. 34–5 Dr Walshe

[357] T62 p. 37 Dr Walshe

> the local context; it was hard to prescribe that "this is the best way" of organising and auditing an organisation.'[358]

297 Mr McKinlay stated that although the structure kept the confidence of the consultants it also presented many opportunities for variations in procedures.[359]

298 Mr Hugh Ross,[360] currently the Chief Executive of the UBHT, told the Inquiry that a properly monitored institutionalised system of audit was lacking.[361]

299 Dr Jill Bullimore, Chair of the Clinical Audit Committee 1995/96, noted that the lack of central co-ordination also resulted in difficulty in obtaining information for audit reports.[362]

300 Mr Ross said that he recognised a problem in the lack of ownership for audit when he succeeded Dr Roylance in 1995. He said that no one was:

> '… actually managing and gripping it [audit] in a way that I felt was necessary.'[363]

301 One consequence of devolution was that any money allocated by the Trust for audit activities was distributed to the directorates for their use. Consequently, the Audit Committee had no resources of its own.[364]

Audit committees

302 Dr Thomas informed the Inquiry that the existing District Audit Committee (DAC) became the UBHT's Medical Audit Committee (MAC) in 1991:

> 'I was … the Chairman of the District Audit Committee of the Bristol & Weston Health Authority which was subsequently renamed the United Bristol Healthcare Trust Medical Audit Committee.'[365]

303 The membership of the MAC was identical to that of the DAC, save that Mr Dean Hart was replaced by Dr M Whitfield, a GP representative. Dr Thomas remained as the Chairman.[366] The constitution of the two committees was identical.[367] After the end of his formal three-year term of office, Dr Thomas remained the Acting Chairman until mid-1994.[368]

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[358] T62 p. 37 Dr Walshe
[359] WIT 0102 0009 Mr McKinlay
[360] WIT 0128 0001 Mr Ross
[361] T19 p. 63 Mr Ross
[362] UBHT 0016 0006; notes of Patient Care Standards Committee, 7 November 1995
[363] T19 p. 89 Mr Ross
[364] UBHT 0030 0024; CAC Minutes 2 March 1994; T25 p. 29–31 Dr Roylance; T41 p. 102 Mr Wisheart
[365] WIT 0323 0003 Dr Thomas
[366] UBHT 0025 0156; constitution of the DAC and UBHT 0058 0149; constitution of the MAC
[367] UBHT 0025 0158; constitution of the DAC and UBHT 0058 0156; constitution of the MAC
[368] UBHT 0024 0076; report of the Regional Audit Team's visit to the UBHT 10 March 1994

304 Dr Thomas stated that:

> 'It was a time of great concern and considerable controversy and new initiatives tended to be viewed with suspicion by both medical staff and management. To set up audit at this time was particularly difficult. It was essential to reassure consultant staff that they could "own" the audit process and the data which they accumulated.'[369]

305 Dr Thomas took the view that the MAC was there to 'establish a formal audit function within the UBHT'.[370]

306 He also expressed the view that it was the role of the MAC to:

> 'ensure funding for audit was spent on audit, but not to scrutinise outcome figures or mortality statistics so as to be able to determine whether or not those were acceptable but rather whether the process of audit was being carried out.'[371]

307 Dr Roylance said that the MAC's purpose was: '…To facilitate and monitor development of an audit process.'[372] And to: '…obviously have a role in advising the Trust Board, probably via the Medical Director.'[373]

Its role, he said: '… would be a supportive one to Directorates' because in future, clinical audit will form an important part of contracts …' because Dr Roylance 'agreed that it was the Clinical Director's role to run the Directorate and the Audit Committee's role was to monitor audit.'[374]

He recognised that there was: '… a requirement for the development and nurturing of acceptable outcome measures …' and accepted that: 'It was clear that members had some concerns that the Committee had no specific resources and that its influence on the conduct of audit would necessarily be an indirect one.'[375]

308 Dr Roylance said:

> '… the Chairman of the Audit Committee was clearly responsible for informing me as the Chief Executive, directly and urgently if necessary, if any management action was required for the introduction [of audit] … and in theory, to deal with any adverse result of audit, although that was necessarily some time in the future.'[376]

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[369] WIT 0323 0004 Dr Thomas
[370] WIT 0323 0004 Dr Thomas
[371] T62 p. 139 Dr Thomas
[372] T25 p. 53 Dr Roylance
[373] T25 p. 31 Dr Roylance
[374] UBHT 0030 0024
[375] UBHT 0030 0024
[376] T25 p. 67 Dr Roylance

309 Further, he told the Inquiry that he considered that it was the responsibility of the Chairman of the MAC to satisfy himself that the process of audit was being carried out:

> '… it was very much divorced from me. This was a function that consultants were charged with pursuing, overseen and monitored by a committee which was a committee of consultants and at that time a subcommittee of the Medical committee. My role was to respond to any management action that arose thereby. It would have been quite counterproductive for me to monitor audit.'[377]

310 Dr Roylance said that if, for example, a Unit failed to carry out the process of audit, that would not be a management issue which would involve him:

> 'No, it would not and quite specifically not, but if the Chairman of the Audit Committee required my assistance, he was charged with asking for it and he did on a number of issues. You … appear to be inviting me to jump into a position whereby management at that time had direct responsibility for audit. Curious as it may seem at this stage, it did not.'[378]

311 These issues were addressed in the Chairman's remarks in the 1993 MAC report itself:

> 'The devolutionary process which has lain at the heart of the Trust's operational philosophy has, in the past, made it quite difficult for the Audit Committee to influence and record audit activities. As the Regional Audit Team observed, the Audit Committee has no budget and is not made up of clinical directors. … It seems likely that these parameters and limitations will also be a frame within which the new Clinical Audit Committee will work. The new Committee may well wish to establish a role in the co-ordination of audit projects across the Trust. It may also wish to play some part in the assessment of the quality and effect of audit projects. These objectives are highly desirable but will remain difficult to achieve unless some agreement can be made between senior management and the Clinical Audit Committee as to the future of audit in the UBHT'.[379]

312 Audit activities were organised at the clinical directorate level, and were monitored and co-ordinated by the MAC. The MAC prepared an annual report based on the returns from all the specialties, which was then submitted to the RHMAC and to the Chief Executive of the Trust.[380]

313 The MAC's terms of reference included the requirement that it '…notify the Steering Committee of the Hospital Medical Committee of any desirable or proposed changes in utilisation of practice.'[381] The Chairman of the MAC, or another representative in his absence, attended and reported to the Steering Committee meetings. In addition,

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[377] T88 p. 137 Dr Roylance

[378] T88 p. 138 Dr Roylance

[379] UBHT 0058 0309; MAC report 1993

[380] WIT 0108 0045 Dr Roylance

[381] UBHT 0058 0157 MAC constitution

the constitution of the MAC provided for its 'ex officio' members to include the Chairman of the Hospital Medical Committee (HMC) or his/her deputy.[382]

314 Dr Roylance stated that:

> 'An Annual Report was prepared by the Committee, based on returns made from all the specialties, and submitted to the Regional Hospital Medical Advisory Committee. I was also sent a copy of the report and I considered it essential that I should see something of that nature that was going to be seen outside the Trust.'[383]

315 Dr Roylance, as Chief Executive, stated that he did not receive copies of minutes of audit meetings. He explained that this was because of the perception that management should be seen to be outside the audit process and because he was reassured by Dr Thomas, having talked with him a great deal '… about the implementation and development of audit within UBHT and beyond. He kept me informed of the problems that were being faced and overcome and I was satisfied that he would come to me if he needed my help.'[384]

316 It was not customary for the Trust Board, as distinct from the Chief Executive, to receive or to discuss MAC's Reports, as Mr McKinlay stated:

> 'In UBHT it was not the custom to circulate these reports to the Board or discuss them at Board Meetings. The only report which I saw [was] in the second quarter of 1995 … I formed the conclusion that the audit process was in its infancy and the Board was not seen as being part of the monitoring process.'[385]
>
> 'Control of individual situations was in the hands of the clinical teams and the Trust executive management. A yearly audit report covering clinical performance was produced by the Medical Audit Committee under a senior consultant. In my time, it was not practice in UBHT for this report to be seen by the Board or the Board Committee.'[386]

317 Dr Roylance agreed with this recollection, although he noted that later the Reports did become available, from around October 1995. Dr Roylance said:

> 'The Audit Report was initially introduced along the provisional line from Region down to District and then became Trust. I was anxious that what was being reported outside the Trust should be made known to people responsible for the Trust, but I had to move very gently and delicately, because at this time the reassurance given to the staff is that it was nothing to do with management … there certainly was a difficulty initially as to whom the audit report, which was a report about the process

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[382] UBHT 0058 0156 MAC constitution
[383] WIT 0108 0045 Dr Roylance
[384] WIT 0108 0045 Dr Roylance
[385] WIT 0102 0023 – 0024 Mr McKinlay
[386] WIT 0102 0011 Mr McKinlay

> of audit and not of audit, should be made available and I think we have seen before, Dr Thomas' view that anything out of the Audit Committee could only go where he said.'[387]

318 The extent to which reports and information obtained by the audit process were made available was the subject of further examination by the Inquiry. Evidence was heard that purchasers requested information upon the work of the MAC, but that the Committee was reluctant to provide that information. In particular, Dr Thomas was referred by Counsel to the Inquiry to the MAC meeting of 10 June 1992[388] where there was a discussion about purchasers' access to audit information:

> 'Q. You are minuted as referring to the constant pressure from the purchasers to have some access to audit information, but you were reluctant to accede to their request, particularly their suggestion that they should receive copies of the committee's annual report.
>
> 'Why was that a request that you were reluctant to accede to?
>
> 'A. I cannot answer your question. I do not know because the annual report had a very wide circulation and went across the Region. I suppose that I was responding to their wish as purchasers to have free access to information which the Audit Committee did not have and had it had that information, it might not have chosen to share it with the purchaser. A provider, fine, because that is within the envelope of the organisation the philosophy within the Health Service had changed quite markedly from a service to a business. Part of that change of culture involved a change of attitude towards many things, including information. Information then became commercially sensitive. This was one of the reasons why I, and I think the UBHT, were resistant to sharing processed information.
>
> 'It was, if you like "What is the recipe for Marmite, because if we know what it is, we might be able to make it cheaper". That is the commercial view. That was the sort of attitude that was beginning to creep into those discussions, and information was regarded as sensitive and not to be shared in a way that would make it accessible to competitors.'[389]

319 It was Dr Thomas' impression that purchasers were receiving mortality statistics for the whole of cardiac surgery, but he was not able to confirm whether they received them. Dr Baker told the Inquiry that they were never received.[390]

320 Dr Morgan stated that: 'Trusts submitted annual reports to the Region which the purchaser Health Authorities were not shown at that time.'[391]

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[387] T25 p. 65 Dr Roylance

[388] UBHT 0067 0083; MAC meeting

[389] T62 p. 115–16 Dr Thomas

[390] T62 p. 137 Dr Baker

[391] WIT 0307 0004 Dr Morgan

321 Mr McKinlay expected that concerns about standards of practice or care within the BRI would reach the Board through the Clinical Director, or the Medical Director, and the Chief Executive. Referring to concerns about paediatric cardiac surgical services, he said:

> 'I would have envisaged that the Clinical Director would go to where the source of the problem lay. We are talking here about consultant anaesthetists having concerns, so the Clinical Director in anaesthesia, in a very logical system, goes and talks to the Clinical Director in paediatric cardiac surgery. … Then I think the logical next step is to the Medical Director … The Chief Executive is the next step, possibly with the Chairman of the Hospital Medical Committee being somebody that might be consulted on the way. … [the next step would be] From the Chief Executive to the Board.'[392]

322 Mr McKinlay stated in his written evidence to the Inquiry:

> '… clinical outcomes and adverse events … were fundamentally a matter for the audit meetings of the particular services involved … were not as a matter of course reported to the Board.'[393]

323 The Clinical Audit Committee[394] (CAC) was responsible in succession to the MAC for encouraging and monitoring the introduction of the process of audit. It produced reports that were sent to Region to say how the development of audit was progressing.[395]

324 Dr Roylance was asked what use was made of the CAC and its deliberations within the Trust since the reports from the CAC, as with those of the MAC, did not go to the Board:

> '… the report … went to the Region and was … processed with all the others … If you say what function did the Audit Committee have, I think I told you: the Audit Committee was charged with encouraging and monitoring the introduction of the process of audit … these were very early days and I cannot really discuss sensibly what we did with the outcome of audit because there was very little outcome of audit at that stage, it was only the process of audit we were concentrating on, but the Chairman of the Audit Committee was clearly responsible for informing me as the Chief Executive, directly and urgently if necessary, if any management action was required for the introduction … of audit, and in theory, to deal with any adverse result of audit, although that was necessarily some time in the future.'[396]

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[392] T76 p. 37–8 Mr McKinlay
[393] WIT 0102 0011 Mr McKinlay
[394] Which succeeded the MAC in 1994
[395] T25 p. 66 Dr Roylance
[396] T25 p. 66–7 Dr Roylance

Audit co-ordinators and audit assistants

325 Following the introduction of the Government's paper *'Medical Audit Working Paper No 6'*,[397] medical audit co-ordinators were appointed for each service to co-ordinate and report to the MAC. Audit assistants were provided, although the use that was made of them differed widely at the outset, from specialty to specialty.[398] The audit co-ordinators reported to the Audit Committee through one of its members.[399]

326 The introduction of audit assistants went some way to rectify earlier problems in developing medical audit, summarised by Dr Stansbie, Vice Chairman, UBHT Medical Audit Committee (1990–1994), in his written evidence to the Inquiry as including:

> '… a lack of secretarial and clerical support, a lack of an adequate audit database and a lack of time to prosecute audit, particularly in the case of single handed consultants in small specialties.'

He noted that:

> 'The provision of audit assistants with computers, who were trained to use word processing and spread sheet packages, went someway to dealing with these needs and were largely in place by 1992.'[400]

327 Ms Sheila Wilkins, Audit Assistant 1991–1993, set up a system whereby clinical information needed for the medical audit of services within the Directorate of Surgery could be recorded. The system used by the Directorate was the Medical Database Index (MDI) which was already in place in the South West Region:

> 'Part of my role was to train clinicians, including junior doctors, in the use of the system and identifying the importance of accurate data recording.
>
> 'As Audit Assistant within the Directorate of Surgery the specialties I supported were general surgery, urology, orthopaedics and Accident & Emergency. I understood that they submitted their data to the National Audit Registry. Paediatric services had their own audit assistant at the Bristol Children's Hospital. I did not know the input clerk of cardiac services. As well as preparing data for monthly audit meetings for the Directorate, my duties included instructing the house officers on rotation into the use of the MDI system used for audit purposes. …
>
> 'Examples of the types of information that were entered onto the MDI system for the Directorate of Surgery were the bloods used; drugs given; procedures undertaken; the reason for death, (if it occurred and when); the length of stay in hospital, (pre and post operatively); if a catheter was inserted and for how long…

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[397] HOME 0003 0124; *'Medical Audit Working Paper No 6'*

[398] WIT 0108 0045 Dr Roylance

[399] T62 p. 74 Dr Thomas

[400] WIT 0324 0002 Dr Stansbie

> ‘My work included planning and implementing audit projects. Medical staff in the Directorate of Surgery would identify an audit subject and, if the data was not already captured, I would liaise with the Information Technology Department to ensure that that specific data was captured.
>
> ‘Monthly meetings were held between Audit Co-ordinators and Assistants throughout UBHT. … They were well attended by both the Audit Co-ordinators and Audit Assistants representatives of the various Directorates, for example from Surgery, from the Eye Hospital and Medicine and sometimes from the Children’s Hospital.
>
> ‘In addition to the monthly meetings, Audit Assistants often met with others doing the same sort of work, throughout the region in a group called SWAANS (South West Audit Assistants Network Services). Meetings took place once every 3 months. As many Audit Assistants from UBHT as possible would go to every meeting. The objective of these regional meetings of Audit Assistants was to obtain clear agreement, on a regional basis, on how the government guidelines on audit should be implemented. … Representatives from Trusts in other areas in the region or elsewhere came to speak to the Group … The purpose of the meetings was to discuss systems and statistics, not individual cases.’[401]

328 Ms Wilkins also commented that there was concern among audit assistants ‘… that they had no representatives on the [Audit] Committee’ and ‘… no knowledge of what decisions the Committee was making on the implementation of audit. …’[402]

329 Ms Wilkins described the experience of the audit co-ordinators and audit assistants:

> ‘Audit Assistants throughout the Trust were using the MDI system in different ways. We nevertheless found it helpful to meet to discuss the problems we were encountering and the ways we were implementing the government guidelines. Meetings took place between ourselves and staff from the Information Technology Department. Although our use of systems within Directorates and specialties were different, many of the problems we encountered were the same and, in principle, solutions were similar…[403]
>
> ‘… annual reports prepared by Audit Assistants and submitted to Clinical Co-ordinators were in standard format, so as to ease identification and comparison of material in the report. This was, I believe, a result of Dr Thomas’s initiative. He sought to ensure that reports on the functioning of audit, from each Directorate, used the same format. I have already identified that the audit data itself was not in the same format, and that different systems were in place within each directorate, but yearly reports were to use the same layout.’[404]

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[401] WIT 0396 0002 – 0003 Ms Wilkins

[402] WIT 0396 0003 Ms Wilkins

[403] WIT 0396 0004 Ms Wilkins

[404] WIT 0396 0005 Ms Wilkins

Role of the clinical director[405]

330 The *‘Regional Audit Team Report’* of 1994[406] observed that the control of audit lay ultimately with the clinical directors.

331 Dr Thomas agreed:

> ‘Effectively they had the responsibility, they had the resource[s], and therefore it was their control that dictated what could or could not be done.’[407]

332 The role of the clinical director and the relative powerlessness[408] of the Audit Committee may have been a product of the uncertainty and change evident in 1991 when the Trust was set up. Mr McKinlay stated:

> ‘… there was a strong suspicion in the Consultant group that this [the creation of the Trust] was the ultimate take-over by the administrators and that their freedom to make clinical decisions would be seriously curtailed. In order to combat this fear, the Trust was set up with 14 Clinical Directorates with a Consultant as the Clinical Director in each case.’[409]

333 The Report said that because the MAC was not constituted of clinical directors it was relatively powerless. It said:

> ‘There was direct admission from a representative of the management team that issues for audit which they (the managers) feel need to be addressed or are asked to address by purchasers, tend to [be] implemented via the clinical directors rather than by any central overview from the Audit Committee.’[410]

334 Dr Roylance was asked about this view expressed in the report in the following exchange:

> ‘Q. …That would be consistent with your explanation, as I understand it, that it was for the Clinical Directors to run the directorate and the Audit Committee’s role was not to control audit but to monitor it?
>
> ‘A. Absolutely. I mean, people who, like, spin on it a direct admission, that always implies that they did not want to let it be known but eventually released it.
>
> ‘Q. Leave aside the spin. What it indicates is that the author of this document from the region, the Regional Audit Team, envisaged audit in a very different way from the way in which it was in fact being delivered?

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[405] The role of the clinical director generally is dealt with in Chapter 8

[406] UBHT 0024 0076; *‘Regional Audit Team Report’* 1994

[407] T62 p. 110 Dr Thomas

[408] UBHT 0024 0076; *‘Regional Audit Team Report’* 1994

[409] WIT 0102 0009 Mr McKinlay

[410] UBHT 0024 0077; *‘Regional Audit Team Report’* 1994

> 'A. No, that is quite wrong. That is quite wrong. He actually attended the Audit Committee, and he was reflecting the view of some of the Audit Committee. I talked to him directly. I talked to the audit group directly, from Region. I spent a lot of time ensuring that audit was set up.'[411]

335 Dr Walshe was of the view that putting clinical directors on the Audit Committee would not have made much difference:

> '… I do not know, but I suspect that it would have made little difference … Because I think that the directorates viewed the resource as theirs and at any meeting to discuss what audit was to be done, that would have coloured people's judgment … given the devolved structure and the fact that the money was going to devolve anyway, I think having the Clinical Directors there would have made little difference to what was done.'[412]

336 Mr Wisheart expressed the view that the clinical director had a responsibility to see that audit was carried out within the directorate, a responsibility for the organisation of the clinical work and a responsibility if there had been any complaints of any sort, to deal with them. It was his opinion, however, that the clinical director was not responsible for the individual work of an individual clinician.[413] Mr Wisheart was asked about the 1990 application from the UBH for trust status which stated, in relation to quality of service, that:

> 'Within the Trust each contract will be the personal responsibility of a Clinical Director supported by a Manager. Quality of service will therefore be their responsibility.'[414]

337 Mr Wisheart did not regard this as meaning that the clinical director was directly responsible for the work of individual clinicians. He said that part of the issue turned on the definition of what 'quality of service' meant:

> '… One has to ask what the "quality of service" means. There are two broad areas under which it could be considered there. There is the area of quality in the sense of the management of the organisation, the waiting times, the promptness with which letters were sent out, the adequacy of the food and so forth and so on. Then secondly, there is the quality of the clinical service, which would be dealt with in a general way within the directorate, within additionally medical audit and later clinical audit.'[415]

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[411] T25 p. 54 Dr Roylance
[412] T62 p. 112 Dr Walshe
[413] T41 p. 1 Mr Wisheart
[414] UBHT 0060 0041; *'Application for NHS Trust Status'*
[415] T41 p. 2 Mr Wisheart

The shift from medical to clinical audit

338 In early 1994, the MAC was reconstituted as the Clinical Audit Committee (the CAC). This change was consequent upon the introduction, in 1993, of the requirement by the Government that clinical audit be carried out. At a Committee meeting, Dr Thomas reported:

> '… there was concern that medical audit will be marginalised under the pressure from clinical audit. The Chairman [Mr Wisheart] pointed out that we must be perceived to be carrying out the national guidance lest we lose audit monies. We must also maintain medical audit as a valuable educational and peer review activity.'[416]

339 When asked about the relationship between medical and clinical audit, Dr Thomas said:

> '… the answer to your question is that the short history of medical audit set up a system which was being used as an educational system, and that the new form of audit, clinical audit, was going to be a much more widely-based type of audit; it was not going to be limited to educational purposes, and it was going to address problems of resource allocation, throughput and so on and so forth in a much wider sense and with a different emphasis.'[417]

340 In Dr Thomas' opinion there were indications that medical audit still had a role and should continue alongside clinical audit:

> 'I believed that … there were indications — … in I think both the government documents of the time that medical audit should indeed continue. I think that there were substantial reservations about the progress that had been made because – and I speculate here you understand – I believe that in Government circles they had anticipated that progress would be much more rapid than it was.'[418]

> '… they also anticipated that medical audit would embrace the wider sphere of information-gathering, which I suspect was sought in the first place. I think that those anticipations of rapid progress were ill-founded and had the government chosen to listen to advice, it would have realised that setting up such a system as they had proposed in the White Paper was actually going to take a substantial amount of time, and not just a couple of years. It was not just a simple thing to put in place.

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[416] UBHT 0098 0013, 0017; meeting of the Steering Committee with Chairmen of Divisions, held on 5 January 1994

[417] T62 p. 99 Dr Thomas

[418] T62 p. 99 Dr Thomas

> ‘There was, among most of the documents at the time, an emphasis on bringing non-medical paramedical, whatever you wish to call them, members of the hospital staff, the teams and so on, into the audit process. It is my memory that we had already done that to a limited extent in the directorates, not in the audit committee, but in the directorate. But that was a another aspect of clinical audit.’[419]
>
> ‘Q. … at a directorate level, some overlap had been taking place?
>
> ‘A. Yes.
>
> ‘Q. Some participation amongst non-medical staff in the audit process?
>
> ‘A. Yes.’[420]

341 Dr Thomas was not able to say how widespread this participation was, except that:

> ‘… the directorates that spring to my mind, as directorates where I was aware that that was happening, were medicine in general, although that was made out of separate subgroups, but general medicine, rheumatology and so on, ophthalmology and the dental services.’[421]

342 There was also a concern that by widening the parameters of medical audit to include other specialties, there would be a dilution of the effectiveness of audit.[422] Dr Thomas commented:

> ‘It is not a question of letting other professional groups into the process, it is a question of how people perceive the time and the opportunity. So, for instance, I might, as I said this morning, wish to explore the complications of epidurals in pain relief. On the other hand, if you enlarge the group beyond me as a medical person and bring in somebody who may, perhaps, manage the resource of the Trust, they might be more interested in how I was going to use the money that they were prepared to let me have to buy kits or whatever.
>
> ‘So the emphasis within the meetings was going to change and that might well have damaged educational processes, I thought.’[423]

343 However, Dr Thomas confirmed that by 1995 medical audit evolved into clinical audit.[424]

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[419] T62 p. 100 Dr Thomas

[420] T62 p. 101 Dr Thomas

[421] T62 p. 101 Dr Thomas

[422] WIT 0120 0405 Mr Wisheart

[423] T62 p. 102 Dr Thomas

[424] T62 p. 103 Dr Thomas; WIT 0323 0007 Dr Thomas

344 This move towards clinical audit resulted in the re-constitution in early 1994 of the MAC, which, as set out above, became the CAC. Dr Thomas stood down as Chairman of the Committee shortly before 22 June 1994. Mr Wisheart then chaired the Committee for six months.[425] Dr Thomas stated to the Inquiry that the transition from one form of audit to the other was completed by the end of 1994.

345 In January 1995, Dr Jill Bullimore, consultant clinical oncologist, took over as Chair of the CAC.[426]

346 Dr Roylance explained a change in reporting structures: the multidisciplinary CAC reported through the Patient Care Advisory Committee to the Trust Board.[427]

347 Dr Roylance described the change from medical to clinical audit:

> '… before medical audit was up and running and in any sense robust, it was changed to clinical audit, and even with clinical audit, it was not expected to produce anything effective, anything that you could rely on as audit, for another five years.'[428]

348 Dr Joffe stated that with the change to clinical audit, the emphasis was placed on shared care of patients by a broad range of carers, including doctors, nurses and professions allied to medicine. Dr Joffe expressed the view that the shift to clinical audit appeared to make the sub-specialties even more marginalised.[429]

349 At about the same time, funding for audit was transferred from regional to district control. Dr Morgan stated that because: '…This change was signalled late during 1993/94 … a contract between Bristol and District Health Authority and the Trusts (including the UBHT) was not agreed until November 1994.'[430]

Collation of audit material by the Audit Committee

350 There was no reference in the *'Annual Audit Report'* to audit activities in paediatric cardiac surgery or in paediatric cardiology in 1992 or 1993.[431] Dr Thomas confirmed that the MAC was aware of this omission. He said that he tried to persuade audit co-ordinators to file a report and sent reminders:

> '… I think we probably sent out one, probably two reminders to audit co-ordinators that they had not yet filed their report with us.'[432]

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[425] UBHT 0024 0267; CAC minutes, 11 January 1995
[426] WIT 0108 0048 Dr Roylance
[427] WIT 0108 0019 Dr Roylance
[428] T25 p. 45 Dr Roylance
[429] WIT 0097 0319 Dr Joffe
[430] WIT 0307 0004 Dr Morgan
[431] T62 p. 148 Dr Thomas
[432] T62 p. 125 Dr Thomas

351 However, Dr Thomas' only means of seeking to ensure that the reports were made were persuasion and exhortation:

> '… I had no big stick with which to beat people into giving me a report.'[433]

352 Failure to provide a report to the Committee did not produce any adverse effect for the department concerned in terms of sanctions except for 'embarrassment', as Professor John Farndon, the Audit Co-ordinator in Surgery in 1992, said:

> '… I had to chase some groups more vigorously than others to get returns, and others found it difficult or impossible. The accident room, I think, found it particularly difficult because of staff shortages to initiate the process. Orthopaedics was gradually getting up to speed. And I would chase and encourage as much as I could, but it was as much as I could do to have responsibility for general surgery… There would be an embarrassment that there was no return from orthopaedic surgery, if that were the case, and it would appear in the Report.'[434]

353 The link between the Audit Committee and cardiac surgery was through the Audit Co-ordinator in Surgery, as described by Dr Thomas:

> 'The route to cardiac surgery from the Committee would have been via the co-ordinator for surgery. That was Professor Farndon. The reason that that was the route was because we had a specific number of members of the Committee and to have divided the major specialties into their integral sub-specialty groups would have produced such a profusion of co-ordinators for the committee members to liaise with that it was not practicable.
>
> 'So Professor Farndon was our contact point with surgery. Certainly, he would have received the letters that went out asking for reports and he would have received the reminders. However, I would make two comments about cardiac surgery: I, as a Chairman of the Committee, and Mr Wisheart as committee member, had a conversation on a couple of occasions in which I pointed out that we had not yet received the report from cardiac surgery. In my memory, as I recall, he said "Well the quality of patient care is improving in cardiac surgery". I said "Well, in that case that makes it even more important that a report is received so that throughout the Region people will know that that is the case".
>
> 'However, we did not receive a report and I regretted the fact that they had been unable to produce one for us. There was some reassurance, I felt, in that we knew that cardiac surgery were carrying out basic audits on mortality outcomes as part of their contract with the purchaser and that they were returning figures to the Central Cardiac Surgery Registry, the national registry.

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[433] T62 p. 127 Dr Thomas

[434] T69 p. 84 Professor Farndon

> 'So although I regretted the fact that they had not been able to produce a report, I was reassured that audit was in fact being done, and I believe that that is the case: it was being done.'[435]

354 In a letter dated 22 March 1993 to Dr David Stansbie, Professor Farndon wrote:

> 'The major problem with Cardiothoracic Surgery is that this is a highly specialist group working in isolation with no other similar group within the region. They, too, are establishing their own audit system which, I understand, will interface with other cardiothoracic units at national level.'[436]

355 Data concerning cardiac surgery did not reach Professor Farndon and was not included in his report to Dr Thomas:

> '… I do not remember Dr Thomas wanting me to pursue this issue further. I think that I and the audit committee were happy that the cardiac unit were submitting to a national comparative audit. I felt that this was logical because of the highly specialised nature of cardiac surgery. It is a speciality[specialty] that does not compare easily to any other sub-speciality[specialty]. We knew that audit was taking place and at the time the focus was on getting audit carried out across the whole Directorate and in every sub-specialty of surgery.'[437]

356 As has been noted, Mr Wisheart's view was:

> '… The actual figures that went to the register were never submitted to the Audit Committee, that was not part of the process as it existed … So what I would have wanted to see … were the appropriate reports that the meetings had taken place, which they had, and of course I knew they had taken place but the reports never reached the committee for those two years.'[438]

357 Professor Farndon stated that his understanding of cardiac surgical procedures in general and, in particular, paediatric cardiac surgery, and their associated morbidity and mortality, was very limited:

> '… I would not have known the bench-marks that the cardiac surgeons should have been achieving. Few other surgical sub-specialties have mortality and morbidity to match that of cardiac surgery. It is a very technical, high risk, area with no comparisons to general surgery. I knew that the cardiac surgeons were submitting data to a national audit where comparisons with other units would be made. The process should have identified problems and corrections to allow closure of the audit loop. When reporting to the Medical Audit Committee I informed them that cardiac surgery were submitting externally. I felt that this national arena was the

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[435] T62 p. 126–7 Dr Thomas

[436] UBHT 0027 0282 ; letter to Dr Stansbie from Professor Farndon dated 22 March 1993

[437] WIT 0087 0003 Professor Farndon

[438] T94 p. 141 Mr Wisheart

> most appropriate way of dealing with cardiac surgery and provided a secure mechanism.'[439]

358 Professor Farndon agreed that the Committee received such information, through him, as people within the directorate chose to send and that his function was much like that of a 'post box'.[440]

359 Professor Farndon told the Inquiry that he had heard of the external register to which the cardiac surgeons submitted their returns but he did not know any detail of it nor the nature and scope of the returns, nor did he ever see them.[441]

360 Dr Thomas confirmed that, as Chairman of the MAC, he thought that the cardiac surgery department was conducting adequate audit in 1991:

> 'We believed it to be so at the time: we knew that audit meetings were occurring and we knew we were assured that returns were being made to the National Registry.'[442]

361 Dr Thomas recalled that it might have been Mr Wisheart who reassured him that returns were being made.[443]

362 Professor Farndon told the Inquiry that he could not ever recall Dr Thomas ever seeking such reassurances from him,[444] although in his written statement to the Inquiry he stated that, when submitting his report to the MAC, he informed them that cardiac surgery were submitting data externally.[445]

363 Dr Thomas told the Inquiry that he could not recall any question as to the acceptability of results within the department of paediatric cardiac surgery ever being brought to the MAC's attention.[446] Dr Thomas said that he had no knowledge of the Bolsin-Black 'audit'[447] nor did either of them raise concerns with the MAC at any time.[448] Dr Black was a member of the CAC from its inception in June 1994.[449]

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[439] WIT 0087 0003 – 0004 Professor Farndon
[440] T69 p. 84 Professor Farndon
[441] T69 p. 74 Professor Farndon
[442] T62 p. 140 Dr Thomas
[443] T62 p. 141 Dr Thomas
[444] T69 p. 81 Professor Farndon
[445] WIT 0087 0004 Professor Farndon
[446] T62 p. 138 Dr Thomas
[447] T62 p. 143 Dr Thomas
[448] T62 p. 141 Dr Thomas
[449] UBHT 0024 0267; CAC meeting, 22 June 1994

Summary of annual Audit Committee reports

364 The MAC report for 1991 was published in March 1992. Specialties were required to report on a quarterly basis to the Audit Committee on a standard form. An annual precis was also requested from the specialty which was included in the report. The annual reports of the specialties were included in the report.[450]

365 In summary, the annual report for 1991 recorded the following:

- 'Paediatric cardiology held five audit meetings in 1991. The annual audit of surgical intervention; the annual audit of non-surgical intervention; and multi-disciplinary meetings (morbidity and mortality) with cardiologists, surgeons, pathologists, radiologists, and anaesthetists were recorded. One new standard was reported as having been adopted: to operate more on patients under 1 year, in particular those with Atrio-Ventricular Septal Defect.

- 'The audit co-ordinator was Dr Martin.

- 'Cardiac Surgery held 12 meetings but attendance was not shown. The co-ordinator was noted as being Mr Hutter. Much of the commentary related to adults.'

366 The Bristol & District Health Authority's (BDHA's) assessment of the MAC's 1991 report was that audit, in the sense of standard-setting, was not always being described. However, it noted that some changes in clinical practice had been introduced and that some of these were being audited. It was not clear whether others would be reviewed.

367 The report for 1992[451] was more comprehensive. However, it was circulated to internal UBHT and Regional officers only, not to the DHAs.[452]

368 The Chairman's introduction stated:

> 'The main purchaser of health care from the UBHT is the Bristol and District Health Authority. A meeting was held between the Trust and the purchaser in order to review audit activities during 1992. During that meeting the responsibility of the Trust and its Medical Audit Committee for the process and prosecution of audit was restated unequivocally. It was agreed however that we would be able to act in concert with the purchaser in assessing some measures of outcome following treatment within the Trust. Audit Co-ordinators in a number of specialties responded most constructively to a request for suggestions of measurable and verifiable outcomes, six of which are being pursued by the Trust and the purchaser in partnership.'[453]

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[450] UBHT 0063 0336; *'Annual MAC Report'* 1991

[451] UBHT 0066 0107; *'Annual MAC Report'* 1992

[452] UBHT 0066 0106; *'Annual MAC Report'* 1992

[453] UBHT 0066 0111; *'Annual MAC Report'* 1992

369 The introduction also noted that difficulties arose because of the low priority that was still accorded to audit by a minority of consultants.

370 The report contained a return from the Department of Anaesthesia but noted that the Department of Child Health did not submit its report in the correct form, so that nothing from that department was included. No report was submitted by cardiac surgery (or paediatric cardiac surgery) nor by paediatric cardiology.

371 The report for 1993[454] reproduced the Regional Audit Team's report criticising the fact that power in relation to audit lay with the clinical directors, who were not members of the MAC. The MAC was by-passed, according to the report, when managers wished issues on audit to be addressed or were asked to address issues by purchasers. The report also noted the need to ensure that traditions of audit and audit methodology in other clinical fields were recognised by the (previously medical) Audit Committee.

372 Again, the 1993 report did not include a report in respect of paediatric cardiac surgery, nor did it explain its omission to do so.

373 The Regional Audit Team report stated that:

> 'This tight directorate structure and approach operates at all levels and for most issues and has, therefore, led to a confusion for the Audit Committee over its role.'[455]

374 Dr Thomas told the Inquiry that he rejected the idea that there was any confusion in this regard and indicated that the MAC had no incentives nor sanctions at its disposal:

> 'I do not think there was any confusion in our minds about what we might be able to achieve. We had … no budget, no staff and therefore the only way in which we could influence people was by persuasion, by cajoling them into doing things which we thought were valuable. Sometimes they agreed with us, sometimes they did not. We knew that we would be able to influence people over such things as hardware, staffing and training, because the members of the Audit Committee had information which was not available easily to the Clinical Directors. So we could pass that information on to them and persuade them to take the steps that we thought were wise.
>
> 'There was, I suppose, the other element to the equation, and that was that they knew at the end of the year they would have to account for how they had expended their money. Certainly when things started the Audit Committee was required to put its seal on those items of accounting and say, "Yes, that is what happened."'[456]

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[454] UBHT 0058 0301; *'Medical Audit Report'* 1993

[455] UBHT 0024 0076 *'Regional Audit Team Report'* 1994

[456] T62 p. 111 Dr Thomas

375 The Regional Audit Team observed that the directorates were able to undertake effective audit in their own specialties, but that decentralised audit functions meant that they were less able than a central body to manage cross-specialty audit, to maintain consistent methodology, to disseminate lessons learned, or to develop and make best use of the audit staff who became isolated.[457]

376 In dealing with what it saw as the bypassing of the MAC, the Regional Audit Team report stated:

> 'The devolutionary process … has made it quite difficult for the Audit Committee to influence and record audit activities … the Audit Committee has no budget and is not made up of clinical directors. It seems likely that these parameters and limitations will also be a frame within which the new clinical Audit Committee will work. The new Committee may well wish to establish a role in the co-ordination of audit projects across the Trust. It may wish to play some part in the assessment of the quality and effect of audit projects. These objects are highly desirable but will remain difficult to achieve unless some agreement can be made between senior management and the Clinical Audit Committee as to the future of audit in the UBHT.'[458]

377 The report for 1994/95[459] was the first report of the CAC. Again, it did not contain reports in respect of paediatric cardiac surgery or cardiology, nor did it explain the omission.

378 The annual reports of the Audit Committee were sent to the SWRHA. Dr Roylance commented on the RHA's use of these reports:

> 'They summated them [audit reports], had a look at them and they issued an encouraging document … to say "Look what has been happening across the region and please, would other people like to do a similar thing", but it was a report on the introduction of the process of audit with a few encouraging notes to say, "and we have found something we can improve on"'.[460]

Nursing audit in Bristol

379 Until the introduction of clinical audit, nursing was audited separately from medical services.

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[457] WIT 0437 0003 Dr Charles Shaw

[458] UBHT 0058 0309; *'Annual MAC Report'* 1993

[459] UBHT 0058 0217; *'Clinical Audit Report'* 1994/95

[460] T25 p. 65–6 Dr Roylance

380 Mrs Margaret Maisey, Director of Operations and Nurse Advisor at the UBHT, was responsible for the audit of nursing. She described her primary concern as being that:

> '… nursing care was of the highest standard, that nurses were trained and had available to them all that they required to carry out their duties correctly and in accordance with our professional standards. I tried to ensure that proper records were kept and that nursing administration was efficient, so that nurses spent as much time with patients as possible, delivering high quality care and constantly looking for ways to improve what they were doing.'[461]

381 Mrs Maisey described her role as being:

> '… to keep up with the standards of the day and ensure systems were in place so that nursing audit happened in UBHT.'[462]

382 She stated that she led the introduction of audit:

> '… firstly as Chairman and later as facilitator on the District Nurse Advisory Committee. … I led my colleagues in the introduction, consultations, discussions and eventual implementation of various nursing processes across the Trust as a whole. One of these processes was nursing audit.'[463]

383 Mrs Maisey stated that she had introduced the notion of nursing audit first through the Nursing Committee of the District, from 1989, then the Trust:

> '… For example, I recall proposing that nurses should ensure that their staff were recording that they had checked on bedfast patients during their period on duty, to ensure that the patient was not left in soiled linen: an apparently minor point but essential to patient care and positive nursing attitudes. Nursing records are traditionally of a higher quality than medical notes. Accurate contemporaneous reports are recognised by all nurses as vital to their proper patient care. I was very concerned to maintain this principle from the time I arrived in Bristol and never failed to make this point at every appropriate opportunity.'[464]

384 Mrs Maisey stated that she ensured that appropriate structures were set up to report on audit measures:

> 'Within the Trust and the Trust Nursing Advisory Committee (TNAC), I worked to produce the forum in which nursing audit, nursing procedures, and policy advice in such matters from the centre, was discussed, adapted and implemented by those nurses with the relevant managerial and professional roles in the Trust. From TNAC, I took their views and decisions to the Regional Trust Nurses Group where such

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[461] WIT 0103 0078 – 0079 Mrs Maisey

[462] WIT 0103 0071 Mrs Maisey

[463] WIT 0103 0071 – 0072 Mrs Maisey

[464] WIT 0103 0073 – 0074 Mrs Maisey

> things were discussed and information given which might assist others and the centre as to what each Trust was doing.
>
> 'Similarly, within the TNAC, following the introduction of a contractual requirement by the Avon Purchasers, annual nursing audit reports were produced. I think I took these reports to the Trust Board or one of its Committees. Clearly, over time, these reports and procedures became far more sophisticated and wide-ranging, as we all learned more about the audit process as a consequence of carrying it out, but also as a result of receiving more and more information from the centre, other Trusts, and the clinical areas, including what other professions were doing.'[465]

385 At the meetings of the TNAC and District Nursing Advisory Committee (DNAC):

> '… each senior clinical nurse reported back on their clinical area of responsibility. Issues raised were debated by the meeting and the greater experience of the group as a whole brought to bear. Subjects discussed at the DNAC/TNAC meetings included Department of Health circulars, UKCC consultative proposals, RHA and Regional Nursing Officer/RGM letters and similar documents, DHA matters, developments in nursing, nursing audit and nursing standards. Various aspects of nursing policy for the Health Authority/Trust as a whole were discussed and agreed upon at the meetings.'[466]

386 Annual nursing away-days were also organised to discuss issues in more depth and to consider standards, research and advanced nursing practice.[467]

387 Nursing audit was reported on a yearly basis:

> 'A Nursing Audit report was prepared annually and sent to the Avon purchasers and to the Trust. These reports were written by the Nurse Advisors for each part of the Trust. The reports evolved over time. They were designed to set standards, measure attainment against those standards, and lead to changes in nursing practice where changes were appropriate. The reports from the Children's Services written in 1995 for the Annual Report 1994/5 is typical of the period and reflects the confusion in the minds of many as to exactly what was expected of us in the matter of 'audit'. To resolve this situation was one of the key tasks of the Trust Nurses'Advisory Committee. It must be understood that until very recently, "audit" was something that was medically driven and nurses were still feeling their way.'[468]

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[465] WIT 0103 0071 Mrs Maisey

[466] WIT 0103 0073 Mrs Maisey

[467] WIT 0103 0073 Mrs Maisey

[468] WIT 0103 0074 Mrs Maisey

388 Mrs Maisey noted that with the commencement of trust status there was much change:

> '… many … relationships were changed; some of them disappeared altogether, while others became more at arm's length, while yet others followed the same patterns as previously but with different players. From being a general manager with general management responsibilities, I became a facilitator and enabler to the managers. As before, I continued to give ethical and professional guidance to the nurses and to give nursing advice to the Trust Board. The Nurse Advisory [TNAC] Committee continued to set standards. These were monitored and later reported as part of the nursing audit process.'[469]

389 Mrs Maisey commented on the evolution of audit in respect of her involvement with the MAC and CAC. She stated:

> 'At Bristol, I attended meetings of the Medical Audit Committee and its successor the Clinical Audit Committee. … At the outset, the meetings of the Medical (later Clinical) Audit Committee which I attended dealt with funding, with the possible processes of recording audit events, the mechanical process by which the annual report would be generated … . The meetings never discussed outcomes. They certainly did not discuss relationships between practitioners, or clinical performance in any way.
>
> 'Generally, these Committees were considering management matters related to clinical practice … We would see summarised "audit"reports. We were aware that certain specialities [specialties] with common interests and concerns met to discuss specified topics, but we were not party to any of their debates, only to the agreed outcome of the debates and what future actions had been decided.'[470]

390 Fiona Thomas, a Sister at the UBHT, described the following difficulties in conducting nursing audit:

> '… a level of expertise was required to undertake audit; diploma or degree nurses may have had these skills. Difficulties arose in conducting audit due to constraints of clinical work or other roles, which led to difficult decisions about what came first. Sometimes nursing staff were so busy caring for patients, it was difficult to find time or spare pairs of hands to carry out audit.'[471]

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[469] WIT 0103 0077 Mrs Maisey

[470] WIT 0103 0078 Mrs Maisey

[471] WIT 0114 0055 – 0056 Fiona Thomas

391 Ms Sarah Hoyle, Directorate General Manager for Women's and Children's Services (and, at one point, Mrs Maisey's assistant in Bristol), stated that:

> '… nurses were always willing to support the development of clinical audit, involving all healthcare professionals.'[472]

Attitudes towards the formal introduction of audit 1990–1993

392 Mr David McCoy, Chairman of the RHMAC, stated that:

> 'The picture of audit at its inception was resented by some, and completely clouded by uncertainty of patient confidentiality, and the legal situation, with the risk of action for defamation as a result of published results.'[473]

393 Dr Morgan stated:

> '… there was much suspicion and a great deal of sensitivity from the professions….'[474]

394 Mrs Liz Jenkins, Assistant General Secretary, RCN, told the Inquiry:

> 'I can think of examples, not necessarily from my own organisation, but … meetings that I went to … across the country, where doctors would not even want medical students to take part in the clinical audit meetings in case the medical students actually really found out what the results were. I mean there was real fear and anxiety about it, and I have to say a lot of lip-service paid to it.'[475]

395 Dr Thomas' view was that:

> '… the profession were wary of the White Paper in general, and I suppose, therefore; any components of it. That was the sort of ambience within which we were working.'[476]

396 As has been seen, Mr McKinlay stated:

> '… there was a strong suspicion in the Consultant group that this was the ultimate take-over by the administrators and that their freedom to make clinical decisions would be seriously curtailed. In order to combat this fear, the Trust was set up with 14 Clinical Directorates with a Consultant as the Clinical Director in each case.'[477]

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[472] WIT 0527 0007 Ms Hoyle

[473] WIT 0436 0002 Mr McCoy

[474] WIT 0307 0011 Dr Morgan

[475] T34 p. 79 Mrs Jenkins

[476] T62 p. 85 Dr Thomas

[477] WIT 0102 0009 Mr McKinlay

397 Dr Roylance expressed this view:

> '... a strong feeling within the medical profession that audit was going to be used as yet another management tool and I felt that its introduction to the formal structure of Bristol and Weston Health Authority, as it was at that time, and then the UBHT, needed to be handled very carefully in order to encourage doctors to participate. (This was a great change in the NHS generally and there were already strong feelings and a great deal of sensitivity about the increasing role of managers in healthcare.)'[478]

398 Dr Thomas told the Inquiry:

> '… the profession was perhaps less enamoured, less convinced, than professional bodies and organisations. That is reflected in some of the papers recruited from individual clinicians, saying "Whilst we sign up to the aims of this, we are not sure it is really going to work and deliver improvement".'[479]

399 Dr Brian Williams, consultant anaesthetist at the BRI since 1977, stated:

> 'Senior management and most Associate Directorates of surgery were initially resistant to the idea of formal audit being conducted in our Directorate [anaesthesia] during in-service hours. They were of the opinion that the disadvantage of the inevitable interruption to elective surgery throughout the Trust would outweigh any possible advantages.'[480]

400 Dr Sally Masey, consultant anaesthetist and Anaesthetic Audit Convenor, explained that the use of clinical time to hold audit meetings was a problem:

> 'As it was considered to be a contractual requirement to be involved in audit the Department of Anaesthesia would ask for all routine operating to cease on those 8 half-days a year so as many anaesthetists could be involved as possible. An emergency anaesthetic service was maintained. Understandably, this met with considerable resistance from surgeons, and the Trust management was also not receptive to the cancellation of routine lists, despite it being clearly stated in the NHS [Management] Executive document *"The Evolution of Clinical Audit"* that adequate time had to be set aside for audit activities. However, we were able to establish this pattern of cancellation of routine working with moderate success by stressing the contractual obligation to audit.'[481]

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[478] WIT 0108 0043 Dr Roylance

[479] T62 p. 17 Dr Thomas

[480] WIT 0352 0025 Dr Williams

[481] WIT 0270 0012 Dr Masey

401 These attitudes persisted after 1993. On 23 February 1994, the minutes of a meeting of the B&DHA recorded that Dr Morgan presented a paper on *'Clinical Audit and Outcome Monitoring'* which stated: 'A significant problem was the feeling of clinical professions that clinical practice was not the concern of the Purchaser'.[482]

Views as to the relative responsibility for aspects of audit

402 Dr Roylance was recorded in the minutes of the clinical audit review meeting of the B&DHA on 11 November 1992 as commenting that: '… the way that care is carried out is the responsibility of the Trust, but the outcome is Bristol & District's domain …'[483] He explained that in placing contracts with the UBHT or other trusts, the B&DHA could not disassociate itself from the benefits those contracts were achieving for patients, and that the District should be concerned with the *value* of the process to their patients, in terms of clinical outcome, and not just the process itself.[484]

403 Ms Evans stated that the District's view of responsibility for outcomes and clinical quality was that:

> '… the primary responsibility for outcome and clinical quality of service lay with Trusts. That was one of their key roles, one of their main jobs, and they reported to the centre through the regional health authorities and later what was called the "regional outpost"of the NHS Executive about quality and about financial matters. So that was their province. I think, at the beginning of the period at any rate, audit was seen as being a professional activity. I think it was seen as being educative about learning and reviewing things, and I think it was seen, therefore, as not being the province of managers and not being the province of purchasers … I think initially it was regarded as being purely professional and not something that Trust managers should be involved in the detail of, other than to know that it was happening. I think that changed over the period between 1991 and 1995.'[485]

404 She added that, in 1991, the role of the District was limited to satisfying itself that audit was taking place.[486] Further:

> 'It was the Trust's responsibility to make sure that it had appropriate frameworks and processes in place for quality assurance, both in terms of clinical audit and in terms of what perhaps might be described as "processes of care".
>
> 'In addition to that requirement, health authorities had specifically laid upon them certain national requirements, many of which came under the Patient's Charter, and these were requirements that we should monitor certain aspects of patient care processes, notably waiting times in Accident and Emergency departments, waiting times in outpatient clinics, between patient arrival and seeing a consultant,

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[482] HAA 0145 0375; minutes of the meeting of the B&DHA, 23 February 1994

[483] UBHT 0271 0020

[484] T25 p. 20 Dr Roylance (emphasis added)

[485] T31 p. 27–8 Ms Evans

[486] T31 p. 63 Ms Evans

> cancellation of operations, and, of course, waiting times for inpatient and outpatient appointment from GP referral.'[487]

In terms of monitoring the standards and outcomes of care:

> '… the primary responsibility was laid on Trusts and their reporting was through the Region to the Centre. I think the Health Authority had a role, and I think a recognition of the Health Authority's role evolved over time, so that, by I think about 1995, it was recognised – and in that encouraged – by the Department of Health that health authorities should have the right to nominate certain audit topics that Trusts would undertake. But that was very much towards the end of the period and I think we saw our role as being to encourage the development of audit and to work with our Trusts, all of our Trusts, on specific audit topics, particularly those which, like the work we did on heart attacks, seemed to be important in terms of illness within our population, and health care for our population.'[488]

405 With regard to collecting data and conducting audit, Sir Graham Hart, Permanent Secretary at the DoH from March 1992 to November 1997, was clearly of the view that it was Region's responsibility after the introduction of trust status:

> 'I would certainly expect the contact with the UBHT to be from regional level.'[489]

He continued in the following exchange:

> 'Q. They should obviously have done the job and collected the data. On the assumption that they did not, as appears to be the case, they are part of the District and the District is part of the Region. What role or function would the District play in this?
>
> 'A. No, I do not think post-1991, I mean, this is a Trust now.'

406 If trusts were not collecting data or making it available, he went on, this was not something which districts could address:

> 'The District obviously has, or a number of Districts have a relationship with the Trust, but it is not such that you could really expect the District to put this right.'[490]

407 Overall responsibility for audit was separated from those who were expected to put it into effect. Ms Charlwood stated:

> '… from 1990 right through to 1996, while the DHA was encouraging monitoring and audit, it was the SWRHA that was primarily responsible for monitoring clinical

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[487] T31 p. 61–2 Ms Evans
[488] T31 p. 62–3 Ms Evans
[489] T52 p. 85 Sir Graham Hart
[490] T52 p. 85 Sir Graham Hart

> audit activity in the NHS Trusts in the South West. I have no evidence available to me showing that SWRHA raised with the DHA any issues which it required the DHA to pursue regarding monitoring of clinical audit. Actual implementation largely lay with the professionals in the NHS Trusts, who organised the clinical audit resource and arranged audit of specific clinical activity.'[491]

Audit of infant and neonatal cardiac surgical services: role and responsibility of the District [492]

408 From April 1984 to March 1994 paediatric cardiology and cardiac surgery for neonates and infants under 1 year old was designated a supra regional service.[493]

409 Ms Evans and Dr Baker told the Inquiry that, as a result, the District was not responsible for monitoring the performance of paediatric cardiac services for the under-1-year-olds.

410 Ms Evans expressed her view in the following exchange:

> 'Q. … it is right, is it, that we must bear in mind that your detailed involvement was with services for the over-1s rather than the under-1s?
>
> 'A. Yes. That is right, and that was because the service for the under-1s was purchased by the NHS Executive because it was designated as a supra regional service for part of the period until the service was de-designated.'[494]

411 Dr Baker explained, in the following exchange:

> 'Q. … in terms of your overall planning function, did you have any responsibility to check that the service for either the under- or the over-1s was producing an acceptable outcome?
>
> 'A. Yes, certainly in terms of children over 1, they were part, obviously, of our overall planned or later commissioned services. Within the breadth of our responsibilities for understanding whether we were getting the services we wanted to, that would have been generally the case.
>
> 'Q. And in relation to the under-1s?
>
> 'A. Not in relation to the under-1s. My understanding always was that the supra regional service was supervised through their own arrangements.'[495]

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[491] WIT 0038 0014 Ms Charlwood

[492] The role of the DoH, Supra Regional Services Advisory Group, Royal Colleges and others is examined in Chapter 7

[493] Designation as a supra regional service is considered in Chapter 7

[494] T31 p. 6 Ms Evans

[495] T36 p. 74–5 Dr Baker

412 When paediatric cardiac surgical services for the under-1s were de-designated with effect from April 1994, commissioning of the service became the responsibility of purchasing DHAs. There was no communication from the NHS Executive to these authorities on the nature or scope of any monitoring of quality that should be established for the service, despite the complexity or specialised services involved.[496]

The audit and review of the paediatric cardiac surgical services in Bristol

413 The Inquiry heard evidence that, during the period of the Inquiry's Terms of Reference, various types of meetings were held in Bristol in order to review results in paediatric cardiac surgery.

414 Mr Wisheart stated:

> 'The practice of audit within paediatric cardiac surgery was set up by the clinicians in that area and it was done on the basis of their interest, enthusiasm and commitment, not because of any management requirement … The practice evolved and developed from the years prior to 1984 and throughout the period [of the Inquiry's Terms of Reference]'.[497]

415 These meetings fell into four main categories: cardiac surgical audit, departmental audit, clinico-pathological meetings and evening meetings.

Cardiac surgical audit meetings

416 Mr Wisheart explained:

> 'Cardiac Surgical Audit was formally instituted in 1990/91 in response to the White Paper. However, it evolved from pre-existing activities which had been labelled educational but which did involve a significant element of audit. All the cardiac surgical staff, junior and senior, attended this meeting which occurred once a month in term time. … To begin with there was no minute of the meeting; a record of the meeting was made by the Sub-Directorate Audit Convenor which was submitted to the Trust Audit Committee.'[498]

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[496] WIT 0159 0035 – 0036 Ms Evans

[497] WIT 0120 0392 Mr Wisheart

[498] WIT 0120 0392 – 0393 Mr Wisheart

417 Mr Dhasmana explained that:

> 'During the eighties and early nineties the records and data were collected by the Registrar/Senior Registrar working with the respective surgeons and presented to the meeting under the supervision of the senior registrar … Things changed with the establishment of UBHT and organisation of an Audit structure in 91/92. Mr Jonathan Hutter was our first audit co-ordinator, who started collection and storage of these data.'[499]

418 Mr Wisheart stated that:

> 'The most common method of presentation of data [at the meeting]was for each consultant's registrar to present the work of the previous month and to draw particular attention to any patients where there had been death or serious complications. This led to a discussion of those events which sought to establish whether any modification of clinical practice would be beneficial. Specific topics were also audited such as wound infection. The annual statistics were usually presented to this meeting for discussion.'[500]

419 Mr Wisheart pointed out that the meetings focused on the review of individual cases, although series of patients were reviewed when 'topics' were audited, or annual statistics presented.[501]

420 Mr Dhasmana stated that prior to 1992 the meetings were attended by members of the Department of Cardiac Surgery although: 'After 1993/94, when the audit was better organised, the attendance increased to include nurses, anaesthetists and adult cardiologists.'[502]

421 Mr Alan Bryan, consultant cardiac surgeon since July 1993, stated that he produced minutes of the meetings which were held at the end of 1993 and in early 1994. He went on:

> 'In 1994 my role in relation to audit was formalised in that I was asked to be audit convenor for cardiac services. This formalisation of my role in 1994 was part of a Trust-wide move to formalise audit procedures. Prior to this my involvement had been on my own initiative … It is worthy of note that there would have been no need to do this immediately upon my appointment [in July 1993] if a regular organised programme of audit was in operation.'[503]

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[499] WIT 0084 0017 Mr Dhasmana

[500] WIT 0120 0393 Mr Wisheart

[501] WIT 0120 0393 Mr Wisheart

[502] WIT 0084 0017 Mr Dhasmana

[503] WIT 0081 0021 Mr Bryan

Audit meetings, paediatric cardiac surgery and paediatric cardiology

422 Regular audit meetings, bringing together those involved in paediatric cardiac surgery and paediatric cardiology, commenced in 1990. Dr Robin Martin, consultant paediatric cardiologist since 1989, was the co-ordinator of these meetings. He explained in his letter of 18 December 1989 to colleagues:

> ‘At a recent meeting it was suggested we ought to hold regular clinical audit meetings and I have volunteered to help co-ordinate these. The purpose of these meetings would be to discuss clinical cases, complications, post-operative management and other relevant problems in the Paediatric Cardiology and Cardiac Surgery Unit.’[504]

423 Mr Dhasmana stated that the meetings were held monthly, initially on Monday mornings, but later (from 1992) on Wednesday lunchtime or in the early afternoon, in the seminar room attached to the cardiac catheter laboratory at the BRHSC.[505]

424 As to attendance at these meetings, Mr Dhasmana stated:

> ‘The meeting was open to all members of staff concerned with the care of children with congenital heart defects … However this was mostly attended by members of paediatric cardiac medical and surgical staff and also by nursing and technical staff from the catheter lab. Dr Peter Wilde the consultant cardiac radiologist and/or his staff and Mrs Helen Vegoda from the paediatric cardiac family support services also attended these meetings from time to time. Others like anaesthetists and junior members of surgical staff were not able to attend these meetings on a regular basis because of their clinical commitment elsewhere in the same hospital or at BRI.’[506]

425 Dr Bolsin told the Inquiry that it was ‘probably’ right that anaesthetists were invited to and did on occasions come to these meetings, but that there were difficulties in attending.[507] Dr Masey told the Inquiry that, because of timetabling difficulties: ‘We did not find that we were able to frequently meet with our surgical colleagues.’[508]

426 There was evidence that these meetings had lapsed before the beginning of 1992. Dr Martin wrote to Dr Jordan on 3 January 1992: ‘I think it is very important that we recommence our audit sessions in 1992 and after discussion I think we ought to hold these monthly on the fourth Wednesday of each month. …’[509]

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[504] WIT 0084 0035; letter from Dr Martin to colleagues dated 18 December 1989. Mr Dhasmana refers to these meetings as ‘monthly paediatric cardiology/cardiac surgery audit meetings’(see WIT 0084 0019), but Dr Martin’s letter is headed ‘Departmental Audit Meetings’

[505] WIT 0084 0019 Mr Dhasmana

[506] WIT 0084 0020 Mr Dhasmana

[507] T81 p. 25 Dr Bolsin

[508] T74 p. 29 Dr Masey

[509] UBHT 0061 0153; letter from Dr Martin to Dr Jordan dated 3 January 1992. Mr Wisheart confirmed that although the letter is headed ‘audit of paediatric cardiology’ it was referring to audit which embraced both paediatric cardiology and paediatric cardiac surgery, see T41 p. 75

427 Dr Martin commented on the lapse of these meetings:

> I think it is difficult in a busy clinical programme sometimes making the time to get people to come to these meetings … That is not to say that people were not interested, it is just the pressure of clinical commitments often makes it very difficult … it was the hurly-burly of clinical work that makes it much more difficult and I am sure it was a problem more clinicians face, to get a regular audit programme going is very difficult ... I think it is probably fair to say the switch [split] site arrangement did not particularly help us to get an adequate number of people together. … Since they moved the open heart surgery up to the Children's Hospital, we have got more people on site and it has been easier to get good consensus and a group of people together, but it is not easy.'[510]

428 These meetings lapsed again during 1992. Mr Wisheart stated that: 'Following the publication of the contents of a paediatric cardiological audit in *"Private Eye"*, this audit programme lapsed for a time.'[511] Mr Dhasmana stated that: '… the confidentiality of the data was broken at least on two occasions, when figures relating to Tetralogy of Fallot and Arterial Switches appeared in the media (*"Private Eye"* 1992). This did have some negative effect on the conduct of these meetings.'[512]

429 A number of witnesses commented on the specific effect of the publication in *'Private Eye'* on 3 July 1992 of an article concerning data about paediatric cardiac surgery in Bristol.[513]

430 Mr Dhasmana told the Inquiry that following the publication of the article: '… I felt the best thing would be really to explain myself to my medical colleagues … so I was continuing with my audit in a similar manner … it did not stop me from presenting our data to the department or monthly audit or anything like that.'[514]

431 Dr Joffe commented in the following exchange:

> 'Q. Mr Wisheart, when he spoke to the GMC, said that the effect of the *"Private Eye"* article … [was] that the audit process of paediatric cardiology was very seriously set back, and really did not occur thereafter for quite some time … How accurate is that?
>
> 'A. I think it is accurate in the sense that the audit process that Dr Martin had developed at the end of the year before and during that year 1992 was to a degree certainly interrupted by the reaction to the *"Private Eye"* article. There were meetings I believe, but they did not follow the same format as the previous ones.'[515]

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[510] T76 p. 159–60 Dr Martin

[511] WIT 0120 0393 Mr Wisheart

[512] WIT 0084 0020 Mr Dhasmana

[513] SLD 0005 0002; *'Private Eye'* 3 July 1992

[514] T86 p. 131 Mr Dhasmana

[515] T90 p. 124 Dr Joffe

432 Dr Martin commented:

> 'Around that time – I think it was around July or August 1992 – we were quite concerned about a report that appeared in *"Private Eye"* at that stage which seemed, appeared to include what appeared to be data from our audit meeting directly. I am sure it had an effect on audits after that, certainly for the surgical results. I think we carried on having some audit sessions for individual catheters, maybe foetal, you know some of the different sub-specialties that we also feel important to audit, but I do not remember that same format being used for the surgical results. …'[516]

Clinico-pathological meetings

433 Clinico-pathological conferences were held when a patient had died. Mr Dhasmana stated that they were held to review individual cases: 'in order to confirm the pre-operative diagnosis and to re-examine the operative procedure.'[517]

434 Mr Dhasmana explained that the meetings were organised by Professor Jem Berry and scheduled to take place once a month, but on occasions were postponed or reorganised due to a lack of cases for presentation.[518]

435 Mr Wisheart stated:

> 'The Clinico-Pathological Conference was instituted in the early to mid 80s and it almost certainly coincided with the arrival of Dr, later Professor, Jem Berry.[519] Cardiologists, surgeons, radiologists, anaesthetists as well as pathologists were welcome at such meetings. Up until the arrival of Dr Ashworth in 1993[520] no record whatsoever was kept of these meetings and in particular there were no minutes or definitive reports of findings. As far as I am aware the occurrence of these meetings were not reported to the Trust Audit Committee.'[521]

436 Mr Dhasmana described that at these meetings:

> 'The clinicians concerned with the case, medical and surgical, would present the clinical details, echo. catheter and angio-graphic findings, the operative procedure and post operative course/events. The pathologist would demonstrate the specimen, describing the autopsy findings. Most of the times the surgeon would also join in the study of operative findings and the technique. The discussion used to centre around the post-mortem findings and if an explanation could be found for the post-operative course and the sad outcome.'[522]

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[516] T76 p. 163 Dr Martin

[517] WIT 0084 0022 Mr Dhasmana

[518] WIT 0084 0022 Mr Dhasmana

[519] Professor Berry was appointed consultant paediatric pathologist at the BRHSC in 1983, see WIT 0204 0002

[520] Dr Michael Ashworth was appointed consultant paediatric pathologist at the UBHT in 1993

[521] WIT 0120 0395 Mr Wisheart

[522] WIT 0084 0022 Mr Dhasmana

Evening meetings

437 The Inquiry heard evidence about informal evening meetings held at the homes of consultants, from the early to mid-1980s.[523]

438 Mr Wisheart described these as 'multi-disciplinary evening meetings' and explained that they 'were attended by cardiologists, surgeons, anaesthetists, radiologists and pathologists' and took place two to four times a year.[524] Mr Dhasmana referred to these meetings as meetings of the 'paediatric club'.[525]

439 Mr Wisheart stated that the agenda of these meetings:

> '… was not limited to audit, but it did include review of the annual statistical summaries and occasional series of patients, particularly before other more formal audit activities began in 1990-1991. The clinical series reviewed included Fallot's tetralogy repair in 1991, VSD closure in 1988 or 89 and the prevention and management of pulmonary hypertension. Thus the emphases was on a series of patients, rather than the individual patients.'[526]

440 Mr Dhasmana stated that at the meetings:

> '… some important issues in the management of postoperative problems were discussed and recommendations implemented. For example an important guideline was formulated for the management of postoperative pulmonary hypertension in patients with complete AV canal and in some cases of Tetralogy of Fallot following this [a] meeting in 1989/90. The issue of Arterial Switch in older children was reviewed in one such meeting in December 1994. Similarly Dr Hayes chose to discuss the topic of Protocol and Review of correct practice in paediatric cardiology in one of these meetings in June 1994.'[527]

441 Dr Masey stated that the meetings:

> '… would quite often be chaired by the person in whose home the meeting was being held … I felt it was a very good opportunity to talk to people because the environment was moderately informal, and … there were also meetings where more people were usually able to attend because they were out of the normal working day.'[528]

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[523] WIT 0120 0396 Mr Wisheart

[524] WIT 0120 0396 Mr Wisheart

[525] WIT 0084 0023 Mr Dhasmana. Although Mr Dhasmana referred to these meetings by a different name, he described them as taking place three to four times a year at the home of one of the consultants (in rotation)

[526] WIT 0120 0396 Mr Wisheart

[527] WIT 0084 0023 Mr Dhasmana

[528] T74 p. 75 Dr Masey

442 Dr Bolsin believed he was 'obstructed' in carrying out audit of paediatric cases. He expanded on that in the following exchange:

> 'A. I think that there was another incident when I produced minutes of one of the informal evening audit meetings and I was told that they were not acceptable outside of the meeting. So that not at the time, when the minutes were being considered to be accepted at the meeting, before the next meeting was arranged I was told: "these minutes will not be circulated, this is not how we do things, I do not want you keeping minutes again". That to me could be construed as obstruction. I probably brought that in as "obstruction" in my statement.
>
> 'Q. We have been told by Mrs Masey [*sic*] that it was her who said that to you, and we have been told by Mr Wisheart and from comments he has made that he did not say that to you. Are they right or are they wrong?
>
> 'A. I think Dr Masey is right, she did say it. Mr Wisheart may be wrong. I believe he also said that to me as well.
>
> 'What surprised me was that here was a concerted attempt by two members of the meeting, not to correct the minutes when they are presented at the next meeting, which is the usual way things are done, but actually to say "You are not to circulate these or keep minutes again".'[529]

443 Dr Joffe told the Inquiry:

> 'We had a very small, close-knit group of five or six people and I think our thorough airing of the situation with a conclusion that we had come to at the end of it was sufficient for all of us to then take on whatever policy changes we had decided upon, and all of us would stick to them. So there was no problem in not having minutes for that kind of discussion.'[530]

444 Mr Dhasmana explained that: 'Since it was an informal meeting, records were not kept regularly,…'.[531] Dr Jordan stated: '… these meetings were not minuted.'[532]

445 Dr Joffe stated that the discussions at these meetings were mainly focused on issues related to paediatric cardiology and surgery. He stated that anaesthetists did not come to every meeting, 'But there were some issues that some anaesthetists did attend to discuss where their presence was certainly very important.'[533]

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[529] T80 p. 14–15 Dr Bolsin

[530] T90 p. 130 Dr Joffe

[531] WIT 0084 0023 Mr Dhasmana

[532] WIT 0099 0019 Dr Jordan

[533] T90 p. 130 Dr Joffe

Other meetings

446 In addition to the four types of audit meeting set out above, Mr Dhasmana pointed out that weekly departmental teaching sessions took place on Friday mornings, and joint cardiac and thoracic surgical meetings took place on Wednesday evenings. Although these meetings were mainly used as teaching sessions for junior members of surgical staff he stated that: '… on some occasions, case reviews, both individual and of series, were presented and unit figures were audited. On occasions specific post-operative problems in case management were also audited at these meetings. Most of these related to adult cardiac surgery.'[534]

447 Mr Wisheart stated that some reviews of series of clinical cases were carried out on an ad hoc basis: 'Some of these reviews took place within the format of the multi-disciplinary evening meeting, some within the paediatric cardiological audit programme and others at ad hoc meetings.'[535]

448 Mr Wisheart also stated that: 'Reviews of series of patients were carried out with the intention of communicating the findings to scientific meetings or publishing them in peer review journals'; for example, in respect of the Mustard and Senning operations, and that 'These might be regarded as being outside the audit process, the findings were usually also presented at an audit or educational meeting within the Department.'[536]

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[534] WIT 0084 0024 Mr Dhasmana

[535] WIT 0120 0397 Mr Wisheart

[536] WIT 0120 0397 Mr Wisheart