Chapter 10 – Outreach Cardiology Clinics

Introduction

1 This chapter addresses the organisation of peripheral, or outreach, cardiology clinics run by the Bristol cardiologists in the UBH/T catchment area. It is closely related to Chapter 11 which deals with referrals to Bristol. It begins that section of this Annex in which the evidence is set out which traces the path of a child needing heart surgery from first identification, at an outreach clinic, or by a paediatrician in a district hospital, through first contact with the Bristol hospitals, pre-operative assessment and care, surgery, surgical management of care (which is of much wider scope than events on the operating table itself), post-operative care, to counselling and, in the event of a child's death, bereavement services.

2 Communication is a theme that runs through all the chapters which follow: between Bristol doctors and local doctors, between Bristol doctors and parents, and between the doctors in Bristol themselves.

The concept of outreach clinics

3 Dr Robert Swanton, consultant cardiologist and President of the British Cardiac Society (BCS), told the Inquiry how outreach clinics work in the area in which he practises:

> 'We send a surgeon out to one of our referring centres every month, to do a sort of joint clinic, and it is very much appreciated by both units. It ensures very good communication and patients like to see their surgeons after the operation, and it works very well. It is time-consuming. It takes essentially a whole day out of the surgeon's or cardiologist's week by the time you have got down there and back again, but it is very valuable.
>
> 'I think in time, it will become less important as more of the DGHs [District General Hospitals] have established two cardiologists per hospital. A lot of these cardiologists are single cardiologists in a hospital managing a whole unit on their own with no support. They are people who need the outreach support from London or the big cities.'[1]

4 Dr Ian Baker[2] explained the concept of outreach clinics in his statement. He said:

> '"Outreach" clinics were clinics where paediatric cardiac clinicians from Bristol practised away from their base facilities at BRHSC and BRI in facilities of other Health Authorities.

1 T7 p. 53 Dr Swanton
2 Formerly the District Medical Officer for B&WDHA from July 1984 to October 1991, and subsequently a Consultant in Public Health Medicine for the B&DHA from October 1991 onwards

'"Outreach" clinics can be considered as serving: children and parents; referring paediatricians; the development of cardiac services in Bristol; and Health Authorities needing access to paediatric cardiac services.'[3]

5 The 1987 *'Annual Report for Paediatric Cardiology and Cardiac Surgery'* at Bristol said the following about outreach clinics:

'During the 1970s, joint clinics with the local consultant paediatricians were established throughout the South Western Region … At the invitation of consultant paediatricians in South Wales, joint clinics were also established in Abergavenny and Newport in 1986 and in Swansea, Carmarthen and Haverford West in 1987. Apart from the obvious benefit of convenience for the families and economy for the host Health Authority, these clinics have an important teaching function for the local Registrars, SHOs and visiting students during their paediatric training in District General Hospitals.'[4]

6 Dr Hyam Joffe, consultant cardiologist, explained the thinking behind Bristol's outreach clinics:

'The peripheral clinic concept was highly successful in fulfilling the following objectives close to the children's homes, instead of the family having to make frequent long trips to Bristol:

- 'assessing new non-urgent patients with suspected cardiac abnormalities, referred by consultant paediatricians,
- 'maintaining observation on previously diagnosed cases to monitor medication, if required, and to assess further progress,
- 'ensuring timely referral for cardiac catheterisation and/or surgical intervention due to evolutionary changes in the nature of the condition,
- 'continuing short- and long-term observation on post-operative cases after the initial one or two assessments by the surgeons in Bristol, …
- 'updating paediatricians throughout the region of the latest advances in the ever-changing medical and surgical treatment of cardiac conditions,
- 'teaching clinical signs, ECG and chest X-ray features, aspects of basic echocardiography and management of children with cardiac disease to medical students and, especially, GP trainees, paediatric SHOs, registrars and SRs, who frequently joined the clinics.'[5]

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3 WIT 0074 0020 Dr Baker
4 UBHT 0166 0006; *'Annual Report for Paediatric Cardiology and Cardiac Surgery'*, 1987
5 WIT 0097 0143 – 0144 Dr Joffe

7 Mr James Wisheart, consultant cardiac surgeon, explained that:

> 'These visits to other centres enabled good professional relationships to be established between the referring paediatricians and the cardiological team in Bristol.'[6]

8 Building relationships with local paediatricians was also considered important, as well as fulfilling an educative role. Dr Baker said of referring paediatricians:

> 'Access to paediatric cardiological and surgical advice and services was achieved through these clinics in the South Western Region and parts of the Wessex Region from 1984.'[7]

Clinics in the South West and South Wales

9 Dr Joffe said:

> 'When I started in Bristol in 1980, Dr Jordan had already organised the "outreach" or peripheral clinics throughout the South Western Region and South East Wales. Between the two of us, we continued to provide clinics in Gloucester, Cheltenham, Swindon, Bath, Newport, Taunton, Barnstaple, Exeter, Torbay and Truro, with occasional visits to Plymouth.'[8]

10 Dr Stephen Jordan, consultant cardiologist, explained the arrangements that had existed in the South West, basically unchanged, since 1984. He said:

> 'All other hospitals in [the South West] Region with the exception of Yeovil were visited on a regular basis by one of the cardiologists doing a cardiological clinic, usually with one or more of the paediatricians and typically occupying all day once a month. Plymouth was otherwise the only exception as I visited only once or twice a year and the other clinics there were done by consultants from Southampton.
>
> 'The clinics in [the South West] Region were: Cheltenham, Gloucester (Dr Martin, morning and afternoon respectively), Taunton (Dr Jordan, all day), Exeter (Dr Martin, all day), Torbay (Dr Joffe), Plymouth (Dr Jordan, afternoon), Truro (Dr Jordan, all day) and Barnstaple (Dr Martin, afternoon or all day).'[9]

6 WIT 0120 0069 Mr Wisheart
7 WIT 0074 0021 Dr Baker
8 WIT 0097 0142 Dr Joffe
9 WIT 0099 0015 Dr Jordan

11 Dr Joffe charted the development of the outreach clinics in Wales in his statement:

> 'In the mid 1980s, several local consultant paediatricians in South Wales individually approached the Bristol paediatric cardiologists to request that Bristol provide a "regional" paediatric cardiological and cardiac surgical service for their patients. The paediatric departments had loosened their connections with London centres through, for example, retirement of the visiting paediatric cardiologist from Hammersmith; a specifically paediatric cardiac surgical centre in Wales did not then exist. …
>
> 'The additional peripheral clinics were started in Abergavenny in 1986, in Swansea, Carmarthen, Haverford West and Merthyr Tydfil in 1987, and in Neath and Bridgend in 1989. These clinics have continued successfully until the mid-1990s. With the establishment of the Cardiff paediatric cardiology and cardiac surgery unit, some paediatric departments have established a connection with Cardiff. Abergavenny, Bridgend, Neath and Swansea have maintained a relationship with Bristol until today.'[10]

12 Dr A Palit, a consultant paediatrician at Pembrokeshire and Derwen NHS Trust in Wales, told the Inquiry that the:

> '… decision to send our children to Bristol was very easy because there were no other centres nearby us, who could give us a regular service. After the death of Dr L G Davies, I approached Dr Steve Jordan (a very eminent Paediatric Cardiologist), who was extremely helpful and supportive and offered his services immediately.'[11]

13 Dr Jordan confirmed that in a number of places in Wales, Dr K Hallidie-Smith had conducted clinics from Hammersmith Hospital and that on her retirement Bristol took over a number of her clinics.[12]

14 As to the clinics run by Dr Leslie Davies, Dr Jordan said that Bristol started to pick up some of his work before he died, because what paediatric cardiac surgery there had been at that time in Cardiff had stopped before then.[13]

15 Dr NK Agarwal[14] explained how, in 1982 or 1983, at the suggestion of a colleague, he transferred a premature infant from Swansea to the BRHSC. He said:

> 'Until this time, to my knowledge no paediatric cardiac patients had been sent to Bristol, however from this time onwards myself and my colleagues in Swansea started to send children requiring cardiac care to Bristol cardiologists … After the

10 WIT 0097 0143 Dr Joffe
11 REF 0001 0092; letter from Dr Palit to the Inquiry
12 T79 p. 134 Dr Jordan
13 T79 p. 134 Dr Jordan
14 Consultant paediatrician, Singleton Hospital, Swansea

death of Dr L G Davies … I persuaded Dr Hyam Joffe … to hold regular clinics with us in Swansea starting some time in 1986.'[15]

16 Dr Baker noted that the paediatricians working in Dr Davies' health authority, that is Gwent Health Authority:

'… found referral to Bristol as being effective and a good service …

'The Chief Administrative Medical Officer for Gwent, Dr Harrett offered honorary contracts to Drs H Joffe and S Jordan for clinics in Gwent.'[16]

17 Dr Jordan said that in South Wales the Bristol cardiologists visited clinics:

'… in Newport (Dr Jordan, afternoon), East Glamorgan (Dr Jordan, all day), Swansea (Dr Joffe, all day), Bridgend (Dr Martin), Carmarthen (afternoon, Dr Jordan) and Haverford West (Dr Jordan, morning or all day).'[17]

18 There was some correspondence on the cost of running such clinics. For example, in a letter dated 24 February 1987 to Ms Jerrard, in the Medical Personnel Department at District Headquarters, Dr Jordan discussed the clinic at Newport in Gwent Health Authority. He wrote:

'In general the main effect of this clinic will not be to increase the numbers of patients being treated in Bristol but to avoid travelling for children and their parents. However, I think it does underline the necessity for the Bristol and Weston Health District with the South West Regional Health Authority to ensure that the financial arrangements with the Welsh Office are adequate.'[18]

19 Later that year, on 8 May, Dr Baker said in a letter to Mr Wisheart, Mr Dhasmana, Dr Jordan and Dr Joffe:

'… several London hospitals as well as Southampton, have cardiologists who are active in holding clinics in South and Mid Wales and referring patients to their own centres for cardiac surgery. Unless the Welsh Office and the constituent authorities decide where they wish to spend their resources and organise the referral patterns through the relevant cardiologist, then we cannot be confident about the volume of service which will be required from our units here in Bristol. If this is not agreed, then we cannot sensibly determine the implications for our services in terms of space and staffing nor can we make appropriate charges upon the Welsh Office or any other DHSS funding source to cover the costs of the service.'[19]

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15 REF 0001 0085; letter from Dr Agarwal to the Inquiry
16 WIT 0074 0022 Dr Baker
17 WIT 0099 0015 Dr Jordan
18 WIT 0074 0449 Dr Baker
19 UBHT 0092 0002; letter from Dr Baker dated 8 May 1987

20 The Bristol cardiologists also conducted clinics in the West Glamorgan Health Authority and the Mid Glamorgan Health Authority.[20]

Conduct of the clinics

21 Dr Barry Keeton[21] explained that outreach clinics could cause communication problems between colleagues:

> 'It is difficult when one is out in the peripheral clinics, which may have you in the car for three or four hours. Today with mobile phones it is easier to communicate with one's colleagues, but it would not be unusual for me to be phoned at a peripheral clinic by the surgeon to talk about something, and I would feel that was proper and correct.'[22]

22 Most of the clinicians who conducted the outreach clinics commented on the length of time the clinics took.

23 Dr Jordan said:

> 'As far as the clinics which I personally carried out (and I believe the same applied to those held by my two colleagues) they were busy clinics, often extending until 7pm or later in the evening and even so the numbers of patients seen often meant that the time available for each was less than ideal. (Unless continued efforts were made, the booking clerks tended to book at the same rate as general paediatric clinics with about 12–15 patients per hour.) One of my main principles was that we should not allow waiting lists for clinics to develop even if it meant doing extra clinics when the load demanded it. In consequence, we were generally able to see any patient referred (mostly from local paediatricians) within a month.'[23]

24 Dr Jordan's oral evidence included this exchange:

> 'Q. These clinics would last all day, would they, wherever you were?
>
> 'A. Yes, I suppose typically the clinic in Truro, for example, I would actually start at half 8 which meant getting up and leaving Bristol at half 5 or so. The clinic itself would go on usually until about 7, 7.30. I would have to do a certain amount of clearing up afterwards, and then get myself back to Bristol, usually via one of the fish and chip shops on the way for sustenance.

20 WIT 0074 0024 Dr Baker
21 Consultant paediatric cardiologist, Southampton General Hospital, and one of the Inquiry's experts
22 T51 p. 145 Dr Keeton
23 WIT 0099 0016 Dr Jordan

'Q. So these were long days?

'A. They were long days. They were not the end of the day, either, because it was not infrequently the case that I would either have a call when I was down there to say "When you come back to Bristol, can you pop into the Children's Hospital", occasionally into the BRI, and see someone, and I would have to continue even after I got back to Bristol.

'Q. So in the course of such a clinic, you can easily see 100 patients, perhaps?

'A. I think 100 is a bit of an exaggeration. The Truro clinic included some time for doing echocardiography, so the numbers would not be that great, but I recall, when Dr Hayes came here, I actually went down with her for the first clinic, because it was one place where she did not know any people and we actually sat there in two separate rooms seeing patients until 7 o'clock, so heaven knows what time I would have got away if I had been there on my own.'[24]

25 Dr Robin Martin, who also conducted outreach clinics, commented on the same issue. His evidence to the Inquiry included this exchange:

'Q. … the peripheral clinics, from your description, they take all day?

'A. Most of the peripheral clinics are all day consultation plus you have obviously the travelling times on top.

'Q. So because of the travelling times, because it is all day, it is unlikely, I suspect, that on those days you managed to get into either the BRI or BCH, or do you start there or finish there?

'A. I might well. Most of the times I would probably not be at either place before the clinic started. That just would not be feasible. If I was on call, which you quite often would be on call with one of your colleagues covering you on the day whilst you are out, then I would call back to my home centre, which I would view as the Children's Hospital, in the evening and see any patients that were there.

'Q. In all of this workload which you have described … did you have the assistance of any junior staff?

'A. Not "on the road", if you like, when I went to the peripheral clinics. Those were totally consultant-based usually, sometimes in conjunction with local paediatricians, so it was very important for building links locally there.'[25]

24 T79 p. 126–7 Dr Jordan
25 T77 p. 43–4 Dr Martin

The involvement of local clinicians

26 Dr Jordan also commented on the input of local clinicians:

> 'In most clinics the paediatricians joined us which although considered to be somewhat wasteful in terms of staffing was an ideal arrangement as it allowed both the cardiologists to learn from the specialised knowledge of the paediatricians and the paediatricians to keep abreast of the way which we were managing patients.
>
> 'Mr Wisheart attended a few of the clinics but it was more difficult for him to fit this in with his operating schedule and gradually he came less, and usually only for part of a clinic …
>
> 'Great efforts were made by the cardiologists and the cardiac surgeons to maintain lines of communication with paediatricians. I personally dictated all my own discharge summaries and copies of letters were also sent. Both of these contained full details of treatment, outcomes and future plans …
>
> 'The paediatric cardiologists and to a lesser extent the surgeons were frequently asked to join in post graduate meetings in peripheral hospitals and present papers or clinical cases at meetings.'[26]

27 Dr Alan Day[27] said:

> 'I have established very close working links with Dr Martin and normally see him when he comes to this clinic and, if possible, sit in on consultations about my patients. In addition we have excellent telephone links, both with himself and colleagues, and I have been impressed by the standard of the cardiac diagnostic services.'[28]

28 Dr David Challacombe[29] recalled:

> 'My contacts with the paediatric cardiac surgical services at the BCH and BRI were mainly through the paediatric cardiologists, who gave an excellent service to patients and parents. After patients were seen at the joint cardiac clinics in Taunton, arrangements were made for them to be admitted to the BCH for cardiological investigations. My next contact with them would have been at the next cardiac clinic in Taunton and I would have received a discharge letter from the cardiologists with details of the operation performed and the patient's post-operative condition.'[30]

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26 WIT 0099 0016 Dr Jordan
27 Consultant paediatrician, Cheltenham General Hospital
28 REF 0001 0012; letter from Dr Day to the Inquiry
29 Consultant paediatrician, Taunton and Somerset Hospital
30 REF 0001 0030; letter from Dr Challacombe to the Inquiry

29 Dr John Tripp[31] said:

> 'We enjoyed a very close working relationship with the Paediatric Cardiologist from the BRI. In the early years I did one or two joint clinics with Mr James Wisheart in addition to frequent joint clinics with Dr Hyam Joffe and Dr Stephen Jordan. Actually doing joint clinics has become rarer over the years and is now not the way these clinics are conducted.'[32]

The involvement of the surgeons

30 Mr Wisheart explained the input of the Bristol surgeons:

> 'Of the two surgeons, I attended outpatient clinics in Taunton on a quarterly basis and in Exeter, on a six-monthly basis; at each place this was a joint clinic with the paediatric cardiologist and the local paediatricians.'[33]

31 Senior Lecturer in Child Health, Royal Devon and Exeter Healthcare NHS Trust
32 REF 0001 0062; letter from Dr Tripp to the Inquiry
33 WIT 0120 0069 Mr Wisheart

Chapter 11 – Referrals

Introduction

1 The aim of this chapter is to set out the extent to which referrals to Bristol from its catchment area followed the pattern that might have been expected, and to present the evidence as to the pattern of referrals from the Bristol cardiologists and surgeons to other centres. The position in South Wales will be considered separately, since distinct factors such as the role of the Welsh Office and the development of a specialist paediatric cardiac unit in Cardiff influenced and altered referral patterns.

2 During the period of the Inquiry's Terms of Reference, the BRI and the BRHSC provided a paediatric cardiac service to a large geographical area, encompassing much of the South West of England and South Wales. This area is referred to in this chapter as the Bristol 'catchment area'.

3 Bristol had historically provided a service to the catchment area through peripheral or 'outreach' cardiology clinics conducted by the Bristol-based cardiologists, and by accepting referrals to Bristol from the catchment area. These arrangements were, in part, formalised for the youngest patients by the designation of Bristol as a Supra Regional Centre (SRC) for Neonatal and Infant Cardiac Surgery (NICS) from 1984 until 31 March 1994.[1] The function and organisation of the outreach clinics are dealt with in Chapter 10.

4 On the establishment of the Supra Regional Service (SRS), initially nine centres were designated to provide NICS: Bristol; Birmingham Children's Hospital; The Royal Liverpool Children's Hospital; Killingbeck Hospital, Leeds; The Freeman Hospital, Newcastle; Southampton General Hospital; Great Ormond Street Hospital for Sick Children (GOS), London; Brompton Hospital, London; and Guy's Hospital, London. From a geographical point of view, Bristol was the obvious referral destination for much of South Wales and the South West of England. However, referrals did not always follow this pattern.

5 The table below shows occupied bed days (OBDs) for NICS by region of referral based on 1992–1993 data[2] and illustrates that referrals to centres outside the geographical catchment area was not something peculiar to Bristol.

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1 Detail of the designation and de-designation of Bristol is set out in Chapter 7

2 The figures are taken from an annex to a letter sent by Sir Alan Langlands to regional general managers in November 1993 (EL(93)100). See DOH 0002 0249 and DOH 0002 0253

Table 1: Occupied bed days for neonatal and infant cardiac surgery 1992–1993 by region of referral

	Birmingham	Freeman	Guy's	GOS	Leeds	Brompton	Harefield	Bristol	Alder Hey	Southampton
Northern	9	1832	-	13	-	-	-	-	117	-
Yorkshire	19	16	-	-	2162	-	-	-	-	-
Trent	202	8	-	135	1057	50	-	-	7	-
E Anglian	-	-	305	693	-	237	44	-	-	-
NW Thames	-	-	198	1082	1	505	919	-	-	-
NE Thames	-	-	362	1796	-	706	85	-	-	-
SE Thames	-	-	1452	196	-	509	-	-	-	-
SW Thames	-	-	173	239	-	936	57	-	-	34
Wessex	-	-	-	52	-	-	-	127	-	1589
Oxford	19	-	27	316	-	28	108	-	-	44
S Western	10	-	-	-	-	5	-	2794	-	346
W Midlands	5018	-	-	-	-	5	-	-	74	-
Mersey	60	-	-	6	-	-	-	-	1971	-
N Western	268	-	-	-	132	-	-	-	1460	-
Others (Scotland, Wales, overseas)	223	13	48	145	-	342	47	807	384	69
Totals	5828	1869	2565	4673	3352	3323	1260	3728	4013	2082

6 The Inquiry heard that, generally, referrals would be from a paediatrician within the catchment area to a Bristol cardiologist (Dr Hyam Joffe, Dr Stephen Jordan and latterly Dr Robin Martin and Dr Alison Hayes) for an opinion or investigation. The cardiologist would see the child either at the BRHSC or at an outreach clinic.

7 If the cardiologist considered surgery was likely to be required, then the child would be referred to a paediatric cardiac surgeon. Usually a child referred to a Bristol cardiologist who required surgery would be referred on by that cardiologist to one or other of the Bristol surgeons, Mr James Wisheart or Mr Janardan Dhasmana. However, on occasion the Bristol cardiologist, or the Bristol cardiologist in conjunction with the Bristol surgeon(s), would refer a child on to another centre for surgery. This is considered in more detail later in this chapter.

8 In setting out the evidence on the extent to which the referrals to and from Bristol followed, or diverged from, the expected pattern, this chapter will consider the factors that may have influenced the pattern. They include:

- referring consultants' personal relationships with cardiologists;
- historical factors (e.g. referring consultants following an established pattern of referral to Bristol or elsewhere);
- contractual constraints;
- waiting lists at Bristol and at other potential alternative centres;
- financial incentives to refer patients in the catchment area to centres other than Bristol;
- views held by referring consultants as to the standards of care at Bristol and other centres;
- special cases such as children with Down's syndrome, children being considered for heart or heart-lung transplant or (after October 1993 in particular) neonatal Switches; and
- requests by parents.

9 This chapter will set out the information that was available to referring clinicians and parents on which to base their decisions on referral. This will include an examination of the extent to which those making referrals had available to them information about the standards of care available at Bristol and the other centres.

10 This chapter will also set out the information that was provided to parents on the referral of their child, whether to Bristol or elsewhere; about why their child was being referred to a particular centre; and whether and in what circumstances referral to centres other than Bristol was offered to parents as an alternative or substitute for Bristol.

11 In July 1999 the Inquiry wrote to consultant paediatricians and cardiologists who had been based within the Bristol catchment area, in 19 NHS trusts, during the period of the Inquiry's Terms of Reference, seeking their comments on their own referral practices. Most of those who replied and were able to provide evidence falling within the Terms of Reference are, or were, consultant paediatricians in hospitals in the South West of England and in South Wales.[3] Their comments and those of parents were a valuable source of information.

12 The Inquiry initially contacted 29 NHS trusts, seeking the names of referring clinicians. As a result, the Inquiry wrote to 88 clinicians employed in 19 NHS trusts. Eighty-one clinicians replied. However, of those 81, nine fell outside the Inquiry's Terms of Reference, either because they were not in post in 1984–1995 or because they dealt only with adults. Thus, the total number of relevant replies was 72.[4]

13 The Inquiry commissioned a statistical analysis of Hospital Episode Statistics (HES) for Bristol for the years 1991–1995 from Dr Paul Aylin.[5]

14 Dr Aylin was asked to look at referral patterns to the UBHT from its catchment area, and to compare them to referral patterns to other centres from their respective catchment areas. The question of different patterns of referral depending on differing socio-economic status was also addressed. The main finding of this analysis, which focused on open-heart operations between 1991 and 1995, was that the ratio of the residents going out of the UBHT catchment area for surgery compared to those coming in from other areas, is high in Bristol.[6] As regards children aged under 1 year, there were none from England *outside* the catchment area that came to the UBHT to be operated on.[7] However, a third of children under 1 year *within* the Bristol catchment area were being treated in centres elsewhere in England. With regard to socio-economic status, there appeared to be a tendency for higher proportions of under-1-year-old children who were from affluent areas to be treated elsewhere for open-heart operations, but other centres in England also displayed this trend.

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3 The Inquiry wrote to 88 clinicians in Bath & West Community NHS Trust, Bro Morgannwg NHS Trust, East Gloucestershire NHS Trust, Gloucestershire Royal NHS Trust, Gwent Healthcare NHS Trust, North Glamorgan NHS Trust, Northern Devon Healthcare NHS Trust, Pembrokeshire & Derwen NHS Trust, Plymouth Hospitals NHS Trust, Pontypridd & Rhondda NHS Trust, Royal Cornwall Hospitals NHS Trust, Royal Devon & Exeter Healthcare NHS Trust, Royal United Hospital Bath NHS Trust, South Devon Healthcare NHS Trust, Swansea NHS Trust, Swindon & Marlborough NHS Trust, Taunton & Somerset NHS Trust, University Hospital of Wales Healthcare NHS Trust, and Weston Area NHS Health Trust

4 Three clinicians commented but were barely within the Terms of Reference (one worked in Taunton for a month in 1995, one worked in Gloucester from March 1995 and one retired in May 1984)

5 Analysis of Hospital Episode Statistics, Aylin et al., 1999. See Annex B

6 Dr Aylin added a caveat that the findings be treated with caution because of the difficulties of defining catchment areas. See INQ 0013 0045

7 Table 1, para 5 above shows a figure for referrals to Bristol from Wessex. It should be noted, however, that Dr Aylin's report focused on open procedures only. So too should his caveat about the difficulty in defining catchment areas. See INQ 0013 0045

Referrals to Bristol – referral procedure, the catchment area and finance

Referral procedure

15 Dr Joffe explained the referral procedure:

> 'It was very rare for a child with suspected heart disease to be referred directly to paediatric cardiac surgeons from GPs, consultant paediatricians, or by self-referral. … The vast majority of such patients were referred initially by GPs, or medical staff in maternity units, to a consultant paediatrician in their area. The local paediatrician would be responsible for referring the patient to a paediatric cardiologist, either immediately, if the child was very ill, or was thought to need therapeutic intervention soon, or to a regular peripheral cardiology clinic in their area in the future … The only general practitioners who referred children with suspected, non-urgent heart abnormalities directly to the paediatric cardiologists' OPD [outpatient department] sessions in BCH were those who practised in the catchment areas of the four Districts of the Avon Area Health Authorities; later, the four local Trusts. The paediatricians in Bristol were by-passed because the paediatric cardiologists were more readily accessible to local families.'[8]

16 Mr Wisheart told the Inquiry that 'All paediatric cardiac referrals came through the paediatric cardiologists'[9] and Mr Dhasmana agreed: 'Children … were referred to paediatric cardiologists at Bristol in the first instance.'[10]

The catchment area

17 Bristol had historically provided a paediatric cardiac service to its catchment area. As the 1982 memorandum[11] prepared by Dr Joffe, Dr Jordan and Mr Wisheart put it:

> 'The paediatric cardiology service already functions as the de facto Regional and Supra Regional Centre (although not yet officially recognised as such), drawing 28% of new referrals to the unit from Avon, 48% from the rest of the SW Region and 24% from South Wales, North Wessex and elsewhere. …
>
> 'The long term management of patients is supervised near their homes through a system of Consultant Cardiac Clinics developed over many years and probably more comprehensive than in any other paediatric cardiology service in England. Regular peripheral clinics are held in Bath, Swindon, Cheltenham, Gloucester,

8 WIT 0097 0289 Dr Joffe
9 WIT 0120 0116 Mr Wisheart
10 WIT 0084 0062 Mr Dhasmana
11 Memorandum on the Designation of Bristol as a Supra Regional Centre (SRC) in Neonatal and Infant Cardiology and Cardiac Surgery, July 1982, JDW 0001 0150 – 0152, and see further Chapter 7 where designation of Bristol as a Supra Regional Centre is discussed

Taunton, Barnstaple, Exeter, Torquay, Plymouth and Truro. Close liaison exists with paediatricians in all these centres, who would resist any curtailment in the services they and their patients receive.'

18 Mr Wisheart said that referrals to the Bristol cardiologists came from:

- 'All the District General Hospitals in the old South Western RHA territory, except … Plymouth, who referred most of the children to Southampton, Yeovil who referred a proportion of their children to Southampton.
- 'Bath and Swindon in the old Wessex Regional Health Authority territory. I do not know whether they sent all their children to Bristol, but I believe that Bath did send virtually all its patients to Bristol, while Swindon sent a significant proportion of its referrals to Oxford, or possibly Southampton.
- 'A number of District General Hospitals in South Wales. The number of hospitals in South Wales referring to Bristol has varied over the period 1984 to 1995. There were some centres referring in 1984; this increased through the mid and late 80s when there was no cardiological facility in Cardiff. After the setting up [of] the paediatric cardiological facility there, the number of DGHs using Bristol decreased.
- 'The General Practices, which before 1991 were within the Bristol and Weston Health Authority, and possibly also the Southmead and Frenchay Health Authorities. After 1991 the practices within the corresponding Trusts.'[12]

19 Dr Jordan[13] and Dr Joffe each provided the Inquiry with a list of the hospitals from which children were referred to them.[14] The hospitals named by them were:

South Western Region:

Gloucestershire Royal Hospital (Gloucester)

Cheltenham General Hospital (Cheltenham)

Musgrove Park Hospital (Taunton)

Royal Devon and Exeter Hospital (Exeter)

North Devon District Hospital (Barnstaple)

Torbay Hospital (Torquay)

12 WIT 0120 0116 Mr Wisheart

13 Dr Jordan told the Inquiry: 'Essentially all patients from consultant paediatricians in [these] hospitals were sent to Bristol', although in relation to the Royal Devon and Exeter he said 'possibly not all Dr Kennaird's "cold" referrals', and in relation to Swindon 'latterly some were sent to Oxford'. See WIT 0099 0035 Dr Jordan

14 Dr Jordan's list is at WIT 0099 0035 and Dr Joffe's at WIT 0097 0290

	Royal Cornwall Hospital (Truro)
	Derriford Hospital (Plymouth)
Wessex:	Royal United Hospital (Bath)
	Princess Margaret Hospital (Swindon)
South Wales:	Royal Gwent Hospital (Newport)
	East Glamorgan Hospital (Mid Glamorgan)
	Princess of Wales Hospital (Bridgend)
	Morriston (formerly Singelton) Hospital (Swansea)
	West Wales General Hospital (Carmarthen)
	Withybush Hospital (Haverfordwest)
	Neath General Hospital (Neath)
	Nevill Hall Hospital (Abergavenny)[15]

Finance

20 The NICS service (for under-1s) was funded through the mechanism of the Supra Regional Services Advisory Group (SRSAG), following Bristol's designation as an SRC for NICS in 1984.

21 In relation to paediatric services for the over-1s, Mr Graham Nix explained that at the beginning of the period of the Terms of Reference (1984), funding was received 'from government and [went] to the Regional Health Authority for the South West Region. That money was allocated out to each of the Districts of which Bristol & Weston Health Authority was one.'[16]

22 A report of a Strategic Planning Working Party in 1983[17] recorded an excess of demand over supply for open cardiac surgery generally (i.e. adults and paediatrics) in the South West Region in 1982. Mr Nix emphasised that the report 'refers to the fact that the South West Region should continue to send patients to London as well'.[18]

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15 See also figures for referrals from the catchment area and 'outreach' clinics in the Annual Reports of the Bristol Paediatric Cardiology and Cardiac Surgery Unit for 1987 (UBHT 0166 0001 – 0014) and 1988 (UBHT 0124 0006 – 0016)

16 T22 p. 17 Mr Nix

17 UBHT 0266 0415; report of a Strategic Planning Working Party dated 14 February 1983

18 T22 p. 26 Mr Nix

However, he pointed out that at that time there were difficulties in identifying the numbers of patients who were referred from the region to London:

> 'Within the South West Region we, all the health authorities, had worked together to use the same computer systems, so it was possible to access data about patient flows, so we were in the infancy around that time as well, but at least we could access information. There was not the sophistication that exists now where we know where every patient comes from'

but as for London

> 'They are in a completely different region so you would actually have had to have gone to those hospitals and said "Do you care for any of the patients in the South West?" and with a lot of the hospitals in this country, they would not have had any idea where their patients were coming from. It would have been a manual exercise, probably, to have gone through every set of notes to find out where those patients' residential address was.'[19]

23 The costs of treating patients from outside the Bristol & Weston District Health Authority (B&WDHA) were charged to the referring district by means of the Resource Allocation Working Party (RAWP) cross-boundary flow mechanism.[20] The report of the Strategic Planning Working Party noted that districts providing regional specialties were deemed to have the financial resources for providing these specialties within their existing allocation.[21] Mr Nix explained, however, that data on the cross-boundary flow was probably two years old, if not older.[22] This meant that expansion of a service took a long time to be reflected in the RAWP funding mechanism.[23] Mr Nix told the Inquiry that the RAWP mechanism was 'basically incapable' of funding regional specialties.[24] Thus, according to Mr Nix, in order to fund regional specialties the RHA had to agree to give some special help to the DHA that happened to host the regional specialty.[25] Assistance did come from the RHA. For example, on 11 July 1983,[26] the South Western Regional Health Authority (SWRHA) agreed to a one-off three-year funding package to B&WDHA for the three years beginning with 1984/85, in order to finance a further expansion of the cardiac capability at Bristol.[27]

19 T22 p. 27–8 Mr Nix. A Working Party report in 1984 recorded that there were facilities for 375 open (adult and paediatric combined) cardiac operations in Bristol in 1984, which was less than two thirds the number of such operations being carried out on residents of the South West Region. See UBHT 0295 0276 and T22 p. 38–40 Mr Nix
20 T22 p. 60 Mr Nix. These issues are dealt with in more detail in Chapter 6
21 UBHT 0266 0417; report of the Strategic Planning Working Party dated 14 February 1983
22 T22 p. 30 Mr Nix
23 T22 p. 30 Mr Nix
24 T22 p. 30 Mr Nix
25 T22 p. 31 Mr Nix
26 Before the years of the Inquiry's Terms of Reference
27 UBHT 0295 0276. See Chapter 6 for more detailed consideration of these issues

24 The Inquiry heard that there was, at least before 1 April 1991, a theoretical financial incentive for hospitals within the catchment area, but outside the District, to refer cases to London rather than Bristol.[28] This was because of the way that certain of the London hospitals 'charged' referring districts through the RAWP formula. The Inquiry heard evidence that London hospital statistics did not regard cardiac surgery as a separate specialty. Their RAWP 'recharge' was based either on the cost per case of thoracic or general surgery, which led to a lower amount than was 'recharged' by Bristol for cardiac surgery, which was treated by Bristol as a separate, more costly specialty.[29] The Special Health Authorities (SHA) such as the Brompton, Hammersmith and Great Ormond Street received separate funding not included in the RAWP allocations and the services they provided were 'free'. Hence it was cheaper to make referrals to London. This did not, however, mean that the actual cost of the operation in the London hospital was necessarily lower than in Bristol. Whatever the actual costs were, however, there was, in theory, a financial incentive to refer to London.[30] However, the Inquiry heard no evidence from referring clinicians that this influenced their own referral decisions.

25 In 1990/91 charging for inter-district cross-boundary flows was introduced, and contracts were introduced from 1 April 1991.[31] As a result of changes introduced following the NHS Review '*Working for Patients*', the resource allocation system changed on 1 April 1991. From then on, allocations were calculated for the purchasers that contracted services from providers.[32]

26 The funding of referrals from Wales is dealt with later in this chapter.[33]

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28 T22 p. 62–3 Mr Nix

29 T22 p. 60–1. Mr Nix was discussing a document from the Plymouth Health Authority, concerned with the needs of Devon and Cornwall residents for cardiac surgery, dated 9 September 1985; UBHT 0295 0516. Mr Nix told the Inquiry that at this time the Bristol 'recharge' for an adult open cardiac operation would be the same as a paediatric open-heart operation

30 T22 p. 62–3 Mr Nix

31 T22 p. 142 Mr Nix

32 See further Chapter 6

33 See para 144

Referrals to Bristol – information available to referring clinicians about standards at Bristol or elsewhere and factors influencing referral patterns

27 Mr Steven Owen[34] told the Inquiry:

> 'I was constantly being told that clinicians had their favourite units, they established working relationships with the people, and in practice, if they referred to unit A, whatever other units were or were not doing, they would in all probability continue to refer to unit A.'[35]

28 Professor David Baum, then President of the Royal College of Paediatrics and Child Health (RCPCH), also explained the culture in relation to referrals at the time of the Inquiry's Terms of Reference:

> 'My memory of the context of the time is that this was not a culture – which I think is a desirable culture, but it was not the culture – of, "This has been the quality of my clinical performance with these outcome measures for the last five years, those are my cards, do you like them or do you want somebody else's cards?" It was very much more broadly an atmospheric of, "This is a good guy, this is not such a good guy". But within that has to be titrated the urgency of the matter, so if the matter was urgent or were urgent tomorrow, there would be the other consideration of, "Is it on my patch or am I going to look at the cards to such a degree I am going to send the patient to another patch?" … in 1990/1994, as a paediatrician, if I feel this child is unwell and there is a cardiological problem of some severity, it would not, I believe, have entered my consciousness to think, "What is the quality, outcome, performance, audit, of my colleague cardiologists?" I would say, "There are competent consultant-trained cardiologists on this corridor who are my colleagues who I trust through their training and I trust them as individuals, that I will refer the care of the baby".'[36]

29 Asked whether his answer would have been any different if he had been a paediatrician in a district general hospital who was referring children to a paediatric cardiologist in another hospital, Professor Baum said:

> '… it would have been different, but the difference would have still hung on an atmospheric of quality of service, rather than on any published measured audit of accuracy of diagnostic skills.'

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34 Administrative Secretary of the SRSAG from January 1992–February 1996
35 T12 p. 40 Mr Owen
36 T18 p. 71–2 Professor Baum

He said that the information on which he would have based judgments was:

> 'Many strands. They would include a reputation of diagnostic skills. And how does that reputation get about? Well, there are the value of clinical meetings, the value of first- and second-hand discussions, the gossip network. So there would be diagnostic skills; there would be matters of professional courtesy; again, the gossip vine of how they are with parents who are worried about their sick child; how they are in terms of their relationship with their firm, with their juniors, as trainers, with their colleagues. There would be an element of their efficiency professionally, of how quickly they could accommodate what I am saying, "This is an emergency", and how far they will put themselves out to come to see the child in my clinic in the DGH or to arrange transport and so forth, and many other elements. So it is professional diagnostic skills and other elements of professionalism.'[37]

30 Dr William Reith, Honorary Secretary of the Royal College of General Practitioners (RCGP), told the Inquiry that referrals by GPs directly to paediatric cardiologists would be rare. A GP would rarely encounter a child with a congenital heart defect in his or her practice due to the rarity of the condition. The average list size would only contain ten patients of all ages affected by congenital heart disease, with one new case arising about every five years. Dr Reith said that as the initial diagnosis of a heart defect would be likely to be made by a paediatrician or a paediatric cardiologist, by the time a GP had contact with the child, it might well be that both diagnosis and a course of treatment, even surgery, had taken place.[38]

31 Asked, in the event that a GP was considering whether to refer to a paediatrician, on what data or information the GP's judgment as to the adequacy of the service likely to be provided by that paediatrician would have been based, Dr Reith told the Inquiry:

> 'Not very much, in all honesty. I mean, much of the general practitioner's decision to refer will be on the basis of personal knowledge. Over time, a general practitioner will get to form a view, an opinion, on the range of abilities and indeed the range of specialisation of consultant colleagues, and again, different specialties have evolved at different rates, so, for example, in surgery, there was some specialisation some time ago, a number of years ago, in many centres into surgeons specialising in breast surgery, thyroid surgery and that sort of thing. In the surgical condition of ophthalmology, it is only now there is specialisation into those dealing with retinal problems, and so on, so again it must be taken in that context.
>
> 'Whether or not one would refer in the particular instance to a paediatrician or a paediatric cardiologist would depend to an extent on local practice. Probably, a large chunk of the population and their GPs do not have immediate access to a major hospital and many of them will be seen through district general hospitals which will tend to have a general paediatrician rather than a paediatric cardiologist. That again, I am sure you will appreciate, is due to population size and

37 T18 p. 70–4 Professor Baum
38 WIT 0059 0010 Dr Reith

so on. So there are many parts of the country where a general practitioner will refer on to a general paediatrician. There may be five or six paediatricians in the hospital and perhaps one or two of them might have a special interest in paediatric cardiology. That would not be the whole nature of their work, but obviously they have a particular interest in that.[39]

Sources of information available to referring clinicians

32 The Bristol surgeons and cardiologists explained the information that was available to referring clinicians, on which they might base a decision to refer a child to a particular unit. In particular, they addressed whether the Annual Reports of the Paediatric Cardiology and Cardiac Surgery Unit at Bristol would have been sent or made available to referring clinicians.

33 Dr Joffe said:

> '… information about individual cases was conveyed to the referring clinicians by comprehensive case summaries and by discussions at the peripheral clinics. A copy of the summaries was also sent to the GPs. I believe the [Bristol's] Annual Reports from 1987 to 1990 were circulated to the referring paediatricians from our department. In addition, the paediatric cardiologists took the opportunity to show the facilities at BCH … to various consultant paediatricians during the South West Paediatric Club meetings, held in Bristol on one of the two meetings each year, or on any other occasion.'[40]

34 Dr Joffe was asked to whom the Annual Reports would have been sent. His evidence included this exchange:

> 'The idea was to send the reports to the then District Health Authority, both the local one and peripheral centres, particularly to the … paediatricians around the region with whom we were related, so to say, by virtue of the peripheral clinics that we held at these various centres and we wanted them to have a view of what we were doing and of our figures and our enterprises.
>
> 'Q. You say the idea was to send the reports to the then District Health Authority, both the local ones and the peripheral centres. That was what you described as the idea; was it also the reality or not?
>
> 'A. Yes, we sent them out.

39 T16 p. 41–2 Dr Reith
40 WIT 0097 0291 Dr Joffe

> 'Q. Do you know whether they went to individual paediatricians who might refer cases to Bristol?
>
> 'A. I believe so. I really cannot recall exactly how the mechanism worked, but I believe my secretary or a secretary within the cardiology department would have been asked to send these reports to … the referring paediatricians.'[41]

35 However, Dr Joffe also stated in his written statement:

> 'As far as I understand the situation, there was no formal structure or requirement for the BRI and the BCH to convey information on the standards of treatment and care in their various departments to referring clinicians or to members of the public. I believe this was the case throughout the NHS and applied to services under the management of the B&WDHA during the 1980s and to UBHT in the early 1990s. This was also true for most, if not all, designated paediatric cardiac centres in the country.'[42]

He added that the Annual Report for 1989/90:

> '… included results for open and closed heart surgery for children over and under one year of age, and a comparison of the mortality rates in Bristol with the average UK results. As far as I am aware, Bristol was one of the first supra regional centres to make such comparisons available to clinicians, on a wide enough basis to put them virtually into the "public" domain. Unfortunately, these annual reports ceased when I became more heavily committed as Clinical Director of Children's Services from early 1991.'[43]

36 Dr Jordan also commented on the information available to referring clinicians. He said that Mr Wisheart personally provided him with information about the surgeons' results, for the purposes of preparing his Annual Report on paediatric cardiology to the management of the Children's Hospital.[44] But, he said:

> 'There was no consistent publishing of results either from Bristol or from the country in general. Paediatricians did receive feedback from parents, but this was likely more to refer to the general care they received than the actual overall comparisons of surgical results.'[45]

37 In his oral evidence, Dr Jordan said that referring paediatricians would probably not have known that there was an Annual Report produced and therefore would not have requested a copy.[46] His evidence was that the Annual Report was first produced in 1987, but that it was essentially for 'internal consumption' at the BRHSC and that

41 T90 p. 16–17 Dr Joffe
42 WIT 0097 0157 – 0158 Dr Joffe
43 WIT 0097 0159 Dr Joffe
44 WIT 0099 0033 Dr Jordan
45 WIT 0099 0036 Dr Jordan
46 T79 p. 153 Dr Jordan

whilst the 1987 report was disseminated more widely outside the hospital as 'a bit of advertising', later reports were not sent out.[47] This is in contradistinction to the evidence of Dr Joffe, referred to above.

38 Dr Jordan also said:

> 'I would have felt able, if someone said, "Can you give me a rough breakdown of how you stand in relation to the whole of the UK?" I would have been quite happy – and I may well have done this – to say "According to the figures that are actually reported to the UK register. I think, as you know, it is not actually comprehensive, there are a number of units that did not supply their data, but if you want to know how we stand, the answer is — the worst side of it is our mortality for open-heart surgery under the age of one year was higher than the national average and the figures, whatever they are, the totals over a year were similar and the totals for closed-heart surgery were rather better." I would not have had any objection or any difficulty in making that sort of statement if I had been asked "How do we stand as far as figures are concerned?"'[48]

In answer to a question from the Inquiry Chairman, Dr Jordan elaborated further on the point:

> 'Q. If an observer having heard your evidence formed a picture that you were someone who, recognising that there were some problems in Bristol, fought within Bristol to effect change while outside quietly suggested or warned people off; would that observer have any right to hold that view?
>
> 'A. There is some truth in it. I will perhaps give you an example: shortly before I retired[49] I had discussions with cardiologists in South Wales, I think this has sort of been obliquely referred to. Basically they were obviously considering whether they should continue to send patients to Bristol and take on a new cardiologist from Bristol, there was going to be a change anyway and they were being offered, in fact being encouraged to use the service in Cardiff instead. The thing I said to all of them, and I used very similar words but not necessarily identical ones were "You have asked my advice and what you are asking is really what is best for our patients. If I thought that the centre in Bristol was absolutely the best centre in the UK and there was no way that anyone else was going to produce comparable or better results, I would say to you, 'Do not try an untried unit in Cardiff'. Frankly, I do not think I am in a position to say that to you and therefore you will have to make up your mind whether you want to try a new unit or stick with Bristol." I think that is the sort of, if you like, comment I made which indicated that I was not going to go around blindly saying "Bristol is wonderful, keep on sending your patients there".'[50]

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47 T79 p. 140–1 Dr Jordan
48 T79 p. 151–2 Dr Jordan
49 Dr Jordan retired in May 1993. See WIT 0099 0010 Dr Jordan
50 T79 p. 188–9 Dr Jordan

39 Dr Joffe's evidence included this exchange:

> 'Q. Dr Jordan, in his evidence to us, in describing the 1980s, when he was asked about Bristol and the performance of Bristol, gently, I think, indicated in reply that Bristol was not the very best of cardiac centres. Would you have said the same had you been asked, let us say, by a referring paediatrician in those years?
>
> 'A. Yes.
>
> 'Q. Did you in fact do so?
>
> 'A. Yes, if asked, I would have done so, certainly.'[51]

40 Mr Wisheart said that the outreach clinics:

> '… enabled good professional relationships to be established between the referring paediatricians and the cardiological team in Bristol. It is my understanding that the referring clinicians were not in receipt of written information about the results of the work in Bristol; I did not send them my annual statistical summary or report and I do not believe that the cardiologists did either … I think that the most important exchanges of information were informal and took place in the clinics in relation to particular patients. The paediatric cardiologists, and to a much lesser extent myself, also gave talks in various post graduate centres and it would have been usual to present information and statistics on the results of work at such meetings.'[52]

41 Mr Wisheart went on:

> 'To the best of my knowledge the publication in January 1996 of the results in Bristol for paediatric cardiac surgery between 1990 and 1995 were quite unprecedented in the UK. This placed into the public arena the detailed discussions of all the paediatric cardiac surgical operations in Bristol in that period with figures from the UKCSR [UK Cardiac Surgical Register] for comparison.'[53]

42 Mr Dhasmana was also asked about the Annual Reports and whom they were intended for. He replied:

> 'I think the Annual Report was mainly produced by the paediatric cardiology department and the last one I was aware of was up to 1990. … so they would have circulated it amongst cardiac surgeons, their own colleagues and probably the Trust, and I would like to think to clinics where they were going to in the periphery.'[54]

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51 T90 p. 53 Dr Joffe
52 WIT 0120 0069 Mr Wisheart
53 WIT 0120 0070 Mr Wisheart
54 T86 p. 137 Mr Dhasmana

43 The pattern which emerged from the letters from those referring clinicians who responded to the Inquiry's initial request for information about referral practice was that they had little or no hard evidence of the results at Bristol or elsewhere. Many respondents (26) made the point that they had no data on which to base conclusions about the quality of care at any particular centre, let alone to make proper comparisons with other centres. The written evidence from referring clinicians included the following examples.

44 Dr M Webb:[55]

> 'The informal sources of information would have been on feedback through patients, and there was no concern being expressed by those patients I did see again. However most patients referred into the cardiology service would then remain within that service for subsequent follow up and I would not necessarily have been aware of significant morbidity, or even mortality, unless patients had continued to be followed up by me for other reasons – patients in this latter category would have been very few in number indeed.'

45 Dr R Trefor Jones:[56]

> 'With respect to the sources of information available regarding standards of treatment and care, this is a wider issue and in fact, there is no adequate information system available for the standard of care anywhere. … It is usually by word of mouth by other colleagues that one establishes what standard of care is in other units. There is always an assumption of course, that units such as Great Ormond Street, The Brompton Hospital, Guy's Hospital, Birmingham Children's and Alder Hey in Liverpool all have very high standards.'

46 Dr P Edwards:[57]

> 'The sources of information available in the years referred to: 1984–1994, were essentially informal, and essentially included our visiting Paediatric Cardiologist and general Paediatric Consultant colleagues, mainly in South Wales, many of whom during this period obtained a service from Bristol.'

47 Dr A Griffiths:[58]

> 'Bristol have always given us a good service and to the best of my knowledge we have had no problems with the children whom we have referred. We have however been highly dependent on the advice given to us by the Bristol cardiologists.'

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55 Consultant paediatrician, Gloucestershire Royal Hospital, REF 0001 0008 – 0009
56 Consultant paediatrician, Princess of Wales Hospital, Bridgend, REF 0001 0115
57 Consultant paediatrician, Princess of Wales Hospital, Bridgend, REF 0001 0109
58 Consultant paediatrician, Nevill Hall Hospital, Abergavenny, REF 0001 0129

48 Two referring clinicians told the Inquiry they were aware of data on outcomes at Bristol. Dr Dewi Evans told the Inquiry:

> 'I recall a report from Dr Joffe sometime in the mid 1990s regarding results. I think the report was commissioned specifically when concerns had been expressed regarding high mortality rates for certain procedures.'[59]

49 Dr T Perham said that information on standards of care may have been available at the South West Paediatric Club:

> 'I cannot definitely remember any discussions regarding this item but have some memory of delivery of a paper by the paediatric medical cardiologists from Bristol on the results of their treatment that was delivered to the club some years ago. I have a feeling that it related to the question of early intervention versus late intervention …'[60]

50 None of the referring clinicians in their initial letters to the Inquiry said that they had seen, or had requested, a copy of an Annual Report from Bristol. However, in light of the uncertain evidence heard by the Inquiry on this point, the 69 referring clinicians that were in post at the relevant time[61] were specifically asked to address whether they had seen or requested a copy of these reports.

51 The Inquiry received replies from 65 referring clinicians. Of those, 64 said, with varying degrees of certainty, that they had not seen the Annual Reports. Some were sure that they had not seen copies, but a number made the point that they were now relying on their memories of events up to 13 years ago.

52 For example Dr Bosley[62] told the Inquiry:

> 'I have received reports from the Bristol Cardiology Service, but I can only be sure of receiving them in more recent years and feel really very unsure regarding these particular [reports] of over 10 years ago'.

53 Dr R Jones:[63]

> 'I do have a copy of the Bristol Audit Report for Cardiac Surgery from 1996/1997, which I believe is the first such report that I was ever sent.'

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59 Consultant paediatrician, Singleton Hospital, Swansea, REF 0001 0087 – 0088. Dr Evans said in his letter that this was 'many years after' he had elected to send his patients to Cardiff, which he did in 1991

60 Consultant paediatrician, Derriford Hospital, Plymouth, REF 0001 0147

61 Those clinicians whose practice fell within the Terms of Reference *and* who were in post at a time when or not long after the reports were likely to have been sent (letters were not sent to clinicians who left post before 1987, or did not arrive in post until 1992 or later)

62 Consultant paediatrician, North Devon District Hospital, Barnstaple, REF 0002 0015 Dr Bosley

63 Consultant paediatrician, Derriford Hospital, Plymouth, REF 0002 0030 Dr Jones

54 Dr A Palit:[64]

> 'I did not receive at any time the Annual Report for the Department of Paediatric Cardiology/Surgery. Neither did I expect it. Even if I had received these reports, I wouldn't have read them for the following reasons:
>
> '1. Statistics produced from a different set up can be totally misleading.
>
> '2. Apart from Cardiology, I also do the following special clinics with visitors from tertiary centres:- Genetics, Paediatric Surgery, Gastroenterology, Neurology, Nephrology, Respiratory Disorder/Cystic Fibrosis, Endocrinology.
>
> 'If I were to read the Annual Reports of each of these specialist departments and try to make any meaningful conclusion out of them, I would be doing no other work at all!'

55 However, Dr P Rudd[65] said:

> 'I believe that I have seen at least one of these reports. I remember hearing a presentation at the Southwest Paediatric Club given by Dr Jordan during this period in which he discussed the annual report and the results of paediatric surgery. I think that this was probably in 1986 or 1987/88. I seem to remember that the report was circulated at that meeting. I believe that more than one report was circulated to me at my hospital address but I cannot be certain about this.'

The role of the referring clinician

56 The letters from referring clinicians provide evidence on the factors influencing their referral patterns. However, it should be noted that six referring clinicians expressed the view that it was not part of their role to monitor or assess standards at Bristol or elsewhere. Many made the point that a consultant paediatrician would only rarely expect to see congenital heart defects in their practice.

57 Dr R Prosser:[66]

> 'I do not feel that a General Paediatrician in a District General Hospital is in a position to compare the level of excellence of different Units in the country especially when considering the variety and rarity of some of the conditions and the lack of any specific directive from any other source.'

64 Consultant paediatrician, Withybush General Hospital, Haverfordwest, REF 0002 0005 Dr Palit
65 Consultant paediatrician, Royal United Hospital, Bath, REF 0002 0031 Dr Rudd
66 Consultant paediatrician, formerly at Royal Gwent Hospital, Newport, REF 0001 0132 Dr Prosser

58 Dr A McNinch:[67]

> 'I knew of successes and failures but I never formed the opinion that results from Bristol were "poorer than expected" in comparison to those from other units, nor did I feel able to make such a comparison. I do recall the subject being discussed at one of the monthly meetings between the Exeter consultant paediatricians, probably in the early 1990s, one of my colleagues said that he was concerned that some of the results were poorer than he would have expected but I argued that he was in no position to make judgement because the evidence was anecdotal and involved small numbers.'

59 Dr D Stevens:[68]

> 'We expected, and still expect, regional centres not to differ significantly in the standard of care and results.'

60 Dr N Gilbertson noted that a change in practice had taken place in recent years:[69]

> 'I would not have seen it as my place as a District General Paediatrician to be overseeing the performance of the regional centre. However, my practice has now changed and I do expect those centres to whom I refer children to provide me with data confirming that their standards of practice are in keeping with national standards.'

Evidence of influences on referral patterns

Relationships with the cardiologists

61 Many (29) of the referring paediatricians stressed that they referred patients to the Bristol cardiologists, and not to the surgeons.

62 Dr Trefor Jones said:

> 'I think it is important to realise that general paediatricians in district general hospitals require first and foremost, a service of a paediatric cardiologist, not a paediatric cardiac surgeon.' [70]

63 Dr P Edwards stated:

> 'The principal linkage for a general paediatrician such as myself in respect of paediatric cardiology services is the Consultant Paediatric Cardiologist, and not the Surgeon. I was, and remain, extremely pleased at the level of service that Dr Martin provided.'[71]

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67 Consultant paediatrician, Royal Devon and Exeter Hospital, Exeter, REF 0001 0046
68 Consultant paediatrician, Gloucestershire Royal Hospital, Gloucester, REF 0001 0007
69 Consultant paediatrician, Royal Cornwall Hospital, Treliske, Truro, REF 0001 0038
70 REF 0001 0114; letter from Dr Jones
71 REF 0001 0109; letter from Dr Edwards

64 Thus, the relationship between referring clinicians and the cardiologists at the BRHSC, and the regard in which the cardiologists were held, would appear to have been an important factor influencing referral patterns to Bristol. These links were forged, and strengthened, by the holding of outreach clinics.

65 Dr J Morgan's[72] evidence was typical: the key referral factor for him was the working relationship that he had with the Bristol cardiologist who held a local outreach clinic.

66 The Inquiry received evidence that once the paediatrician had made a referral to a cardiologist, the paediatrician would expect any subsequent referral to a surgeon to be a matter for the cardiologist.

67 An example of this was the evidence of Dr S Ferguson:[73]

> '… the referral for surgery was very much from the Cardiologist and not directly from myself as a general paediatrician. My role was to try and detect heart problems and then ask for a cardiology opinion from Dr Jordan who I might add was perceived here in Newport as a hard working, dedicated, senior clinician who was held in high regard by myself and my colleagues here.'

68 Dr S Lenton's[74] evidence was to the effect that, while any reference to a surgeon was a matter for the cardiologist, the referring paediatrician who referred a patient to a Bristol cardiologist would have been almost certain that in practice, if the patient needed surgery, he or she would be referred on, in turn, to a Bristol surgeon. Dr Lenton said:

> 'Once referred to Bristol for assessment it was automatic that the surgeons would operate in Bristol rather than transferring the child elsewhere.'

69 Commenting on the view expressed by Dr Lenton, Dr Jordan said:

> 'It is over 99 per cent accurate. … I/we did refer patients to other centres. I think the commonest reason was when we had doubts about the diagnosis or the problem of diagnosis together with the actual management, and merely wanted a second opinion, if you like, there were some operations at different times, not very many by the time I retired, that were only done in a few centres. For example, replacing the aortic valve by taking the patient's pulmonary valve and using that, and then putting a homograft in the aortic area. I believe that is now done in Bristol, but it was not, I think, done during my time. So that would be an example of a procedure that was known to be done elsewhere and not available in Bristol. I mean, I can continue. I did actually, I think, make a list of these and I think it ran to about ten possibilities. There were other things. There were social reasons, and I suppose the other important group, really, were the parents who were unhappy with the advice

72 Consultant paediatrician, East Glamorgan General Hospital, Mid Glamorgan, REF 0001 0136 – 0138
73 Consultant paediatrician, Royal Gwent Hospital, Newport, REF 0001 0126 – 0127
74 Consultant community paediatrician, Bath West Community NHS Trust, Bath, REF 0001 0017

that they were given, and said, you know, "Can we go and see someone else and see what they have to say about it?"'[75]

Contracts

70 The use of contracts or service agreements, introduced by the 1991 reforms of the NHS, was not in place in the early years of the Inquiry's Terms of Reference. The Inquiry received evidence that the introduction of contracts did have an influence on referral patterns, by making it more difficult for a clinician to refer a patient to a centre other than that with which the contract was held. The evidence included the following comments from referring clinicians.

71 Dr M Quinn:[76]

'The Royal Devon and Exeter Healthcare NHS Trust held a contract for paediatric cardiac surgical services with Bristol. This together with the fact that Bristol was the regional centre for cardiac surgical services influenced me to continue to make referrals along this path.'

72 Dr R Orme:[77]

'Contracts did, however, make it significantly more difficult to refer patients to other centres, even if one were so minded. This could only be done through the means of an Extra Contractual Referral for which the Health Authority would have to pay. In practice one would have had to have been able to show that the treatment necessary could not have been provided by the Centre holding the contract.'

Geographical convenience

73 Dr C Vulliamy:[78]

'Strong links had been established with the Paediatric Cardiologists between North Gwent and Bristol. That was geographically convenient and supported by a well-established retrieval service.'

Supra regional status

74 Some referring clinicians mentioned, and appeared to place reliance on, the fact that Bristol was a designated SRC or NICS.

75 Dr Stevens[79] referred to Bristol being:

'… approved by the NHS as a regional [*sic*] centre for paediatric cardiac surgery'.

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75 T79 p. 129–30 Dr Jordan. The issue of referrals elsewhere by Bristol clinicians is dealt with in more detail below
76 Consultant paediatrician, Royal Devon and Exeter Hospital, Exeter, REF 0001 0058
77 Consultant paediatrician, Royal Devon and Exeter Healthcare NHS Trust, REF 0001 0056 – 0057
78 Consultant paediatrician, Breconshire War Memorial Hospital, Powys, REF 0001 0095
79 Consultant paediatrician, Gloucestershire Royal Hospital, Gloucester, REF 0001 0005

Dr Stevens also made the point that 'no reservations' were expressed either by the SWRHA or the NHS Executive about the standard of paediatric cardiac surgery at Bristol.

Established pattern

76 A theme which recurred in the referring clinicians' correspondence was that they tended, upon taking up a consultant's post, to find that a link between their centre and a cardiologist at a particular unit was already established, such that thereafter they themselves followed the pattern of referral already in place.

77 Dr D Challacombe[80] was typical:

> 'By tradition, children needing cardiac surgery or investigation from West Somerset were referred to cardiologists from Bristol, while those from East Somerset went to Southampton. I continued this tradition in West Somerset as I had no reason to be dissatisfied by the service given to my patients.'

78 Dr S Maguire:[81]

> 'When I came into post in 1991 there was a well established outreach cardiac clinic from Bristol. My clinical colleagues were very satisfied with the service we received and I was also happy therefore we maintained the referrals.'

79 Sometimes clinicians on taking up a new post continued a referral pattern to a particular centre that they themselves had previously developed links with. For example, Dr L Smith[82] told the Inquiry that he saw few children with cardiac problems, but those whom he did see he 'almost exclusively referred to the Brompton Hospital where I had an extensive historical association and knew the service to be of high quality'.

Down's syndrome

80 The Inquiry received evidence from both parents and clinicians that the Bristol centre was regarded as more prepared than at least some other centres to operate on children with Down's syndrome.

81 Dr A Salisbury[83] told the Inquiry that he felt that the Bristol team were 'very sympathetic' to the assessment and surgical treatment of children with Down's syndrome. As a result he referred practically all such cases to Bristol, whereas in general his referrals were split between Bristol and Oxford.

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80 Consultant paediatrician, Taunton and Somerset Hospital, Taunton, REF 0001 0030
81 Consultant paediatrician, Royal Gwent Hospital, Newport, REF 0001 0130
82 Consultant cardiologist, Royal Devon and Exeter Hospital, Exeter, REF 0001 0061
83 Consultant paediatrician, Princess Margaret Hospital, Swindon, REF 0001 0029

82 Sheila Forsythe, whose son Andrew has Down's syndrome, said:

> 'We actually felt that we were extremely lucky, in that we lived virtually on the hospital doorstep of a regional cardiac centre and we had absolutely no doubts and trusted Dr Joffe and trusted Mr Wisheart implicitly. We did not even think to question where we were being referred to. … I had had contact with a lady who subsequently did actually set up the Down's Heart Group who knew a very global picture of Down's syndrome. She was asking the question, should she or should she not have surgery for her child. She had asked the question in the Down's Syndrome Association national newsletter and had a very wide variety of input from parents. Some was very, very positive and some was very, very negative. Also, at the time, she obviously had contact with families who were not having surgery because they had not been referred by the cardiologists so presumably their children were within the optimum surgical — there was an ability to offer surgery for them, but it was because of the discrimination of the cardiologists in those — there were two centres that we knew of, that children with Down's syndrome were not being referred. So with that, for a quick afternoon, to sort of go out and find out all this, we then had no qualms about having surgery for Andrew.
>
> 'Q. So the picture that you were given was that in some parts of the country Andrew would not have had the offer of surgery?
>
> 'A. That is right.
>
> 'Q. That was the information that you had, that he was being given in Bristol?
>
> 'A. That is right.
>
> 'Q. The reason he might not have been offered elsewhere appeared from the enquiries you were making to be because he was a Down's syndrome child?
>
> 'A. That is right.
>
> 'Q. Was there any sense of hesitation at all in Bristol in offering an operation?
>
> 'A. Absolutely not.
>
> 'Q. Was there any sense, to you, that the Bristol unit treated Down's syndrome children in any different way than they might treat other children?
>
> 'A. Absolutely not.'[84]

[84] T95 p. 62–4 Sheila Forsythe

The split service/site

83 A number of referring clinicians (six) were aware of some shortcomings at Bristol, related to the split service/site at Bristol. Dr T Perham[85] said:

> '… my impression … is of a somewhat disjointed service which particularly seemed to be the result of problems related to a split site delivery.'

84 Professor J Osborne:[86]

> 'I knew they were operating under difficult circumstances on a split site.'

85 Dr Vulliamy:[87]

> 'I had held the Paediatric Cardiac Surgical Services in Bristol in high regard though I was aware there had been limitations on the type of procedure that would be undertaken. The separation between the BCH and BRI seemed to present some practical difficulties.'

Waiting lists

86 Other referring paediatricians (14) pointed out that referrals would be made to other centres if there was no bed available at Bristol. [88]

87 One, Dr T French,[89] was critical of the waiting list at Bristol:

> 'My only reservation about the paediatric cardiac surgery for children in Bristol was the timeliness of operations for elective, non-emergency treatment. Parents, children and others were disappointed when planned arrangements had to be deferred because of lack of surgical time.'

88 However, Dr A Griffiths told the Inquiry that patients referred to Bristol 'had their surgery within a very acceptable timescale'.[90]

89 Dr P Rowlandson[91] pointed out that delays were not peculiar to Bristol. He explained that, from Swindon, patients were referred to either Bristol or Oxford:

> '… when Oxford had appointed a paediatric cardiac surgeon the choice was still Bristol for many patients because of lack of beds in Oxford. Bristol too often had a problem finding a bed. The whole service seemed chronically under resourced.'

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85 Consultant paediatrician, Derriford Hospital, Plymouth, REF 0001 0147
86 Consultant paediatrician, Royal United Hospital, Bath, REF 0001 0021
87 Consultant paediatrician, Breconshire War Memorial Hospital, Powys, REF 0001 0095
88 See Chapter 12 for discussion of the waiting list
89 Consultant paediatrician, Yeovil District Hospital, and Taunton and Somerset Hospital, REF 0001 0032
90 REF 0001 0128
91 Consultant paediatrician, Princess Margaret Hospital, Swindon, REF 0001 0036

90 Dr Quinn[92] told the Inquiry:

> 'Children were occasionally referred to centres … to Birmingham and Southampton but only because Bristol was unable to look after them.'

Awareness of standards at Bristol

91 Few of the referring paediatricians told the Inquiry that they knew or had heard anything adverse about standards of care at Bristol.

92 Most referring paediatricians told the Inquiry that their impression was that services at the BRI were satisfactory and that they had no concerns regarding the treatment offered there, except for the comments on the split site, referred to earlier. As noted above, many referring paediatricians formed their impressions without the benefit of hard data about Bristol's relative or absolute performance.

93 Dr J Tyrrell:[93]

> 'I have always felt that we have had an excellent service from the paediatric cardiologists, particularly Dr Joffe … He is an exceptionally kind man who is very skilful and explains problems in details to the patients.'

94 Dr Trefor Jones:[94]

> 'My experience of the Unit at Bristol has always been satisfactory and the children whom I have had under my care, from the years 1984–1995, who underwent paediatric cardiac surgery there have done well.'

95 Dr P Rudd:[95]

> 'It was my impression that the paediatric cardiac surgical service between 1986 and 1995 was of high quality.'

Concerns about standards at Bristol

96 The evidence of seven referring clinicians suggests some were aware of concerns about Bristol, albeit not supported by hard data.

97 Dr R Verrier Jones[96] dated his awareness of such concerns to 'the end of the 80s'. He said that by then '… there were some adverse comments being expressed about Bristol but it was only hearsay'.

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92 Consultant paediatrician at the Royal Devon and Exeter NHS Trust, Exeter, REF 0001 0059
93 Consultant paediatrician, Royal United Hospital, Bath, REF 0001 0025
94 Consultant paediatrician, Princess of Wales Hospital, Bridgend, REF 0001 0114
95 Consultant paediatrician, Royal United Hospital, Bath, REF 0001 0023
96 Consultant paediatrician, formerly at Llandough Hospital, Penarth, South Glamorgan, REF 0001 0105

98 Dr J Tripp:[97]

> 'I did raise with my own colleagues and with the Trust Executive the possibility that we should consider transferring the contract from the BRI to Southampton. This was based partly on concerns about surgical results, even though these were based on hearsay rather than on data and partly on the costs which appear to be more favourable at Southampton.'

99 Dr W Forbes:[98]

> 'I knew that Mr Dhasmana had unsuccessfully attempted several switch operations for transposition but not on any of my patients.'

100 Dr G Taylor[99] was one of the few paediatricians to tell the Inquiry that he was aware of rumours in the early 1990s that, as he put it, 'all was not well at Bristol'. He told the Inquiry that he could not recollect the precise source of the rumour, but that it was significant enough for him to discuss with Dr Jordan. Dr Taylor said that he 'received reassurance [i.e. from Dr Jordan] that the situation was under review and that there was no cause for concern'.

101 Dr Jordan was asked about Dr Taylor's evidence. Dr Jordan said:

> 'We used to have sort of what one might call general discussions and I cannot recall Dr Taylor standing out from other paediatricians that I did clinics with as particularly pursuing any sort of discussion of this sort. … All I can say is that we did discuss very generally not only our plans but also our results and to some extent the discussion included a "warts and all" approach to it so it may well be I had actually, you know, talked about things that were of concern to us as well … for example that we still had not, right up to the time that I retired, got the cardiac surgery moved up the road. That is of particular importance to paediatricians because paediatricians are really very keen on the idea that children should be looked after in a paediatric environment.'[100]

102 Asked whether such a 'warts and all' discussion with paediatricians would have included discussion of particular procedures being carried out at Bristol, Dr Jordan said:

> 'I think it would only be if I was specifically asked. Bear in mind that if we are dealing with transposition with intact intraventricular septum … paediatricians … would see one case in every five years or something like that. I do not think it is reasonable to suppose that Dr Taylor specifically had a problem over his patients or indeed from any information that he would have got from what I might call reliable

97 Consultant paediatrician, Royal Devon and Exeter Hospital, Exeter, REF 0001 0063
98 Consultant paediatrician, Swansea, REF 0001 0089
99 Consultant paediatrician, Royal Cornwall Hospital, Treliske, Truro, REF 0001 0042
100 T79 p. 142–3 Dr Jordan

> sources. … I think it would be very difficult for a paediatrician to form a view on his own about, for example, what our success rate was in neonatal Arterial Switch operation.'[101]

103 In the light of the evidence of Dr Phillip Hammond[102] in particular, the evidence from Bath paediatricians is of interest.

104 Dr Hammond suggested that unnamed doctors in Bath were aware of the 'problems' at Bristol before they reached public attention. He told the Inquiry:

> 'From sources within the Trust I was told … that the problem was now so grave (in 1992) that I should attempt to alter the referral pattern of the GPs I knew for children with complex heart conditions such that Bristol would be bypassed. This apparently already happened with areas/referring doctors "in the know".'[103]

105 He also told the Inquiry that, following evidence given to the Inquiry by Miss Catherine Hawkins, *'Private Eye'* had been contacted by consultants at Bath Royal United Hospital:

> 'I have since been sent information to *"Private Eye"* anonymously that some of the doctors in Bath did try to raise concerns with Region about the Bristol service, possibly before 1992 …'[104]

106 The Inquiry heard from six paediatricians in Bath.[105] Dr Lenton, who was in Bath throughout the period, told the Inquiry:

> 'I was only aware that there might be a problem with the cardiac services offered in Bristol due to indirect feedback via SHOs [senior house officers] and specialist registrars who had previously worked in UBHT.'

However, Dr Lenton did not suggest that he had any direct evidence of poor standards at Bristol and told the Inquiry that he 'had assumed that the … service … was about average'. The only other 'concerns' expressed were by Professor Osborne, who was in Bath throughout the period, and Dr Tyrrell who was in Bath from 1992. Both told the Inquiry that they were aware that Bristol had a split site.

107 All six Bath paediatricians confirmed that they referred children to Bristol during the period. Dr Hutchinson, who had been working in Bath from 1991, told the Inquiry that he had 'no inkling of any problems … At no time did I have any reason to be other than fully confident in the surgery services'.[106] Dr Cain, who had been a consultant

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101 T79 p. 144–5 Dr Jordan
102 GP assistant, Keynsham, and columnist 'MD' for *'Private Eye'*
103 WIT 0283 0004 Dr Hammond
104 T64 p. 21 Dr Hammond
105 Dr T Hutchinson (REF 0001 0016), Dr S Lenton (REF 0001 0017 – 0018), Dr ARR Cain (REF 0001 0019), Professor JP Osborne (REF 0001 0020 – 0022), Dr PT Rudd (REF 0001 0023 – 0024) and Dr J Tyrrell (REF 0001 0025 – 0026)
106 Consultant community paediatrician, Bath West Community NHS Trust, REF 0001 0016

paediatrician at Bath from 1973, said that he 'had nothing but praise for the service' and had 'no reason to refer children other than to Bristol'.[107] Dr Rudd, who was in Bath from 1986, said his impression was that the service at Bristol 'was of high quality … because we had no concerns about the quality of care being provided in Bristol, this centre seemed to be the obvious choice'.[108]

108 The Bath clinicians also stressed the importance of their relationships with the Bristol cardiologists.

109 Professor Osborne stated:

> 'I think it is important for background information, to know that I held and hold Dr Joffe in the highest possible esteem as a clinician and as a paediatrician. He is one of the kindest and most compassionate people I know.'[109]

110 Dr Rudd:

> 'I had close contact with … Dr Joffe. I was impressed with the very high quality of care that he was able to offer.'[110]

111 Dr Tyrrell:

> 'I have always felt that we have had an excellent service from the paediatric cardiologists, particularly Dr Joffe. … He is an exceptionally kind man who is very skilfull and explains problems in detail to the patients.'[111]

Information provided to parents/choice of treatment centres

112 Mr Wisheart said:

> 'With regard to the general public there really was no significant channel of communication. Individual patients and their families gained detailed and precise information in the pre-operative discussions with their surgeons and cardiologists. The patient information unit of the Trust made an important contribution to the provision of information to patients, but I do not believe that it made information available about the standards of treatment attained at the BRI. Talks were given to bodies such as the Bristol and South West Children's Heart Circle and occasionally talks were given at the health centres.'[112]

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107 Consultant paediatrician, Royal United Hospital, Bath, REF 0001 0019
108 Consultant paediatrician, Royal United Hospital, Bath, REF 0001 0023 – 0024
109 REF 0001 0020; letter from Professor Osborne
110 REF 0001 0024; letter from Dr Rudd
111 REF 0001 0025; letter from Dr Tyrrell
112 WIT 0120 0069 – 0070 Mr Wisheart

113 Dr N Agarwal[113] told the Inquiry that:

> 'Parents were always offered the choice, consequently some children were sent to other centres but most accepted the advice and were sent to Bristol.'

114 Eileen Martyr, whose son, Aaron, was referred to Bristol from Treliske Hospital, explained that shortly after his birth she was told that her 'son would be transferred to a hospital in Bristol … There was no suggestion of Aaron going anywhere other than Bristol'. She told the Inquiry of conversations with clinicians in Treliske:

> 'At some stage after our meeting with Mr Wisheart, Dr Taylor made a passing comment that, if Aaron was being treated at Great Ormond Street Hospital, the operation would have been done almost straight away. That stuck in both our minds. We later asked Dr Eades whether she thought it would be a good idea if we paid for the operation privately, and then it would be done straight away. She told us that Mr Wisheart was "the best surgeon in Britain" and that to have the operation done privately would be a waste of money.'[114]

115 One mother, whose child was transferred to Bristol from Gloucestershire Royal Hospital, said:

> 'The possibility of [my child] being dealt with anywhere other than Bristol and by Bristol surgeons was not, at any time, discussed; neither was I concerned about that because I had confidence in Dr Martin and subsequently Dr Dhasmana who would do the operation on [my child] . I believe [my child] was too ill to be moved anyway.'

116 Penelope Plackett, mother of Sophie, said:

> 'I saw Dr Orme in outpatients at the Royal Devon and Exeter Hospital … He told me of a child from the Exeter area who had undergone the same operation and was now living a normal life. He said the results at Bristol were excellent. Although there were "risks" as with any operation, Sophie would have a normal life if she survived. He told me this several times. He did not quantify the risks or specify what they were.'[116]

117 The Inquiry also received evidence from parents who were offered the choice of more than one centre. For example, Justine Eastwood, mother of Oliver, was told at Cheltenham General Hospital that she had a choice:

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113 Consultant paediatrician, Singleton Hospital, Swansea, REF 0001 0086
114 WIT 0174 0006 Eileen Martyr

116 WIT 0012 0003 Penelope Plackett

> 'The doctor explained to me that Oliver would have to be transferred to a specialist centre. He explained that the hospitals that specialised in heart problems were in Bristol, Birmingham and Oxford. We were told that Oliver could be transferred to any one of these centres and we opted for Bristol because we felt it would be easier for my parents to come and visit Oliver as they could fly into Bristol airport.'[117]

Her evidence included this exchange:

> 'A. When we were in Cheltenham, because we were in a central position, we had a choice between Birmingham, Oxford or Bristol. We chose Bristol for personal reasons, because the family were travelling over from the Channel Islands, but we were given the choice.
>
> 'Q. Was anything said to you about why you might prefer one place to other?
>
> 'A. No, never.
>
> 'Q. So a choice, but no guidance?
>
> 'A. No, not at all. I think more choice for travelling. I think that was the reason. We were travelling from Cheltenham, but it certainly was not because one place was better than another. That was definitely never mentioned to us.'[118]

She was asked:

> 'Q. Do you think you would have reacted well in the 1990s to have been told, "Well, it is Bristol we are sending you to"? Would you have asked, "Well, why there, why not —"
>
> 'A. There would have been no reason to. As far as we were concerned if we were being sent to a specialised centre, there was no reason to doubt where we were going, or why we were going. All we wanted to do was to get our child to a place where they were going to try to help us. We did not ask those sort of questions.'[119]

118 A parent told the Inquiry that she was offered a choice of centres in theory, but not in practice. She said:

> 'At Gloucester Royal I was told that no treatment could be carried out there and given the choice of going to the Bristol Royal Infirmary or the John Radcliffe Hospital. John Radcliffe, however, had no beds.'[120]

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117 WIT 0022 0003 Justine Eastwood
118 T95 p. 58 Justine Eastwood
119 T95 p. 61–2 Justine Eastwood
120 WIT 0520 0001. 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

119 Another parent said:

> 'I was told that the Morriston Hospital always transferred its cardiac cases to the London Hospitals, but [the child's] condition was so grave that [the child] was rushed to the Bristol Children's Hospital … We were told that the BCH was a centre of excellence and we were happy with [the child] being taken there.'[121]

Referrals to Bristol – evidence of the actual pattern of referrals from the South West of England

120 Both the cardiologists and the surgeons at Bristol were aware that some paediatricians within the catchment area were not routinely referring all or some of their patients to Bristol.

121 Mr Wisheart told the Inquiry:

> 'Hospitals in the South Western RHA: Plymouth referred nearly all children elsewhere, Yeovil referred a proportion elsewhere. Hospitals in the Wessex RHA: Swindon referred a significant proportion elsewhere. I do not know why … '[122]

122 Dr Jordan said:

> 'Most of the following hospitals either did not routinely refer or only referred a minority of patients to Bristol: Plymouth Hospitals, Yeovil District Hospital, Cardiff Hospitals.'[123]

He explained the referral patterns from Plymouth and Yeovil thus:

> 'I was, of course, aware that paediatricians in Plymouth and one in Yeovil were referring most of their patients to Southampton. The original reasons for this were geographical in the case of Yeovil and historical in relation to both sites, coupled with the fact that the surgical waiting lists in Bristol were longer than elsewhere.'[124]

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121 WIT 0353 0001. 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
122 WIT 0120 0118 Mr Wisheart
123 WIT 0099 0035 Dr Jordan
124 WIT 0099 0037 Dr Jordan

123 Dr Joffe said:

> 'I believe it was an accepted reality that most paediatricians would support the nearest tertiary or specialty unit within their region, if (a) there was one present at their teaching institution, where these units tended to be located, and (b) they were satisfied with the overall management, both cardiological and cardiac surgical that their patients had received from us in the past.'[125]

However, Dr Joffe told the Inquiry:

> 'I have no knowledge of whether clinicians within Bristol's catchment area refer children to centres other than the BRI, except for those in Plymouth who refer their patients to Southampton. This has been the situation from well before my arrival in Bristol in 1980, and continues today despite the transfer of all paediatric open-heart surgery to BCH, and the excellent results being achieved currently. I don't know why, since I have had no dealings with them.'[126]

124 Asked what, in their view, referring clinicians thought of the service at Bristol, Dr Joffe said:

> 'As far as I could judge, the view held … was generally positive and favourable. I cannot recall being confronted by any other clinician in the referring centres with adverse comments or concern about results.'[127]

Dr Jordan said:

> 'I cannot recall during my time as a consultant that any paediatricians in the regions expressed concerns about the service provided. I discussed on several occasions with some of the paediatricians in Plymouth, when *they* raised the issue, the possibility of sending more patients to Bristol. They certainly did not say that they considered the standard in Bristol was deficient. The advice which I gave was that I could not say that the standard of treatment they would receive in Bristol would be better than in other centres to which they were currently referring (notably Southampton) and that as Southampton had no waiting list and Bristol had considerable waiting lists I could see advantages in patients continuing to go to other centres.'[128]

Referrals from Plymouth

125 As noted above, the Bristol clinicians were aware that there were few referrals to Bristol from Plymouth. The Inquiry heard from six Plymouth paediatricians.[129] A number of factors influencing this practice emerged from their letters.

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125 WIT 0097 0291 Dr Joffe
126 WIT 0097 0292 Dr Joffe
127 WIT 0097 0290 Dr Joffe
128 WIT 0099 0035 Dr Jordan (emphasis in original)
129 Dr H Baumer (REF 0001 0076 – 0077), Dr AJ Cronin (REF 0001 0078), Dr R Evans (REF 0001 0079 – 0080), Dr RWA Jones (REF 0001 0081 – 0082), Dr P Ward (REF 0001 0084) and Dr TGM Perham (REF 0001 0146 – 0148)

126 Dr Perham,[130] who was appointed at Derriford Hospital in 1972, explained:

> 'You should know historically why Plymouth has had a different service compared to other paediatric centres within the South West peninsula. … in 1972 the consultant paediatricians here … had regular visits from Dr Ronald Gibson, Consultant Cardiologist from the Royal Brompton Hospital, London. Children were referred to his hospital for investigation and paediatric surgery if necessary.'

Dr Perham explained how, on the retirement of Dr Gibson, Plymouth had contact with Dr Barry Keeton who had previously been a senior registrar in paediatric cardiology at the Royal Brompton and had moved to Southampton. Dr Perham explained that:

> 'The [Southampton] unit offered an extremely good clinical, caring service both from the paediatric cardiology medical point of view as well as the surgical point of view. Gradually this became formalised with the team from Southampton undertaking regular joint outpatient appointments with us and these now occur every two weeks. … We therefore had a contact with the Southampton team and very seldom would the children be referred elsewhere …'[131]

127 Professor Sutherland was a cardiologist at Southampton General Hospital from 1983 until 1987. He told the Inquiry that at some time in 1986–1987 Dr Perham contacted his colleague Dr Barry Keeton.

128 Professor Sutherland told the Inquiry:

> '[Dr Perham] expressed concern to Dr Keeton that the surgical results for complex congenital heart disease in the Bristol centre were worrying him and asked if it would be appropriate for the Southwest region to send complex cases to the surgeons in Southampton where the surgical results were documented and appeared substantially better. Dr Keeton discussed the problem with me and we decided to set up a clinical service for the Southwest region … This involved one of us performing a monthly clinic in Plymouth General Hospital and the surgical cases who were complex being subsequently referred to Southampton General Hospital. Dr [Perham] and his other paediatric colleagues wished to continue to support the Bristol centre and continued to send their non-complex cases for surgery there.
>
> 'During 1986 I was personally contacted by Prof. A Henderson … with regard to paediatric cardiology services in Wales. … Prof. Henderson expressed his concerns to me about referring children from Wales to Bristol in view of the poor surgical results in that department. He suggested that it would be appropriate that I offer a service to Cardiff similar to that Dr Keeton and I were offering to Plymouth.'[132]

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130 Consultant paediatrician, Derriford Hospital, Plymouth, REF 0001 0146
131 REF 0001 0146 – 0147
132 REF 0001 0149; letter from Professor Sutherland

129 Dr Keeton responded:

> 'Patients were referred to me from Plymouth starting soon after I was appointed to Southampton in October 1978 as the first paediatric cardiologist in the Wessex Cardiothoracic Centre. I think that, initially, this happened when the Brompton were unable to accept emergency referrals but gradually more and more of the patients came to Southampton. My diary indicates that I visited Plymouth in 1979 and although I cannot be certain precisely when the regular Plymouth clinics performed by Dr George Sutherland and myself started I was certainly visiting to do clinics in 1984 and have been going regularly since then.'[133]

130 Dr Perham referred to a meeting in the early 1980s with the members of the Bristol Unit that he thought was the result of pressures exerted on the Bristol paediatric team by its management to increase paediatric numbers. He said:

> 'I believe the request was management driven but there seemed to be no way that the Bristol surgical unit could cope with increased numbers, particularly from the Plymouth district.' [134]

131 Similarly, Dr A Cronin[135] referred to a long-standing relationship between Plymouth and Southampton (although he also pointed out that the Bristol cardiologists, Dr Jordan and Dr Hayes, saw some children from Plymouth).

132 Dr R Evans[136] confirmed that when she was employed by Plymouth NHS Trust in 1991 she followed the 'established local practice' of referring children to Southampton.

133 Dr P Ward[137] also told the Inquiry that he followed the established Plymouth pattern of referring to Southampton.

134 Dr R Jones[138] thought highly of the Southampton service, and was 'aware of [its] good results'. He told the Inquiry that he thought Bristol was unlikely to be as good. The reason he gave for thinking this was that:

> 'Whilst I was aware that Mr Wisheart had a good reputation, backup surgical services when he was unavailable or on leave were not entirely satisfactory.'

133 REF 0001 0152; letter from Dr Keeton
134 REF 0001 0147; letter from Dr Perham
135 Consultant paediatrician, Scott Hospital, Plymouth, REF 0001 0078
136 Consultant community paediatrician, Scott Hospital, Plymouth, REF 0001 0079 – 0080
137 Consultant paediatrician, Derriford Hospital, Plymouth, REF 0001 0084
138 Consultant paediatrician, Derriford Hospital, Plymouth, REF 0001 0082

135 Dr C Sainsbury[139] told the Inquiry:

> 'I did become aware that my colleagues in Plymouth chose to refer children to Southampton as their tertiary centre, rather than Bristol. I recall being surprised by this, because of the difficult nature of the journey from Plymouth to Southampton. I do recall discussing this with my colleagues, at South Devon Healthcare Trust … and I remember at the time we agreed the service that we were getting from Bristol seemed to be a good one and I did not see any reason to refer differently to the established practice for South Devon Healthcare.'

Referrals from Yeovil

136 The referral pattern from Yeovil to Southampton also appears to have had a historical explanation. The Inquiry heard from two Yeovil paediatricians.[140]

137 Dr M Webster[141] explained that he worked in Taunton and Yeovil from 1982 to 1991. He said:

> 'At the time of my appointment paediatric cardiological services to each hospital were long established. … The clinics in Taunton were attended by a visiting paediatric cardiologist from Bristol and those in Yeovil by visiting paediatric cardiologists from Southampton. My understanding was that the Yeovil clinics had originally taken place in Dorchester (for which Southampton was the natural referral centre) and although the clinics subsequently transferred to Yeovil, the same arrangements stayed in place.'

138 Dr T French[142] said:

> 'When I was a Yeovil-based doctor I referred all children from that area to Southampton as per existing arrangements.'

139 Consultant paediatrician, Torbay Hospital, Torquay, REF 0001 0066 – 0067
140 Dr TJ French (REF 0001 0032 – 0033) and Dr M Webster (REF 0001 0034 – 0035)
141 Consultant paediatrician, Taunton and Somerset Hospital, Taunton, REF 0001 0034
142 Consultant paediatrician, Taunton and Somerset Hospital, Taunton, formerly of Yeovil District Hospital 1982–1991, REF 0001 0033

Referrals to Bristol from South Wales

The catchment area

139 Mr Peter Gregory, Director, NHS Wales, explained why referral patterns from Wales differed by area, and thus why it was essentially South Wales that fell within the Bristol catchment area:

> '… there are quite significantly different patterns of referral, for reasons which obviously spring from geography. The natural connection, socially and economically and in the NHS for North Wales is to the major conurbations in the north west of England and there has been traditionally a significant dependence on Liverpool for this service and Manchester and Liverpool for a variety of tertiary specialist services. Mid-Wales often drains down into Birmingham, although there are connections to the south; and South Wales, at this time, would be dependent … on the significant hospitals in the south of [England].'[143]

140 The South Glamorgan Health Authority's Approval in Principle Submission entitled '*Regional Cardiac Service for Wales*'[144] described the paediatric cardiology clinics available to children resident in Wales in June 1986:

> 'North Wales is served by cardiologists from Liverpool who carry out 22 clinics per year. Clinics are held in Wrexham, Rhyl and Bangor.
>
> 'Mid Wales receives a visit from a cardiologist from Cardiff who performs a clinic in Aberystwyth 4 times a year, seeing mainly adults, but small numbers of older children also.
>
> 'South Wales is served principally by one cardiologist from Cardiff who, in addition to holding weekly paediatric clinics in the University Hospital, performs clinics in Newport (12/year), East Glamorgan (3/year), Camarthen (5/year), Swansea (3/year) and Pontypridd (4/year). In addition, a cardiologist from London performs clinics in Bridgend 5 times per year, seeing patients referred from paediatricians in Bridgend, Swansea, Neath and Pontypridd.'[145]

143 T10 p. 9–10 Mr Gregory

144 South Glamorgan Health Authority's Approval in Principle Submission, *'Regional Cardiac Service for Wales*', is discussed in detail in Chapter 7

145 WO 0001 0148; South Glamorgan Health Authority's Approval in Principle Submission: '*Regional Cardiac Service for Wales*'

141 The document also identified the patterns of referral to cardiologists in June 1986:

> 'Gwynedd, Clwyd, Northern Dyfed and Northern Powys: All neonatal and infant emergencies and almost all older children are referred to Liverpool. Small numbers of older children from Northern Dyfed are referred to Cardiff.
>
> 'Southern Dyfed: Almost all children are referred to Cardiff.
>
> 'West Glamorgan: Almost all neonatal and infant emergencies are referred directly to London, the majority going to the Hammersmith Hospital and the remainder equally divided between the Brompton Hospital, the National Heart Hospital and Great Ormond Street Hospital. Of the 4 paediatricians in West Glamorgan, 2 refer all their older children to a visiting cardiologist from the Hammersmith Hospital at her Bridgend clinic and 2 refer some older children direct to London but most to Cardiff.
>
> 'Mid Glamorgan: Most neonatal and infant emergencies are referred directly to London; a small number go to Cardiff. Three of the five paediatricians refer their older children to the Hammersmith cardiologist at Bridgend. The other 2 refer to Cardiff.
>
> 'South Glamorgan: Almost all neonatal and infant emergencies and older children are referred to Cardiff.
>
> 'Gwent and Southern Powys: Most neonatal and infant emergencies are referred to Cardiff except when the paediatric cardiologist is unavailable, in which case they are referred to Bristol (very small numbers). Most older children also go to Cardiff apart from those living in the Chepstow area who are referred to Bristol.'[146]

Referrals for surgery were described thus:

> 'All children requiring cardiac surgery seen by cardiologists in England or visiting from England are referred for surgery to their surgical colleagues in England. Of children requiring surgery referred to Cardiff, two thirds are referred to cardiac surgeons in Cardiff, the remaining third being shared between surgeons at the Brompton Hospital, Harefield Hospital, Great Ormond Street Hospital and the National Heart Hospital.'[147]

142 Professor Crompton told the Inquiry that in his view there had been little immediate impact on referral patterns after the designation of NICS as a SRS in 1984.[148]

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146 WO 0001 0148 – 0149; South Glamorgan Health Authority's Approval in Principle Submission: '*Regional Cardiac Service for Wales*'
147 WO 0001 0149
148 WIT 0070 0002 Professor Crompton

143 Mr Gregory told the Inquiry[149] that he was not aware that referral patterns changed at all between the 1981 Working Party Report[150] and the time when the Approval in Principle document was submitted.

Funding of referrals from Wales

144 Mrs Maclean of the Inquiry Panel asked Mr Angilley about the financing of Welsh referrals to Bristol:

> 'Q. … To go back to the finance implications, when you were describing clearing the top-slicing procedure with the regions, could you just tell me how that worked out in Wales? Were there different procedures, given that this is an England and Wales thing?
>
> 'A. I do not think that the money, from recollection — I would need to look at that and come back to you, if I may.'[151]

145 Subsequently, Mr Angilley wrote to the Inquiry in answer to Mrs Maclean's question:

> 'Towards the end of my oral evidence to the Inquiry, Mrs Maclean asked a question which I was unable to answer. Her question concerned the procedure by which the Supra Regional Services Advisory Group's recommendations for top-sliced funding were cleared with Welsh interests. The answer is that the cost of these services were met entirely by the NHS in England, so it was not necessary to clear the funding proposals with the Welsh. I believe that at the inception of the Supra Regional Services, the Department of Health agreed with the Welsh Office that in view of the relatively small number of patients and the bureaucracy involved, it was not worth charging the Welsh NHS for its use of these services. However, the Welsh Office had a standing invitation to send an observer to meetings of the Advisory Group, which they normally did during my time as Secretary. Although their representative was not a voting member, he or she would be free to advise the Group on any issue affecting Wales.'[152]

146 Mr Steven Owen, Administrative Secretary to the SRSAG from January 1992 to February 1996, was asked in oral evidence whether or not the SRSAG took into account the existence (or non-existence) of facilities on the other side of domestic borders when deciding which centres to designate, and if so what were the cross-border funding arrangements. He said:

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149 T10 p. 42 Mr Gregory
150 The Working Party was set up in 1979 to report on cardiothoracic services in Wales. It reported in 1981. Its report is considered in detail in Chapter 7
151 T11 p. 81 Mr Angilley
152 WIT 0034 0005; letter from Mr Angilley to the Inquiry dated 6 May 1999

> 'Because of the funding quirk – and I understand Mr Angilley has undertaken to provide a paper on this – essentially there was an understanding and agreement that patients from Wales could be treated in English units without any cross-funding matters being undertaken. That also operated for Scotland, but that is almost by the by. Scotland and Wales were entirely free to provide whatever healthcare facilities they chose for their own patients in whatever infrastructure and formation they decided was best for their patients.'[153]

147 Mrs Maclean questioned Mr Owen further. His evidence included this exchange:

> 'Q. … Perhaps I might take the opportunity to pursue my enquiries about the impact of the SRS funding mechanism for Wales. I know that Mr Angilley is dealing with this and you may prefer to leave it to him, but to deal with my impatience, can you enlighten me as to the impact of SRS funding for the Welsh Office?
>
> 'A. There was no impact at all. SRS funding was for the English units, but because of a quirk in the financing system, which will be the subject of a paper Mr Angilley is providing, it was allowed that Welsh residents could be treated in English units without a bill, if you like, going back to the patient's district of residence in Wales.
>
> 'Q. So this was a "freebie", in effect?
>
> 'A. In effect, yes, that is right.'[154]

Evidence of influences on patterns of referral from South Wales

148 A number of factors appear to have influenced referral patterns from the South Wales catchment area. One event was the establishment of the Paediatric Cardiac Unit in Cardiff in 1991. Before considering the impact of the establishment of this centre, the influences on referrals from South Wales prior to 1991 are considered.

Funding and resources pre-1991

149 In relation to the funding of referrals from Wales, Mr Nix told the Inquiry:

> 'Bristol and Weston HA also provided paediatric cardiac surgery and cardiology services to South Wales. However, the level of service provision was increasing annually and the Welsh Office wanted to provide a service in Cardiff. In 1987/1988 there were discussions with the Welsh Office about providing Paediatric Cardiac Surgery which did result, because of delays in reaching agreement, in the sending of letters to each Health Authority, stating that services would be restricted if funding for children over 1 year old was not provided. This was because children over 1 year old were not within the Supra Regional remit and were therefore the responsibility of the Health Authorities, whereas, those under 1 year old were the responsibility of the Welsh Office/DHSS. The SWRHA was present at the majority of the meetings and

153 T12 p. 13 Mr Owen
154 T12 p. 114 Mr Owen

kept informed of discussions. The Welsh Office did, I recall, fund some additional workload as an interim measure with a view to setting up a service in Cardiff.'[155]

150 He stated:

'So as to protect the service to the South West, the HA asked the Welsh HAs for money to pay for the increased work for the over 1 year of age group. The Welsh Office was asked for additional money for patients under 1 year old, as this age group was the responsibility of the Welsh Office in a similar way to DoH being responsible for Supra Regional services for the under-1s for England. There were a number of meetings with the Welsh Office (Mr Gregory). …'[156]

151 Mr John Watson[157] told the Inquiry:

' … there was an issue in respect of the possible expansion of cardiac services in general, from which there developed serious concern about funding of referrals from South Wales … The history for this was that the paediatric cardiologists would conduct "outreach" clinics in South Wales and would refer cases to Bristol, leaving it to others to sort out the funding for this work. I became involved in referral issues in 1986 when it became apparent that the number of referrals from South Wales to Bristol exceeded the resources available (and by this I mean both finances and staff). … we entered into discussion with the Welsh Office to try to ensure that they were paying for the services that they were receiving. It was felt that we needed to reach agreement with the referring bodies before the situation got out of hand.'[158]

152 Mr Watson continued:

'Irrespective of any such processes performed by us as managers, the decision on whether or not to refer a case to Bristol would essentially rest with the clinicians. With this background we had to address a very real problem of lack of funding of the Welsh referrals, to a point where a decision had to be made, probably by the district management team, about whether or not more patients could be taken until the funding position was sorted out.'[159]

153 Mr Watson referred to discussions and correspondence, particularly that passing between himself and the Welsh Office in 1987 in relation to the funding for adult and paediatric cardiology referrals. He referred to a note of a meeting he had with Dr Baker,[160] Miss Stoneham[161] and Mr Nix in May 1987.[162] The note records:

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155 WIT 0106 0006 – 0007 Mr Nix
156 WIT 0106 0174 Mr Nix
157 John Watson, General Manager, Central Unit, B&WDHA from 1986. Chief Executive, Avon FHSA, from March 1990 onwards
158 WIT 0298 0012 – 0013 Mr Watson
159 WIT 0298 0013 Mr Watson
160 Formerly the District Medical Officer for B&WDHA from July 1984 to 1988, and subsequently a consultant in public health medicine for B&DHA from October 1991 onwards
161 Manager of the Children's and Obstetric Sub Unit from February 1986
162 UBHT 0062 0299; meeting on 6 May 1987

> 'It was reported by Mr Nix that we have funding for services to adults and children under the age of one year. It was also noted that the expansion to 670 cases per annum excludes the Welsh position, other than Gwent. Mr Nix and Miss Stoneham indicated that they were in the process of ascertaining the maximum number of patients who could be treated within the resources which would be available … It was agreed that it would be necessary to put some constraints upon the medical staff with regard to where referrals could be accepted from if the services were to be maintained within the funds available. Dr Baker agreed to write to the clinicians involved.'

154 Dr Baker wrote to Dr Joffe, Dr Jordan, Mr Wisheart and Mr Dhasmana on 8 May 1987. In the letter he referred to:

> '… considerable uncertainty and confusion over the nature of the cardiological and cardiac surgical response that those in Wales wish to receive. As you may be aware, several London hospitals as well as Southampton, have cardiologists who are active in holding clinics in South and Mid-Wales and referring patients to their own centres for cardiac surgery. Unless the Welsh Office and the constituent authorities decide where they wish to spend their resources and organise the referral patterns through the relevant cardiologist, then we cannot be confident about the volume of service which will be required from our units here in Bristol. If this is not agreed, then we cannot sensibly determine the implications for our services in terms of space and staffing nor can we make appropriate charges upon the Welsh Office or any other DHSS funding source to cover the costs of the service.
>
> '… Until we have formal arrangements with the Welsh Office and individual health authorities, I do not think that we should be undertaking any services to Welsh patients other than to neonates and infants from Gwent Health Authority. Even with Gwent HA we do not have full formal agreements, although I know that the DMO [District Medical Officer] from Gwent is anxious to establish such agreements. This can probably proceed and we can make sure that resources are covered appropriately including travelling time. I am aware that there have been some informal visits to West Glamorgan and Dyfed Health Authorities, but I must advise that until the matters which I have raised above are settled … these unresourced services should not continue.
>
> 'I have been careful to indicate in all my communications that we are most anxious to assist South Wales and the onus is upon them to get their house in order. Unfortunately, I learn that there are mounting political pressures to limit any out of Wales cardiological and cardiac surgical services.'[163]

[163] UBHT 0092 0002 – 0003; letter from Dr Baker dated 8 May 1987

155 Mr Watson told the Inquiry:

> 'Whilst the assessment throughout 1986/1987/1988 of the disproportionate numbers of referrals to resources was going on, we still got new cases in. Throughout that time, from a management perspective, it remained the view that we could not manage the patients at that continuing rate … the situation at the BRI, with regard to resources and the Welsh issue, continued for some time. It was not until 1989 that funding deals were agreed with the Welsh Office.'[164]

156 In September 1987 Dr Baker wrote to Mr Watson.[165] The letter referred to a forthcoming meeting between the Welsh Office and health authorities in South Wales to discuss cardiac services. Dr Baker asked Mr Watson to assist in preparing an estimate of the service that Bristol could generate in the future. In the letter, Dr Baker wrote:

> 'I have received a request from Dr Skone of South Glamorgan Health Authority to undertake 50 coronary bypass procedures[166] for patients from their health authority. I am aware that our own services have been slowed by the absence of James Wisheart recently, but I realise also that we are trying to progress some cases from our waiting list through facilities in London. Can you advise me whether you wish to entertain any number of these adult cases from South Glamorgan. Regarding our waiting list initiative, I did write to Gerald Keen indicating that he maximises the flow of patients to London during James Wisheart's absence. He has replied indicating that he himself has a very short waiting list, that Mr Dhasmana has referred nine cases, and they await James Wisheart's return for cases to be progressed from his waiting list.'

157 On 2 November 1987 Dr Roylance wrote to Professor Gareth Crompton, Chief Medical Officer for Wales.[167] This letter was centrally concerned with paediatric cardiac referrals from Wales. Dr Roylance wrote:

> 'It seems that until now there has been a somewhat ill-defined and underfunded referral pattern from the Welsh District Health Authorities. Referrals from Gwent Health Authority are part of a recognised supra regional service for infants and neonates and this service is funded appropriately. There are referrals also for children above the age of one and these referrals are not funded. Clinicians in other health authorities in South Wales have been anxious to have the assistance of our cardiologists, Dr Jordan and Dr Joffe and a number of clinics have sprung up in West Glamorgan, East Dyfed and Pembrokeshire Health Authorities which are visited by these cardiologists. The referral pattern which is emerging from these authorities is unfunded presently. Officers of South Glamorgan Health Authority are considering the future pattern of their referrals and the extent to which they may

164 WIT 0298 0016 Mr Watson
165 UBHT 0278 0302; letter dated 8 September 1987
166 That is on adult patients
167 UBHT 0062 0354 – 0355; letter dated 2 November 1987

wish to use services in Bristol. Liaison and any further referral patterns from Mid-Glamorgan Health Authority are uncertain.

'It is apparent that the current volume of our services has outstripped the resources available for their operation and it has been necessary to redress this situation. It would appear that in 1985 our services were funded adequately and that it is since that year that unfunded growth in the services has taken place. It has been necessary therefore to recognise these facts and to discuss with individual health authorities in South Wales the pattern of referrals that has emerged since 1985, the intention to continue the pattern and the funding required to undertake the service. It is understood that for neonates and infants supra regional funding arrangements can be made between the Welsh Office and the DHSS. Referrals for children in other age groups is not covered by any formal arrangement as for cross boundary flow adjustment. It has been necessary therefore to consider some form of direct charging for services with individual health authorities.'

158 The letter to Professor Crompton enclosed copies of the letters sent to the chief administrative medical officers of DHAs in South Wales[168] on the same day. These letters set out the number of referrals Bristol would accept from each DHA, based on its 1985 figures. In these letters Dr Roylance wrote:

'As you are aware, we have been pursuing for some time with the Welsh Office the need to clarify arrangements for the referral from Wales to Bristol of children requiring cardiology or cardiac surgery services. We still seem to be some way from reaching a longer term agreement and are now encountering considerable difficulties because the number of referrals is outstripping the resources available.

'It is therefore our intention to restrict the number of referrals we can accept to the number of referrals accepted during 1985 when we believe the service was funded adequately, unless arrangements are made regarding funding with those authorities who wish to refer patients in excess of these numbers. Neonatal and infant cardiology and cardiac surgery services can be funded as supra regional services through the Welsh Office and the DHSS directly if future workloads are forecast … On advice from our cardiologists and cardiac surgeons, the rate of admissions and procedures for children (infants in parenthesis) per million total population are as follows: Admissions 150 (65), Catheterisations 75 (35), Closed operations 30 (20), Open operations 35 (12).'

159 Each letter went on to apply these rates to the particular district and to set out the actual number of referrals which would be accepted by Bristol.

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[168] Dr Reynolds, East Dyfed Health Authority (UBHT 0278 0287 – 0288), Dr Skone, South Glamorgan Health Authority (UBHT 0278 0291 – 0292), Dr Harrett, Gwent Health Authority (UBHT 0278 0283 – 0284), Dr R Doyle, Pembrokeshire Health Authority (UBHT 0278 0285 – 0286), Dr Hughes, Mid Glamorgan Health Authority (UBHT 0278 0293 – 0294), and Dr Littlepage, West Glamorgan Health Authority (UBHT 0278 0289 – 0290)

160 The letters concluded:

> 'I regret having to pursue this type of approach whilst being aware that this matter is under active discussion at the Welsh Office with professional staff in Wales. It is certainly not our intention to put undue pressure on those who have the difficult task of finding the longer term solutions to the problem. However, in common with many other health authorities, we are faced with ever increasing demands within a relatively static resource base. The inevitable consequences of allowing continued development of unfunded work from outside the region is to produce a deleterious effect on the services we can provide to the population in our own district.'

161 In December 1987 Mr Watson wrote to Mr Dhasmana, Mr Wisheart, Dr Joffe and Dr Jordan, enclosing a copy of a draft letter he intended sending to the Welsh Office regarding referrals.[169] In the letter he stated:

> 'Since we met and discussed this subject, various attempts have been made to make progress and I feel that this firmer action is needed. Hopefully, it will be possible to meet representatives from Wales early in the New Year and reach some agreement on funding.'

162 That month Dr Roylance wrote to Mr Owen, Director of the NHS in Wales:[170]

> 'As you are no doubt aware, on 2 November 1987 I wrote to Dr Crompton, Chief Medical Officer for Wales, regarding children's cardiology and cardiac surgery services for Wales. I understand that this matter has now been referred to yourself. Since that time we have not received a clear response from yourself and, unfortunately, the situation within this district is becoming increasingly difficult and it is therefore necessary to take some action on the matter. We have now decided that as from 1 February 1988 we are unable to receive any new patients aged over 1 year from Wales. I should emphasise that although no new cases in this category can be accepted until agreement on appropriate funding is reached, I would anticipate that in the case of children under the age of 1 year there should not be difficulty with reaching agreement via the DHSS for supra regional funding.'

163 In January 1988 Dr Baker wrote to Mr Watson,[171] enclosing correspondence from Mr Gregory[172] and Professor Crompton:[173]

> 'Our conclusion might be that the Welsh like writing letters and find it difficult to make decisions. … There seems to be some confusion about their future plans in so far as they talk of a new paediatric cardiac unit to be built in Cardiff with work expected to begin in 1988 whilst Dr [Professor] Crompton's letter indicates that

169 UBHT 0165 0019; letter dated 22 December 1987
170 UBHT 0165 0020; letter dated 18 December 1987
171 UBHT 0062 0384; letter dated 11 January 1988
172 UBHT 0278 0268 – 0269; letter dated 23 December 1987
173 UBHT 0278 0270 – 0271; letter dated 15 December 1987

there is still some uncertainty as to the nature of this unit and where it will be located … In spite of the Welsh efforts to reassure us I am sure that you will feel that we are still dealing with under funded over referrals of Welsh cases to BCH/BRI and I would have thought there were grounds for proceeding with the letter we composed for John Roylance.'

164 Of this correspondence Mr Watson said:

'It can be seen here that Dr Ian Baker was recommending in January 1988 that we should stick to our guns in terms of limiting the referrals. The clinicians would have been generally unhappy about this as they were looking to expand the Department. There was discussion with the cardiologists who had direct input … naturally they were quite frustrated as they simply wanted to treat the patients.'[174]

165 Negotiations with the Welsh Office continued during 1988. It was during this period that paediatricians in West Glamorgan approached Dr Joffe to take over an 'outreach' clinic at Bridgend previously undertaken by Dr Hallidie-Smith. Dr Baker wrote to Dr Mason, SWRHA Regional Medical Officer:[175]

'The facility with which the Welsh Office and its health authorities serve their populations with English based cardiologists is amazing. John Watson however, the Unit General Manager responsible for cardiac services here feels that whatever is agreeable on the professional networks must have the agreement of the Managers concerned. His position as stated previously is one of wishing to curtail all services to South Wales until he is compensated appropriately for the services he renders. … matters are clearly getting worse rather than better.'

166 In July 1989 Mr Watson wrote to Mr Gregory.[176] The letter, headed 'Cardiac Services for Wales – Children Over 1 Year', confirmed that agreement had been reached for funding referrals for the year commencing 1 April 1989, with discussions for funding for the following year planned to take place in December 1989. The letter recorded:

'Based on advice from our cardiologists and surgeons, the expected total referrals is 75 cases. The basis of the charge will be the number of cases over 28.'

1991 onwards

167 The Paediatric Cardiac Unit at University Hospital Wales, Cardiff, admitted its first patients in June 1991.[177] Once the Cardiff unit was established, the Welsh Office sought to encourage referrals to it. Professor Crompton told the Inquiry:

'… the most important factor from 1991 on in Cardiff was the huge commitment of time that the paediatric cardiologist, with support from the others in his team, made

174 WIT 0298 0016 Mr Watson
175 UBHT 0278 0174; letter dated 18 October 1988
176 UBHT 0103 0045; letter dated 20 July 1989
177 WIT 0058 0008 Mr Gregory

in the visiting and the revisiting, and the persistent seeking of trying to influence the District General Hospital paediatricians in Wales to give the Cardiff centre a chance to show what it could do, if I can put it like that. They were very assiduous in doing that.'[178]

168 Once the Cardiff unit was established, the Welsh Office ceased to fund centrally the referral of paediatric cardiac cases to Bristol. Mr R Williams, Assistant Director, Health Services Division, Welsh Office, outlined this change of policy in a letter to the general managers of East Dyfed, Gwent, Powys and Mid, South and West Glamorgan Health Authorities:

'Since the new paediatric cardiac unit at UHW will be centrally funded to provide a service throughout South and Mid Wales, it is proposed that central funds will cease to be available for the referral of new patients to Bristol and Weston Health Authority for paediatric cardiac services once the paediatric cardiac unit at UHW becomes operational. It would, therefore, fall to individual health authorities wishing to continue with current arrangements to contract with, and fund from their own resources, Bristol and Weston Health Authority in respect of any new patients referred to that Authority once the paediatric cardiac unit at UHW comes into operation.'[179]

169 Mr Gregory told the Inquiry:

'In February 1991, the Welsh Office wrote to the six relevant South and Mid Wales Health Authorities advising them of the arrangements which would apply to the central funding of paediatric cardiac services, and to seek advice in quantifying continuing reliance on Bristol in financial year 1991/92.'[180]

Referral to cardiologists

170 The Inquiry heard evidence that referrals to Bristol increased in the period to 1991, and that the establishment of the Cardiff unit in 1991 did not lead to all patients within its catchment area in South Wales thereafter being referred to it.

171 As with the referrals from the South West of England, the Inquiry heard evidence that the contact between referring paediatricians and cardiologists was a key influence on the pattern of referrals. Both during the period 1984 to 1991 and afterwards, relationships between paediatricians and cardiologists were a significant influence on referral patterns from South Wales.

172 Mr Gregory said: '… up to the present day, there are referrals out of Wales of children who, when the unit was fully operative, could, but for clinical preference, have been treated in Cardiff'.[181]

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178 T21 p. 16–17 Professor Crompton
179 UBHT 0194 0010; letter from Mr Williams dated 26 February 1991
180 WIT 0058 0008 Mr Gregory
181 T10 p. 50–1 Mr Gregory

173 Mr Gregory told the Inquiry that a change in referral patterns occurred in 1987, because:

> 'a) The premature death towards the end of 1986 of Dr Leslie Davies, the well respected cardiologist who saw the vast majority of the young patients referred to the Cardiff centre in what was largely an adult cardiac practice, created a crisis in the local service in South Wales.
>
> 'b) The specialties of cardiology and cardiac surgery in the UK by this time were noticeably understaffed to meet the demands of the population for treatment … The London Centres, in particular, found it less easy to accommodate the Welsh referrals within desirable timescales for treatment.'[182]

174 Professor Crompton explained how referring paediatricians in Wales responded:

> 'Welsh paediatricians responded by arranging for additional visits by other cardiologists to their hospitals and we see Bristol and Southampton based clinicians visited South Wales on a regular basis. Whilst patients from the Royal Gwent Hospital, Newport and Nevill Hall Hospital at Abergavenny had traditionally referred to Bristol, we now see others, but not all in South Wales using the Bristol centre.'[183]

175 Mr Gregory was asked for his views as to why children from South Wales were referred to London hospitals. His evidence included this exchange:

> 'Q. For what reasons do you understand children were referred to Brompton, the National Heart Hospital or Great Ormond Street?
>
> 'A. Because those were the hospitals with which the referring paediatricians had established relations. The Inquiry will know that can be for a variety of reasons. As a consequence, there was an established pattern of referral. At that time, the pattern of referral, once established and once regarded as satisfactory, is likely to be retained. Indeed, the patterns of referrals to England throughout the period with which the Inquiry is concerned, indeed, up to the present day, are agnostic of the establishment of a specialist service if the clinician concerned believes it is in the best interests of the child they be referred elsewhere. Even when the Cardiff unit was up and fully functioning as a comprehensive unit, children were still referred to centres in England. So it comes back to an issue of the clinical preference of the referring clinician.

[182] WIT 0070 0002 Professor Crompton
[183] WIT 0070 0002 Professor Crompton

> 'Q. The clinical preference, the way you describe it, your understanding would be very much influenced by habit and personal relationships?
>
> 'A. I think those are factors. I think in this case we are talking about London hospitals with significant reputations for providing specialist services of this kind, which at that stage were not available in a comparable specialist service in Wales. So the logic of that would be that clinicians, for the reasons you have described, but also for the reasons I have referred to, would be looking to England to provide the service.'[184]

Evidence of the actual pattern of referrals from South Wales

176 Dr Jordan confirmed that, in a number of places in Wales, Dr Hallidie-Smith had conducted clinics from the Hammersmith Hospital and that on her retirement Bristol took over a number of her clinics. He said: 'I think particularly one that I dealt with in the East Glamorgan General Hospital'.[185] As to the clinics run by Dr Leslie Davies, he said that Bristol started to pick up some of his work 'before Dr Davies' death, because what there was of paediatric cardiac surgery at that time in Cardiff had stopped before then'.[186]

177 Dr Agarwal[187] told the Inquiry:

> 'When I joined Swansea in 1976, the paediatric cardiac service was far from satisfactory. Children with cardiac problems were either referred to Cardiff or hospitals in London … The follow-up of these children locally was often lost. Initially I persuaded Professor Muir and later Dr LG Davies from Cardiff to hold joint cardiac clinics with us in Swansea but because of lack of neonatal cardiac surgery in Cardiff, the situation was still not satisfactory.'

Dr Agarwal went on to explain how, in 1982 or 1983 at the suggestion of a colleague, he transferred a premature infant to the BRHSC. He said:

> 'Until this time, to my knowledge no paediatric cardiac patients had been sent to Bristol, however from this time onwards myself and my colleagues in Swansea started to send children … to Bristol cardiologists. … After the death of Dr LG Davies … I persuaded Dr Hyam Joffe … to hold regular clinics with us in Swansea starting some time in 1986.'[188]

184 T10 p. 14–15 Mr Gregory
185 T79 p. 134 Dr Jordan
186 T79 p. 134 Dr Jordan
187 Consultant paediatrician, Singleton Hospital, Swansea
188 REF 0001 0085; letter from Dr Agarwal

178 Dr Dewi Evans,[189] who was appointed at Swansea in 1980, did alter his referral pattern when the Cardiff unit became operational in 1991. He told the Inquiry:

> '… the services in Swansea were very ad hoc at that time [in 1980]. I arranged a link with the Hammersmith Hospital, with the late Dr Hallidie-Smith. As she came up to retirement I established links with Dr Hyam Joffe in Bristol. … about 1985 I transferred my allegiance to the cardiac team in Cardiff when it was formed in 1991.'

Dr Evans said that whilst Dr Agarwal continued to refer all his patients to Dr Joffe until his retirement, Dr Evans began to refer to Cardiff 'for reasons of expediency and practicality'.

179 Dr Palit of Haverfordwest[190] started to refer to Bristol when Dr Davies died. The reason for choosing Bristol was geographic. Dr Palit told the Inquiry that he 'started a joint clinic in paediatric cardiology with the late Dr LG Davies from Cardiff, who used to visit Dyfed periodically … he would then refer the patients further away for surgery … [The] decision to send our children to Bristol was very easy because there was no other centre nearby us, who could give us a regular service.' After the death of Dr Davies, Dr Palit approached Dr Jordan and then had 'no cause to refer children with heart problems elsewhere' until Dr Jordan retired.

180 However, Dr Palit's colleague, Dr G Vas Falcao,[191] told the Inquiry that 'During this period all paediatric cardiac problems from Pembrokeshire were referred to the paediatric cardiac unit at University Hospital of Wales'.

181 Dr I Hodges[192] explained that in Mid Glamorgan, children's cardiological services were, at the beginning of the period of the Inquiry's Terms of Reference, provided by Dr Hallidie-Smith. Subsequently, referrals were to Dr Jordan until his retirement, and then to Cardiff.

182 Dr Hodges' colleague, Dr J Morgan, said that when he started practice in 1981 'children with cardiac problems were referred to the Hammersmith Hospital in London. Dr K Hallidie-Smith came down to Wales three times a year.' Any child needing ultrasound had to go to London, and any surgery was carried out at Hammersmith or Great Ormond Street.

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189 Consultant paediatrician, Singleton Hospital, Swansea, REF 0001 0087 – 0088
190 Consultant paediatrician, Withybush General Hospital, Haverfordwest, REF 0001 0092 – 0093
191 Consultant paediatrician, Withybush General Hospital, Haverfordwest, REF 0001 0094
192 Consultant paediatrician, East Glamorgan General Hospital, Mid Glamorgan, REF 0001 0096 – 0097

183 Dr Morgan's evidence was that by 1989:

> '… there were difficulties with continuing this service and negotiations between Bristol and Mid Glamorgan Health Authority resulted in cardiac services both medical and surgical being transferred to Bristol. … The service that was then established from Bristol consisted of a very senior paediatric cardiologist, Dr Stephen Jordan who came to our hospital on a much more frequent basis. He was able to perform ultrasound cardiac scans as part of his clinic with us and this was very much appreciated by parents as they no longer had to go up to London for this investigation. … When Dr Jordan retired, a cardiac service was being developed in Cardiff and the care of our patients were transferred to this service …'[193]

184 Dr A Griffiths[194] of Abergavenny was appointed in 1969. He told the Inquiry:

> '… initially our cardiac patients were referred to the teaching centre at Cardiff. In those days there was no paediatric cardiologist on the staff but the children were referred to Dr Leslie Davies who was an adult cardiologist. From the surgical point of view however this service became gradually more unacceptable, children being left on the waiting list for very long periods of time and eventually Dr Davies retired. … therefore we contacted the Bristol team and their paediatric cardiologists would come out and run a combined cardiac clinic with us. … The service for children with cardiac problems improved dramatically.'

185 This was confirmed by Dr Griffiths' colleague Dr T Williams[195] who was appointed in 1986, and who told the Inquiry:

> '… in 1986 we had an inadequate service from Cardiff. We made contact with Bristol and have continued with their support since that time. Establishing the service led to a considerable improvement in the quality of care given to our local children…'[196]

186 Dr Edwards[197] said that from 1979 he referred to the Hammersmith and Dr Hallidie-Smith:

> 'When Dr Hallidie-Smith retired in mid 1980s there was still not a fully functioning cardiac unit at Cardiff. … We were also aware of the fact that peripheral clinics had been established from Bristol, mainly by Dr Jordan, in many hospitals in South Wales, with Consultant General Paediatricians being very pleased with the level of service that they were receiving, both from the local clinics and from Bristol itself.

193 REF 0001 0136 – 0137; letter from Dr Morgan
194 Consultant paediatrician, Nevill Hall Hospital, Abergavenny, REF 0001 0128 – 0129
195 Consultant paediatrician, Nevill Hall Hospital, Abergavenny, REF 0001 0133
196 REF 0001 0133; letter from Dr Williams
197 Consultant paediatrician, Princess of Wales Hospital, Bridgend, REF 0001 0108

> For these two reasons therefore … we decided to link in with Bristol and established a pattern whereby bi-monthly clinics were held locally…'

187 His colleague, Dr Trefor Jones,[198] provided the Inquiry with a copy of a report prepared by him and Dr Edwards and Dr A Goodwin in November 1996[199], confirming that they had referred to Dr Hallidie-Smith until her retirement, and thereafter to Dr Joffe, and then to Dr Martin.

188 Dr Ferguson[200] wrote:

> 'I don't recall referring any patients with heart problems to centres other than BRI again for the reason that the referrals were always invariably made through the visiting cardiologist, Dr Steve Jordan, who was based there.'[201]

189 Not all paediatricians who changed their referral pattern from Bristol to Cardiff as a result of the establishment of the unit in Cardiff or the later retirement of Dr Jordan were entirely happy to do so.

190 Dr Prosser[202] told the Inquiry:

> '… from the opening of the first Severn Bridge in 1966, with the support of Dr LG Davies, Cardiologist at the University Hospital Wales, we started referring neonates and other small infants to paediatric cardiology services in Bristol. This was done because of the proximity of the Unit to the Royal Gwent and that as far as we were able to ascertain the services there were equal to those of other centres in the UK. … Following the death of Dr Davies we decided to ask Dr S Jordan to take over our monthly paediatric cardiology clinic … and our association with Bristol was strengthened. … Even with the establishment of the Paediatric Cardiology Unit in Cardiff in 1990 or thereabouts I and my colleagues were reluctant to give up our association with Bristol and were more or less forced to do so by the financial constraints imposed on us by the Welsh Office.'

191 Dr Maguire[203] spoke of a change in the pattern in 1993:

> 'We changed our cardiac services from Bristol to UHW on the basis of a desire by Welsh Office to have the Welsh units using the newly developed paediatric cardiac services in Cardiff …'

198 Consultant paediatrician, Princess of Wales Hospital, Bridgend, REF 0001 0114 – 0115
199 REF 0001 0116 – 0121; *'A Review of the Provision of Paediatric Cardiology at Bridgend',* dated November 1996
200 Consultant paediatrician, Royal Gwent Hospital, Newport, REF 0001 0126 – 0127
201 REF 0001 0126; letter from Dr Ferguson
202 Consultant paediatrician, formerly at Royal Gwent Hospital, Newport, REF 0001 0131 – 0132
203 Consultant paediatrician, Royal Gwent Hospital, Newport, REF 0001 0130

192 Dr Cawdrey[204] commented on the situation following the death of Dr Davies, who had previously carried out a clinic at the Royal Gwent Hospital. Dr Cawdrey wrote:

> 'Dr Steve Jordan started a regular clinic with us from that time. … Therefore, from this time, all children and babies with heart problems were seen by Dr Jordan and consequently most if not all of those requiring surgery received this in Bristol. In 1991, a full paediatric cardiology and cardiac surgery service was established in Cardiff. As we understood at the time the reasons for doing this were largely "political". It was felt that establishing such a service would enhance general cardiology training in Cardiff, but there was also considerable public pressure to establish a unit in Wales so that children in Wales would no longer need to travel "abroad" for their treatment! We in Newport saw no reason to change our arrangements immediately and continued to use Bristol until the spring of 1993, when Dr Jordan retired, and we thought it opportune and more convenient to switch to Cardiff for paediatric cardiology and paediatric cardiac surgery ...'

193 Dr Jordan commented on the letter:

> 'I think Dr Cawdrey at that time was Chairman or President of the Welsh Paediatric Association and they were the people who had – well, some of them had at least supported the idea of having a new unit in Cardiff. We discussed this. I think he admitted to a certain amount of embarrassment that he was still sending his patients to Bristol when in theory the body of which he was the Chairman or the President had apparently supported the establishment in Cardiff.'[205]

194 Dr J Matthes,[206] however, told the Inquiry that she had been a senior registrar in Cardiff and, on appointment as consultant in 1993, wished to transfer the list that she inherited to Cardiff. She said that Dr Joffe 'resisted this … I was told that the Bristol cardiologists felt that it was not in the patients' interests to transfer them to Cardiff as some of them had quite complex conditions. At no time was it ever intimated to me that there might be poorer results with the surgery at Bristol than at other centres.' Her patients continued to be treated in Bristol.

Concerns[207]

195 Some (five out of 27) referring paediatricians in Wales cited concerns about the standard of care at Bristol as a factor influencing their referral pattern.

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204 Consultant paediatrician, Royal Gwent Hospital, Newport, REF 0001 0123
205 T79 p. 133 Dr Jordan
206 Clinical Director, Paediatrics, Singleton Hospital, Swansea, REF 0001 0090
207 Concerns are set out in detail in Chapters 20–30. The extent to which any concerns of referring paediatricians may have influenced their referral patterns is set out here for completeness

196 Professor I Hughes[208] told the Inquiry:

> 'I had formed an impression that the service for complex cardiac cases was less than satisfactory if only on the basis that the pattern of referral of any cases from Cardiff utilised centres other than Bristol … That transportation of cases to Southampton which would have travelled past Bristol is illustrative of the concern prevalent at that time regarding services in Bristol.'

197 Dr C Weaver[209] said:

> 'My patients were mainly referred to GOS [Great Ormond Street Hospital] or to Southampton; personal acquaintance with a cardiologist in London was part of the reason for the referral pattern … I do have one recollection of a rather unsatisfactory post-operative arrangement when a baby needed emergency admission on my "intake", who had recently undergone cardiac surgery in Bristol … Even after telephone discussion (I believe with Mr Wisheart) there seemed to be a certain lack of support and interest.'

Parents' requests

198 Evidence from Welsh-based parents whose children were referred to Bristol reflected the same issues as mentioned earlier in the case of parents based in England.

199 Samantha Harris, whose daughter Kimberley was referred from the Princess of Wales Hospital, Bridgend, to Bristol, said:

> 'The staff informed me that they had decided to transfer Kimberley to Bristol, in an ambulance, since there was a specialist heart unit there. I was not very pleased that this hospital had been selected, since it would have been much easier for me to go to London, where I have relatives. I also knew that hospitals such as Great Ormond Street had an excellent reputation, whereas I had never heard of the unit at Bristol before. … At no time was it explained to me that I had any choice in the matter …'[210]

200 Robert Briggs, whose daughter Laura was also referred from the Princess of Wales Hospital, Bridgend, to Bristol, said:

> 'It was the Consultant's decision to refer her to Bristol, and no alternative referrals were discussed with us, but we had no problems with that decision either at the time or at any subsequent time. We were simply told that it was the nearest hospital that dealt with children with severe heart problems.'[211]

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208 Professor of Paediatrics, Cambridge, formerly Department of Child Health, Cardiff, REF 0001 0100 – 0101
209 Consultant paediatrician, formerly at University Hospital of Wales, Cardiff, REF 0001 0106 – 0107
210 WIT 0302 0004 Samantha Harris
211 WIT 0136 0002 Robert Briggs

201 Carol Colclough, whose son Andrew was referred to Bristol from the Royal Gwent Hospital, Newport, said:

> 'Mr Ferguson [Dr Ferguson][212] recommended that Andrew be referred to Bristol for specialist attention and consideration for surgery. He recommended Bristol, and at that time there was no other specialist centre in South Wales. Later in 1991 a Specialist Unit was opened at the Heath Hospital in Cardiff but that option did not exist for us at the time and we were content enough to go to Bristol to get the necessary treatment. No other alternatives, such as London, were mentioned to us, but Mr Ferguson seemed very happy with Bristol, and we were content to go along with his recommendation.'[213]

202 Gail Booth, whose daughter Elisa was referred to Bristol from the Royal Gwent Hospital, Newport, said:

> '… they thought she may have a problem with her heart and that she would be transferred to Bristol. The staff told me that Bristol was one of the best heart hospitals in the whole country.'[214]

203 A parent explained that her child was referred from Neath General Hospital to Hammersmith. However, she said:

> 'When Dr Hallidie-Smith retired, [the child] was referred from Hammersmith Hospital to Bristol Children's Hospital. We were simply notified that this was what was to happen.'[215]

204 Some parents were given a choice, together with an opinion from the paediatrician as to the respective standards of the alternative centres. Caroline Jones, mother of Matthew, said that Dr Palit saw him at Withybush Hospital, Haverfordwest:

> 'He gave us the choice of sending Matthew either to Bristol or to Great Ormond Street Hospital in London. Dr Palit told us that the unit at Bristol had a good reputation and was on a par with Great Ormond Street. Because of this recommendation, and because Bristol is nearer, we chose Bristol.'[216]

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212 Consultant paediatrician, Royal Gwent Hospital, Newport
213 WIT 0176 0002 Carol Colclough
214 WIT 0410 0001 Gail Booth
215 WIT 0216 0003. 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
216 WIT 0238 0002 – 0003 Caroline Jones

Referrals to other centres by Bristol cardiologists and surgeons

Referral procedure and reasons for referral

205 The Inquiry heard evidence from the Bristol cardiologists and surgeons about the nature and extent of referrals to centres other than Bristol.

206 Dr Joffe explained the procedure once a child had been investigated by the Bristol cardiologists:

> 'If the cardiologist considers that surgery may be indicated, the results of investigative procedures are reviewed at a joint cardiology/cardiac surgical/radiological meeting.'[217]

He told the Inquiry:[218]

> 'It was, and still is, up to the paediatric cardiologists and cardiac surgeons together to determine the best course of action for each individual child.'

207 Dr Jordan told the Inquiry that he referred patients elsewhere:

> '... usually for one or more of the following main reasons:
>
> - 'There was a surgeon able to offer an operation that was not available in Bristol. This included, at different times, the Rastelli operation, arterial switch (Magdi Yacoub), Fontan operation (Brompton and GOS), autograft aortic valve replacement (Donald Ross) and heart or heart-lung transplantation (Harefield Hospital).
> - 'A surgeon or a team had shown a particular interest in the management of an unusual condition such as ventricular septal defect with prolapsing aortic valve cusp (Donald Ross and Jane Somerville at the National Heart Hospital).
> - 'Parents requested such a referral either because it was more convenient (e.g. they had relatives with whom they could stay in London) or had some other association, such as a relative or godparent who was a cardiac surgeon.
> - 'I or my colleagues were uncertain about the actual diagnosis, such as differentiating aorto-left ventricular tunnel from sinus of valsava aneurysm.

[217] WIT 0097 0164 Dr Joffe
[218] WIT 0097 0292 Dr Joffe

- 'I or my colleagues were uncertain as to the correct procedure and we wanted a "second opinion".

- 'Parents requested a "second opinion", usually because they were uncertain as to the need for surgery or were unhappy with the risk that they had been given by the surgeon.

- 'Parents where a previous child had been operated on in Bristol and had died, in which case I always offered to send the child elsewhere.

- 'When surgery had previously been carried out by another surgeon and the patient had moved into the area (or we had taken over an area formerly served by another unit). Not all parents wished to be referred back to the original surgeon.'[219]

208 Asked on what basis a unit would be chosen for a referral, Dr Joffe said:

> 'A variety of reasons, including a personal connection between someone who had trained, let us say, at the Brompton, knew the surgeon and knew he did an operation particularly well; the overall perception that cardiologists, as a group, would have of a particular unit's performance on another condition. The relationship between one surgeon and another, because these cases would be referred either by the cardiologists or after our joint meetings, by a cardiac surgeon, with whoever he or she, in this case he, was referring that patient to. So it is a variety of reasons, but I think, as you will see at that time, it was mostly Great Ormond Street, sometimes the Brompton, but later on Birmingham.'[220]

209 Dr Jordan acknowledged the comparatively short waiting list at Southampton, but explained why he would not have referred patients from Bristol there. His evidence included this exchange:

> 'Q. Southampton, if I have understood it correctly, had no or very short waiting lists compared to Bristol?
>
> 'A. The information I was given by the paediatricians in Plymouth was if a patient was seen by one of their paediatric cardiologists in outpatients, requiring a catheter and presumably an operation, they will be admitted within about three weeks for the catheter and they will have their operation next week. That is what they described to me as being a typical situation. Whether, you know, it always quite worked like that, I cannot say, but that was the information given to me.

219 WIT 0099 0037 Dr Jordan
220 T90 p. 52 Dr Joffe

'Q. And that was about this sort of time, three years or thereabouts before your retirement?

'A. Yes. We had this discussion on odd occasions, but, yes, I mean, there was certainly a discussion about 1989/90, something like that.

'Q. So were the Bristol children who were facing the long waiting list at Bristol referred to Southampton where there were very short waiting lists?

'A. … No, they were not.

'Q. Would that not have been a more sensible way of proceeding?

'A. It is like all of these things: it is sensible in that it deals with the immediate problem. What then happens when Southampton builds up a waiting list because they have been sent twice as many patients as they can cope with?

'Q. What would be the bars, the disincentives for you and Dr Joffe in sending a patient to Southampton, say?

'A. Can I say, I have absolutely no criticisms of the surgery in Southampton, so let us get that out of the way. That is not a bar. Firstly, it would almost inevitably mean a longer journey for the patients and their parents. Secondly, there would then be problems of communication between the surgeons there and the patients: where do they follow them up? If it was a patient who came from Haverfordwest in South Wales, they would not want to be sending one of their teams out to Haverfordwest just to see one or two patients. There were those sort of logistic problems, basically, that it seemed to us desirable to avoid, if they could be avoided. Having said that, I did refer patients not to Southampton but to other hospitals for specific reasons, and obviously we had to make the best that we could of those particular objections.'[221]

210 Mr Dhasmana and Mr Wisheart gave evidence to the Inquiry about the circumstances in which a child might be referred to another centre for surgery. They identified Great Ormond Street, Harefield, the National Heart Hospital, the Royal Brompton Hospital and Birmingham as centres for such referrals. Mr Dhasmana told the Inquiry that such decisions were made in conjunction with the cardiologists and others, usually in joint meetings held on Mondays at the BRHSC. Mr Wisheart acknowledged that there might have been referrals elsewhere by the cardiologists about which he had not been told.

[221] T79 p. 89–91 Dr Jordan

211 Mr Dhasmana said that a record of these referrals would usually be kept at the BRHSC with the cardiologists, and provided a list[222] produced by Dr Joffe illustrating referrals to other centres between 1992 and 1994. Mr Dhasmana added: 'There were similar patterns of referrals before 1992.'

212 Mr Wisheart told the Inquiry:

> 'There were always a small number of referrals away from Bristol to other centres, such as Great Ormond Street, the Brompton, the National Heart Hospital or in recent years to Birmingham. In many instances the decision to refer elsewhere was a joint one between the surgeons and the cardiologists. It is impossible for me to say whether or how many were referred elsewhere by the cardiologists without consulting the surgeons.'[223]

He added:

> 'I would now find it very difficult to indicate the extent of these referrals, other than to say that apart from [the neonatal Arterial Switch], it was relatively uncommon.'[224]

213 Mr Dhasmana told the Inquiry[225] that the reasons for such referrals included:

- 'Patients for consideration for heart or heart and lung transplantation;
- 'surgical treatment not available at Bristol i.e. patients with hypoplastic left heart requiring Norwood Procedure and Neonatal Switches after October 1993;
- 'for second opinions, when the risk of surgery was considered very high or surgical options were not clearly defined;
- 'I recall an instance when parents asked me for referral to Mr Yacoub at Harefield for a second opinion, before returning to me for surgery on their child;
- 'there were instances when patients were transferred to other centres, for example when an urgent surgery could not be provided at Bristol, for the lack of a bed.'

222 WIT 0084 0064 – 0065 Mr Dhasmana
223 WIT 0120 0119 Mr Wisheart
224 WIT 0120 0120 Mr Wisheart
225 WIT 0084 0062 Mr Dhasmana. See Chapter 3 for an explanation of these clinical terms

214 Mr Wisheart told the Inquiry[226] that reasons for such referrals would include:

- 'At the beginning of the period, before Mr Dhasmana was appointed, an urgent patient who presented when I was on leave would have had to be sent elsewhere.
- 'Patients with conditions whose rarity and/or complexity placed them outside our experience would have presented from time to time, and referral elsewhere would have been considered.
- 'There were patients about whom it was difficult to be confident as to what was the appropriate advice and therefore from time to time we would have consulted with colleagues elsewhere, most commonly with Great Ormond Street. In the light of their advice, there were some occasions when we asked the surgeons at Great Ormond Street to undertake a surgical procedure they had recommended. On other occasions we undertook the surgical procedure in Bristol.
- 'After we stopped the neonatal arterial switch programme, children with simple transposition who were suitable for an arterial switch operation in the neonatal period were sent elsewhere, mainly to Birmingham.'

215 Mr Watson commented on referrals from Bristol to other centres. He said that this:

> '… would occur where the unit would be unable to deal with the specific patient and a more specialist referral would be needed. This is a separate issue to the waiting list issue which was one of capacity and does not fall within the meaning of what is normally understood by "tertiary referral".'[227]

216 In relation to the waiting lists, Mr Watson explained:

> '… there are often waiting list initiatives in hospitals because waiting lists are always of concern … The waiting list initiative was not in any way limited to paediatric cardiology but was across the board.'[228]

217 He referred in particular to an arrangement with the Royal Brompton Hospital. In October 1987 he wrote to Dr Roylance.[229] Of the letter he said:

> '… [It] advised of my concerns about not hitting our targets of 50 patients for onward transfer to the Brompton Hospital for cardiac surgery. There was a question over whether the patients were reluctant to go to London, and this was potentially more so with paediatrics as a local hospital would be favoured by the visiting family … The issue in October 1987 was that a deal had been struck with the

226 WIT 0120 0119 – 0120 Mr Wisheart
227 WIT 0298 0017 Mr Watson
228 WIT 0298 0014 Mr Watson
229 HAA 0119 0051 – 0052; letter dated 6 October 1987

Brompton to take a certain number of cases under the waiting list initiative and the BRI was not referring as agreed.'[230]

218 He wrote to Dr Roylance:

'I have discussed the situation covering the next few months with the three cardiac surgeons concerned. Dr [*sic*] Dhasmana informs me that he would expect to be able to send a further 15 patients, although he may be able to increase this number if he was more forceful in not giving referred patients a choice between London and Bristol. Mr Keen informs me that he has a waiting list of only about 6 weeks at the moment and would not envisage the need to refer patients to the Brompton. Mr Wisheart has contacted all of the patients on his waiting list informing them that they can receive treatment more quickly at the Brompton and so far hardly any have found this possibility acceptable. He does feel, however, that it may be possible to refer on new patients as they come onto the waiting list … it would appear that if the trend continues as at present, we will not meet the number of 50 which was originally proposed, mainly because of a considerable number of patients who would rather wait to have their operations in Bristol.'[231]

It should be noted that this letter refers not only to paediatric cardiac surgery but also to adult heart surgery.

219 Mr Watson told the Inquiry:

'In all such situations there is a continual balancing act by those who allocate budgets. One inevitably has to consider looking to constrain this service, for example by restricting the number of incoming cases (as was the case with the Welsh referral of paediatric cardiology cases). The only options are to either get more resources or to take on fewer cases.'[232]

Evidence of referrals from Bristol to other centres

Parents' request for a referral to another centre

220 As has been noted above, the Inquiry heard that some parents were not offered a choice of referral to another centre.

221 Amanda Boyland, whose son James was referred to Bristol from the Royal Gwent Hospital, Newport, said of her discussions with the Bristol team:

'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.'[233]

230 WIT 0298 0014 – 0015 Mr Watson
231 HAA 0119 0051; letter of 6 October 1987
232 WIT 0298 0015 Mr Watson
233 WIT 0232 0008 Amanda Boyland

222 Helen Johnson, mother of Jessica, told the Inquiry that she lived in the Bristol/Bath area and took Jessica to the BRHSC herself due to concerns about her health. She said:

> 'I can remember asking someone when Jessica would go to Great Ormond Street Hospital, because I assumed that that was where she would have her operation. The reply was that she would not have to go because Mr Dhasmana was an excellent surgeon and he was in Bristol. They also said that Jessica was too ill to move, anyway.'[234]

223 Although clinicians told the Inquiry that a request by parents could be a reason for a referral to another centre, there is evidence from parents to suggest that such a request was sometimes discouraged by the clinicians caring for the child.

224 Nigel Dymond, father of Naomi, said:

> 'I specifically recall during one of our meetings with Dr Martin at the North Devon District Hospital [Barnstaple] that my wife asked him if it might be better to take Naomi to somewhere like Southampton or London as opposed to going to Bristol. The reason my wife asked this question was at that time she was the secretary and I was the treasurer of the North Devon branch of the Bristol & South West Children's Heart Circle. At that time there were about five children that went up to Bristol for heart operations and only one survived. We were therefore concerned to ensure that Naomi received the best treatment possible. Dr Martin told us that Bristol was equal to the other hospitals and was a centre of excellence. He told us that the figures for Bristol were comparable to anywhere else and that there was no advantage to going elsewhere.'[235]

225 Marie Hill, whose daughter Kate was referred to Bristol from the Princess Margaret Hospital, Swindon, said:

> 'I cannot comment on the medical correctness of what was done and what was not done, but the very operation that Bristol was against, Brompton did and with success … As I left Bristol on the removal of Kate to Brompton Dr Jordan said to me, "If you go to Brompton, don't you ever put your foot back in Bristol again"'.[236]

Dr Jordan was given the opportunity to respond to this statement by way of a written comment, but did not do so.

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234 WIT 0259 0002 and 0006 Helen Johnson
235 WIT 0310 0006 – 0007 Nigel Dymond
236 WIT 0554 0005 Marie Hill

226 Colin and Gaynor Griffiths, parents of Zara, told the Inquiry of their attempts to have her treated at Great Ormond Street rather than Bristol. Prior to her first operation they discussed their options with a nurse who had previously worked there:

> 'He told us that GOS was one of the best centres in the world and that Marc de Leval was one of the best surgeons … When we came home Colin went straight to our GP and told him that we were not happy with Bristol. He said to him "If it was your child would you send her to Bristol or to Great Ormond Street". Dr Lupini said he would send her to Great Ormond Street so we decided to move her. While Colin was there Dr Lupini called Bristol. When he told the person on the phone that he wanted Zara transferred, they said no and he fell into an argument with them.'

Zara was transferred and had her operation at Great Ormond Street.[237]

227 Jennifer Manfield, whose son Brad was referred to Bristol from Southmead Hospital, Westbury on Trym, explained that she and her husband became increasingly concerned about Mr Dhasmana carrying out Brad's operation in April 1995, after seeing two BBC television reports critical of Bristol. They raised this with Mr Dhasmana shortly before the operation. She said:

> 'My husband and I saw Mr Dhasmana … and we talked to him about the television reports … and he was clearly unhappy about the media coverage. He said we could take Brad home now if we wanted, but he did not offer us the possibility of a referral to another hospital.'[238]

A second opinion

228 Parents confirmed that children were sometimes referred to other centres for a second opinion, whether at their request or at the instigation of the Bristol clinicians.

229 Cynthia Baker, whose daughter Sarah was referred to Bristol from Exeter, said:

> 'I remember Mr Wisheart took the precaution of seeking a second opinion and he contacted Great Ormond Street Hospital in London to ask whether they considered he was doing the right thing in considering a Fontan operation.'[239]

230 However, Susan Perry, whose son Martin was operated on at the BRI, told the Inquiry about Martin's post-operative care. She said:

> 'My husband was pretty uptight and he asked [Helen Vegoda[240]] where we could get a 2nd opinion about Martin's condition and treatment. She obviously told

237 WIT 0393 0003 – 0004 Colin and Gaynor Griffiths
238 WIT 0007 0005 – 0007 Jennifer Manfield
239 WIT 0524 0004 Cynthia Baker
240 Counsellor in Paediatric Cardiology

Mr Dhasmana about this request and he was quite aggressive with us. He told us that there was no one else as good as he and Mr Wisheart.'[241]

Previous death of another child

231 The Inquiry heard from Diana Hill, mother of Jessica and James. Jessica had died following surgery at the BRI. Of James' operation, Diana Hill said:

> 'I did not want the operation to be performed at Bristol, and I put this request through the GP, who had to contact Dr Martin … Dr Martin was reluctant to refer us elsewhere, and wrote to our GP stating that this course of action was not necessary. In the end, my husband wrote to our GP, making it clear that … we wished to be referred to another hospital. We also asked Hugh Ross, the Chief Executive of UBHT, to intervene. James was subsequently referred to a cardiologist at the Birmingham Children's Hospital.'[242]

Previous operation at another hospital

232 Robert Joyce, father of Thomas, explained that when his family lived in London, Thomas had been treated at Guy's Hospital. On their move to Exeter, Thomas was first treated at the Royal Devon and Exeter Hospital, and was then transferred to Bristol. He said:

> 'Mr Wisheart explained that Thomas required major surgery and said that he could have it in Bristol or be referred back to Guy's – whichever we chose.'[243]

233 William Hine, father of Thomas, explained that although Thomas was born in Bristol and was under the care of Dr Jordan, he had a number of cardiac catheterisations at Great Ormond Street in 1982 because, as Mr Hine was told, 'they were unable to carry out this procedure in Bristol'. Thomas then had surgery at Great Ormond Street in 1983. Mr Hine told the Inquiry of discussions before Thomas' second operation:

> 'Dr Jordan told me that the operation could now be carried out at the BRI and gave Philippa and me the choice of having the operation carried out there or back at Great Ormond Street. We assumed that the treatment Thomas would receive at the BRI would be exactly the same as at Great Ormond Street and did not realise that the risks would be any different at Bristol.'[244]

Waiting list

234 A number of parents told the Inquiry that they had considered paying for their child's operation to be carried out privately elsewhere.

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241 WIT 0462 0005 Susan Perry
242 WIT 0263 0015 Diana Hill
243 WIT 0528 0002 Robert Joyce
244 WIT 0333 0002 William Hine

235 Aubrey Lewis, whose daughter Kirsty was referred to Bristol from the Royal Gwent Hospital, Newport, spoke of having been told of a waiting list, but not of being offered the option of going elsewhere. He said:

> 'Mr Wisheart explained there was a waiting list of about 2 months, although he told us he could sort out the problem on the Monday if we were able to pay privately. … If we had been able to have the operation done privately, Mr Wisheart would have done it – there was no question of going elsewhere.'[245]

236 Mr Wisheart commented on this evidence:

> 'There is no record and I have no recollection of this part of the conversation. The possibility of private treatment occasionally arose in these conversations but *only* because the family raised the matter. I never did so. I never sought to recruit a private patient from my National Health Service practice: indeed I discouraged virtually everyone who raised this possibility … I believe that [Mr Lewis' remarks] show clearly that I was discouraging him from proceeding in this way.'[246]

237 Robert Langston, whose son Oliver was referred to Bristol from Bath, said that Mr Dhasmana had explained that if Oliver was to have an Arterial Switch operation it:

> '… would have to be performed before he was fourteen days old. Because of circumstances at the BRI, Mr Dhasmana said that he could not guarantee that Oliver would be operated upon within this time frame, and that he would have to beg for bed space, and time in the operating theatre. … When we saw Mr Dhasmana the next day, my father (who was present at the meeting) told him of his intention to arrange for the operation to be done privately. Mr Dhasmana stated that there was no way that he was going to let us take Oliver out of the BCH to have his operation performed elsewhere. The reason he gave for this was that Oliver needed the operation as soon as possible …'[247]

245 WIT 0185 0005 Aubrey Lewis
246 WIT 0185 0013 Mr Wisheart (emphasis in original)
247 WIT 0184 0006 – 0007 Robert Langston

Chapter 12 – Waiting Lists

National guidelines

1 The *'Patient's Charter: Implementation Guidance'*[1] introduced, with effect from 1 April 1992, three new patients' rights. Patients were:

- to receive detailed information on local health services including standards and maximum waiting times;
- to be guaranteed admission for treatment no later than two years from referral; and
- to have any complaints investigated and answered promptly.

2 Such rights were not legally enforceable rights. Prior to April 1992, patients needing or awaiting treatment did not, however, enjoy even these rights.

Waiting lists at Bristol

3 In the management of cases awaiting surgery, there are three categories of case for the purposes of understanding waiting lists: the emergency, the urgent and the elective. Mr James Wisheart, consultant cardiac surgeon, explained these three categories of patient:

> 'For some of the patients, the question of timing and the optimal timing varies. For an emergency case, the optimal timing is now. For an urgent case it will be within the next few days, a week or two. For those sort of patients, those requirements would be met, or at least, something very close to them.
>
> 'Then there are a group of patients who are not as urgent as that and who would generally be called elective, and amongst those there will be some for whom the timing is really not particularly critical and there will be others at the other end of the spectrum for whom it will not be urgent but it should probably be within — or at a particular time, plus or minus a few months.'[2]

4 This chapter sets out the evidence relating to waiting lists and waiting times for elective paediatric cardiac surgery.[3] Although the focus is on paediatric cardiac surgery, reference is also made from time to time to adult patients. This is because both Mr Wisheart and Mr Janardan Dhasmana, consultant cardiac surgeon, operated on

1 WIT 0159 0320 – 0328; *'Patient's Charter: Implementation Guidance'* HSG (92) 4
2 T40 p. 98 Mr Wisheart
3 It is recognised that an elective case could later become an urgent or emergency case

both adults and children and because open-heart surgery could only be carried out at the BRI,[4] such that both adults and children were operated on there. Thus, the interaction between the management of adult and paediatric cases becomes relevant. The process of designating patients as emergency, urgent or elective is described elsewhere.[5] By focusing on elective patients, it should not be assumed that patients in the other categories were seen without waiting. It is merely that they were not subject to the waiting process described here.

5 Mr A Jooman[6] prepared tables for the Inquiry describing the cardiothoracic waiting list for the period 1984 to 1995 at both the BRI and the BRHSC. However, these tables are of limited value in ascertaining waiting lists in respect of paediatric cardiac surgery because he said they cannot be categorised between adults and children.[7]

6 An understanding of waiting times at Bristol within the period 1984–1995 can, however, be gained from other documents submitted to the Inquiry. But that understanding is somewhat limited, as records showing the position in regard to paediatric cardiac surgery for the entire period with which the Inquiry is concerned were not available.

7 The Inquiry heard some evidence that waiting times were around 12 months in 1987. For example, on 4 June 1987, the Secretary of the South Gwent Community Health Council (CHC) wrote to Mr J Evans at the Association of Welsh CHCs regarding a delay in operating on patients awaiting paediatric cardiac surgery:

> 'I thought I should let you know that I have recently had occasion to accompany two young parents from Gwent, whose 3½ year old child died the day following cardiac surgery in Bristol last December … The child had been referred to Bristol when a few months old and the parents had to take him to the Out-Patient clinic every 12 weeks initially. The frequency was then increased to every 6 weeks. The child was also seen by a paediatrician in Gwent every 12 weeks.
>
> 'In November 1985 the parents were told that the time had arrived for surgery to be undertaken and that it was hoped to admit the child in January or February 1986. In spite of repeated requests by the parents and several letters from the Royal Gwent Paediatrician expressing concern at the boy's condition, he was not reviewed in Bristol during this 10/11 month delay in admission. During the interview, Mr Wisheart said that the delay in admission was entirely due to the pressure of demand faced by the department and the inadequacy of resources to meet that demand. He said that it was impossible to determine whether the delay had had any serious adverse effect on the baby's prospects …'[8]

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4 Until October 1995
5 See Chapter 13
6 District Statistical Information Officer, B&WDHA
7 UBHT 0349 0001; note from Mr Jooman
8 HAA 0119 0035; letter dated 4 June 1987

8 Commenting on that letter Mr Wisheart said:

> 'I would have to make reservations about when the optimal time was and how long the optimal period might have been. I do not know who told the parents January or February 1986, but with that reservation, I would certainly agree that there were delays, significant delays, in surgery both for adults and children at that time and probably at all times during my consultant career. We were working constantly to try and change that by increasing the facility. You will have noticed that this was immediately prior to the significant expansion of the facility in 1987/88.'[9]

9 In March 1987 Mr Wisheart wrote to Dr Stephen Jordan and Dr Hyam Joffe, consultant cardiologists:

> 'I just want to let you know that at the present time my paediatric waiting list stands at 74 patients. This represents a good year's work but, of course, many patients will not have their operation for more than a year in view of the urgent cases who will inevitably present during that period.'[10]

10 On 2 April 1987 Mr Dhasmana wrote to Dr Joffe referring to Mr Wisheart's letter:

> '… I wish to add that I have got about 30 paediatric patients on my Waiting List for routine open-heart procedures. On my present schedule I cannot operate on more than one paediatric case per week, that means already a seven and a half months Waiting List has developed. Combining these with Mr Wisheart's, our Waiting List for paediatric cases at this Centre stands at more than 100 cases. Even with the expansion, I do not foresee the possibility of operating on more than three or maximum (rarely) four cases a week without affecting the adult cardiac surgery. As we are all well aware the plans for any future project take a long time to implement, it may be feasible to look into the prospect of open heart surgery at the Children's Hospital now rather than in the distant future.'[11]

11 In September 1987 Mr Dhasmana wrote to Dr Rees and Professor Vann Jones, consultant cardiologists at the BRI, saying:

> 'There are 55 CHILDREN (of whom 21 went on the waiting list before 1.1.87).'[12]

12 A table dated 7 March 1988 indicated that Mr Dhasmana had 29 children on his cardiac surgery list and Mr Wisheart had 57, making a total of 86.[13]

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9 T40 p. 95 Mr Wisheart
10 UBHT 0092 0006; letter dated 26 March 1987
11 JPD 0001 0005; letter from Mr Dhasmana dated 2 April 1987
12 UBHT 0154 0220; letter from Mr Dhasmana dated 25 September 1987 (emphasis in original)
13 HAA 0120 0011; table dated 7 March 1988. Note that Mr Dhasmana commenced work in 1986 and his waiting list is, as a consequence, shorter than Mr Wisheart's, who began in 1975

13 In April 1988 Mr Dhasmana wrote to Miss Marion Stoneham:[14]

> 'The Waiting List … is still considerably high under my care. I hope that with the expansion … it would be possible to reduce some of the Waiting Lists.'[15]

14 The Inquiry also heard evidence that between 1988 and 1991 the 'usual' waiting time for elective paediatric cardiac surgery was between six and nine months.[16]

15 In 1990 the report of the B&WDHA, referring to waiting times generally for cardiac surgery at the BRI and the BRHSC, noted:

> 'Waiting lists of unacceptable length, up to 12 months (dependent on Consultant)'[17]

but did not distinguish between adult and paediatric patients.

16 This 12-month waiting period is referred to in a strategy document prepared by the SWRHA in May 1991. Although again, it does not distinguish between adults and children, it states in relation to waiting lists for cardiac services in general at the BRI and the BRHSC that:

> 'While urgent patients appear to be treated by giving them a date for operation, some wait for over a year which is not acceptable and will be remedied by the booking system. For those who are referred to London hospitals some long waits are known to the referring consultants.'[18]

Explaining the waiting list

17 In a letter to Mr Arthur Wilson, Regional Treasurer, SWRHA, dated 17 February 1992, Dr John Roylance, Chief Executive, UBHT 1991–1995, wrote:

> '… waiting time is the glaring problem, and of course is due to the historic and ongoing pressure which has been relentlessly placed on the Cardiac Unit in Bristol, in the context of the inadequate provision in the region as a whole.'[19]

Volume of cases

18 The Inquiry heard evidence concerning the increase in the numbers of paediatric cardiac operations during the period of the Inquiry's Terms of Reference.

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14 Manager of B&WDHA's Children's and Obstetric Services
15 UBHT 0190 0008; Mr Dhasmana wrote a memorandum to Mr Wisheart dated 28 February 1989, saying that he had 25 patients on his waiting list. See UBHT 0179 0141
16 T84 p. 113 Mr Dhasmana; UBHT 0179 0138; letter from Mr Dhasmana to Dr Roylance dated 25 February 1991
17 JDW 0001 0333; report *'Development of Cardiac Services'* dated 30 November 1990
18 UBHT 0156 0209; *'Towards a Strategy for Cardiac Services in the South Western Regional Health Authority'* dated 29 May 1991
19 UBHT 0038 0407; letter dated 17 February 1992

19 The 1987 *'Annual Report on Paediatric Cardiology and Cardiac Surgery'*[20] noted that:

> 'Total admissions have more than doubled, and infant admissions have more than trebled, since 1980. This is in keeping with the unit's growing regional role, and its designation as supra regional centre for infants since 1984. Although admissions from the SW Region appear to have stabilised in 1987, those from Wessex and especially South Wales continue to increase. This trend is even more striking in respect of infants.'[21]

20 Mr Wisheart said:

> 'Prior to 1980 and in the early 1980s, we had been undertaking a total of about probably on average between 60 and 70 operations for congenital abnormalities each year.
>
> 'By the end of the 1980s, we were doing about double that number, namely, 140 to 150.
>
> 'One might ask, well, how come that the total number increased when you have the same number of abnormalities occurring in the community, give or take a little bit? I think that at the time we thought some came from South Wales, and that was undoubtedly true but it was not the whole answer, so I do not know the whole answer to that question.'[22]

21 Mr Wisheart explained that the throughput at the BRI increased in the 1980s but that the increase 'was predominantly in the adult area at that time'.[23] He stated:

> 'Over the period as a whole, the constant pressure to increase adult work did of course impinge on me because I was constantly involved in efforts to increase the facility, but in terms of my operating, the number of adults I operated on obviously fluctuated from year to year, but broadly stayed the same over the whole period of time.
>
> 'In other words, the proportion of my time that was devoted to children was nearly protected.
>
> 'The sessions which Mr Dhasmana and I did devote to children amounted to three a week — I do not mean three half days; there were three operations a week of whatever length, at least, which were children, so that meant that we could achieve 150 a year, plus or minus, and in that sense, we were actually meeting in full the demand that we understood to exist for paediatric cardiac surgery each year.

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20 UBHT 0055 0009; *'Annual Report on Paediatric Cardiology and Cardiac Surgery'*, 1987
21 UBHT 0055 0011; *'Annual Report on Paediatric Cardiology and Cardiac Surgery'*, 1987
22 T40 p. 111 Mr Wisheart
23 T40 p. 120 Mr Wisheart

'That could never be said for the adult work.'[24]

22 Mr Dhasmana explained that the pressure to obtain beds for adults and the pressure on operating theatres from adults had an effect upon the waiting list for children. It later became known that the children were waiting longer for operations than they would have been if the Unit had been solely a paediatric unit. He said:

'We now know that is the case. At that time, I did not know that.'[25]

23 Mr Wisheart was asked whether the fact that he and Mr Dhasmana both carried out adult as well as paediatric cardiac surgery meant that, in effect, the paediatric work suffered in a way it would not have done had one dedicated paediatric surgeon been appointed. Mr Wisheart told the Inquiry that there were enough sessions to deal with the paediatric demand, but the waiting list remained. He said:

'I believe that, had there been one full-time paediatric surgeon rather than the two of us, and that that one surgeon had been working in the Infirmary as we were working, that he would have had a number of allocated operating sessions to use for his paediatric work in exactly the same way as Mr Dhasmana and I …

'So I think that in that context … a full-time paediatric surgeon would have made a marginal difference.

'If we consider an alternative context … that the full-time surgeon was able to operate in the Children's Hospital and had … full control of his operating and post-operative care resources, then I think that that would probably have made a substantial difference. …

'I suppose the final point I would like to make is that there is a difficulty about having one single surgeon, even if he is full-time, and that is the obvious one, that it means he is on call all the time when he is present, but when he is away, then there is nobody in town to look after that work.' [26] [27]

24 Mr Wisheart's evidence included this exchange:

'Q. If there was enough time available and enough resources available to cope with the demand – to cope with the demand and no more – the only way of reducing the waiting list will be to have some form of waiting list or additional time spent on attacking the waiting list, presumably?

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24 T40 p. 114–15 Mr Wisheart
25 T84 p. 90 Mr Dhasmana
26 T40 p. 114–15 Mr Wisheart
27 The paper – *'Options for Development of Audit and Paediatric Cardiac Services in UBHT'* of May 1994 – also noted that one of the benefits of relocating paediatric cardiac surgery to the BRHSC would be 'impact on waiting times'. See UBHT 0088 0135

> 'A. Or else the ability to be more flexible and to operate from time to time on children in sessions when one would have normally operated on adults. But, I mean, we are not just talking of access to an operating theatre. The ability to operate on a child requires a whole package. You need to have a paediatric cardiac anaesthetist. Most of the nurses in theatre would have been able to do the work with a child, but some were certainly better than others, and again, as the nurses will describe to you, they tried to have nurses with experience looking after children in intensive care.
>
> 'So the whole package has to be provided and not just access to an operating theatre slot.'[28]

25 On 18 January 1987 Mr Dhasmana had written to Dr Robert Johnson, the Chairman of the Division of Anaesthesia, asking for an extra operating session at the BRHSC. He was then only operating on alternate Wednesday mornings:

> 'As you are well aware, we have been designated as a supra regional Specialty Centre … As a result, an increasing amount of work has been coming from all parts of the South West and also from South Wales. … Having been given only one half day list in a fortnight, my Waiting List to deal with these problems has progressively lengthened and in many of these cases I have been operating as an emergency in the evenings or during the weekend. Some of these would have been operated during the routine hours if I had an operating session allocated to me during the week.'[29]

26 Mr Wisheart was asked whether the letter meant that, if Mr Dhasmana did an extra session at the BRHSC, he would have done one less adult session at the BRI. Mr Wisheart said:

> 'I do not think he would have, although I think you would need to ask him, because it would depend on the details of his programme at that time, but I think he is actually saying that he has the freedom to operate at whatever time he is proposing.
>
> 'I would like to say, this is of course closed work we are talking about now, not open-heart work, and I mean, he only had one half-day alternate weeks, I think. …
>
> 'Had he had more, then some of his other operating could have been accommodated on it, but of course, emergency work by its nature does not occur in proximity to your planned operating sessions.'[30]

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28 T40 p. 116 Mr Wisheart

29 JPD 0001 0002; letter dated 27 January 1987. Seven years later, the paper – *'Options for Development of Adult and Paediatric Cardiac Services in UBHT'* of May 1994 – warned, 'With the loss of designation as a supra regional centre, BRCH [*sic*] must compete for paediatric services with other centres which are known to have shorter waiting times'. See UBHT 0088 0140

30 T40 p. 117–18 Mr Wisheart

27 Mr Wisheart commented on the suggestion in the letter that some operations which were described as 'emergency' could have been done during routine hours. Mr Wisheart said:

> 'Some of it, but that certainly was a problem, because for each of us, in the Children's Hospital there was a much higher proportion of work that was urgent or emergency than in the Infirmary, amongst children, and it was work that did have to be done within a day or two, frequently, and so it was not uncommon to operate in the evening or at the weekend. It had to be done. That was the need of the child. Certainly, if that could have been reduced, that would have been a very good thing.'[31]

Attempts to reduce the waiting list

28 There was clearly pressure within each Directorate within the BRI[32] to reduce waiting lists, especially towards the end of each financial year, particularly after the introduction of trust status.

29 Mr Wisheart described the attempts made to reduce the waiting lists in general as 'a constant battle'.[33] He said:

> 'When we were doing 100 [operations] a year it [the waiting list] was too long. When we were doing 1,000 a year, it was still too long. So although we were running faster and faster, we never actually caught up.'[34]

30 Mr Wisheart was asked what efforts were made to improve the waiting list situation at the BRI and the BRHSC. He told the Inquiry:

> 'In the Children's Hospital, first, a number of things happened. … perhaps the more important thing was that the number of closed-heart operations that we did peaked around this time and subsequently became less, and there were two reasons for this — at least two reasons. The first one was that the cardiologists developed the ability to carry out certain interventions as a non-surgical procedure, in other words, as part of the cardiac catheterisation, so that some procedures that we had done at surgical operations were carried out at the time of catheterisation, so that reduced the number of operations. The second thing is that the trend towards earlier total correction of intracardiac abnormalities meant that we did less palliative work in young children to tide them over. So for those two reasons amongst others, the actual number of closed procedures declined following this time.
>
> 'So that is what happened at the Children's Hospital.

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31 T40 p. 118–19 Mr Wisheart
32 The establishment of the Directorate system is dealt with in Chapter 8
33 T40 p. 105 Mr Wisheart
34 T40 p. 107 Mr Wisheart

> 'In the Infirmary, the total capacity of the Infirmary did continue to increase, as I think you have pointed out, but I would have to say that the increase in throughput was predominantly in the adult area at that time. We had, by 1989 or 1990, achieved this level of 150 operations per year. It is not my recollection that there was a significant increase beyond that.'[35]

31 Miss Deborah Evans[36] indicated that over the period 1991 to 1995 waiting times were the biggest single issue in contract negotiations between the B&DHA and the UBHT. She also indicated however, that:

> 'This was a much bigger issue for adult services than it was for children's services across the District as a whole. In children's cardiology and cardiac surgery services (excluding those services covered by the supra regional contract for which Bristol and District Health Authority did not have a responsibility)[37] waiting times were rarely if ever an issue.'[38]

32 At the Cardiac Surgery Board meeting held on 23 November 1993,[39] it was noted:

> '10.1 Waiting list initiative[40]
>
> 'James Wisheart asked if anyone wanted to discuss this.
>
> 'Janet Maher reported that planning was in progress and we were negotiating with Bath and Somerset.'[41]

33 Dr Christopher Monk, consultant anaesthetist and Clinical Director of Anaesthesia at the UBHT from January 1993,[42] wrote a letter to Mr Wisheart as Clinical Director dated 22 January 1993 on behalf of the Directorate of Anaesthesia, complaining about the introduction of waiting list initiatives at the end of the financial year. Dr Monk described how various waiting list initiatives were undertaken during the year, allowing sufficient notice for resources to be allocated to implement the initiatives, but at the end of the financial year:

> 'As in the previous two years, the end of the current financial year results in a number of requests by the Purchaser for new waiting list initiatives. The aim of these being to decrease the number of patients with prolonged waiting times. Unfortunately, these requests are made at short notice, to multiple Surgical Directorates and for a large number of cases of varying surgical complexity. …

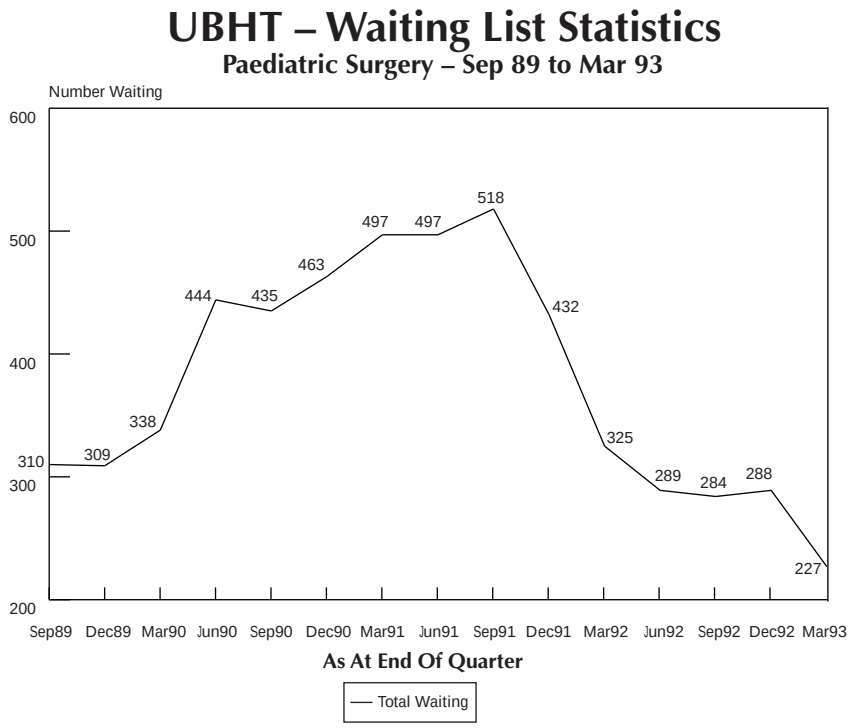
35 T40 p. 118–19 Mr Wisheart
36 Director of Contract Management, B&DHA, 1991–1995
37 For example, paediatric cardiac surgery until 1994
38 WIT 0159 0023 Ms Evans
39 UBHT 0084 0163; minutes of the Cardiac Surgery Board meeting held on 23 November 1993
40 The Waiting List Initiative was launched in 1987 and was aimed at reducing the number of people waiting over two years for treatment
41 UBHT 0084 0166 minutes of meeting held on 23 November 1993
42 Presently the Associate Medical Director for Strategic Planning, UBHT

'… considerable moral pressure is placed upon all clinical staff to avoid the failure of care for these patients … Yet by the simple expedient of planning more routine care for the Bristol and Weston patients then these waiting list initiative patients could have been treated as routine cases, with the highest standards of care during normal working hours.

'Should we, despite all our efforts, fail to respond to these initiatives, I do not feel it would be a failure of the Anaesthetic Directorate or the Surgical Directorate but that of a Purchasing policy which relies on last minute waiting list initiatives to provide medical care for the patients.' [43]

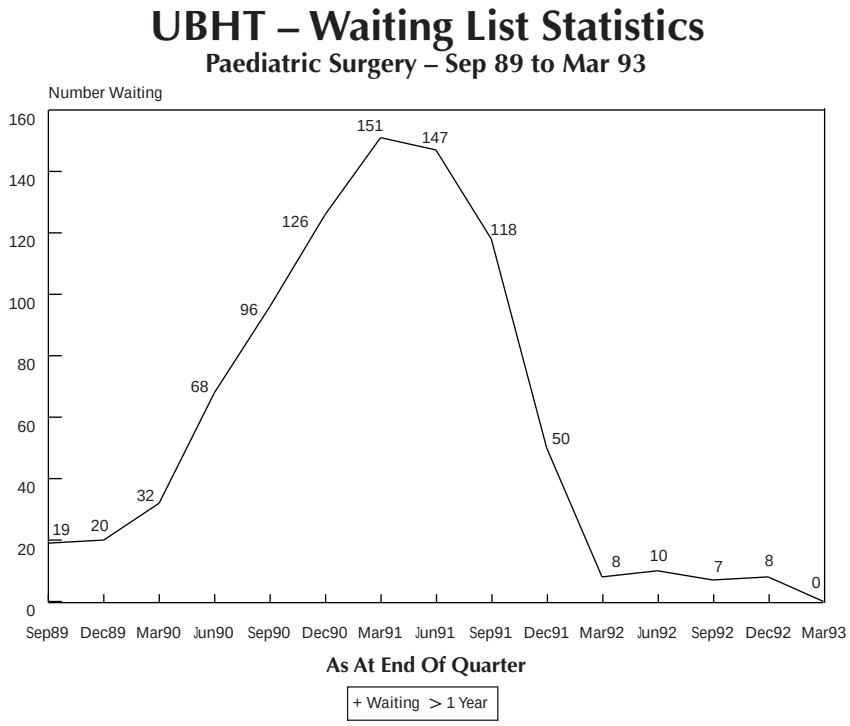
34 On 26 March 1993 Mr Jooman produced a report detailing waiting list statistics from September 1989 to March 1993. The graph in relation to paediatric cardiac surgery showed an overall trend of increase from 1989 to September 1991 and a dramatic reduction from September 1991 to March 1993.[44]

35 The first of these graphs shows the total numbers waiting, and the second shows the numbers waiting for more than one year.



43 UBHT 0247 0183 – 0184; letter dated 22 January 1993

44 UBHT 0270 0187; report produced by Mr Jooman dated 26 March 1993



36 In December 1993 Miss Lesley Salmon, Associate General Manager for Cardiac Services, and Mr Dhasmana wrote a memorandum addressed to 'all cardiac surgery staff' regarding a waiting list initiative. It stated:

> 'We recognise and sympathise with the pressure this places on everyone and are grateful for the co-operation and willingness people have shown under the circumstances. No one is in much doubt, after three years of contracting, how important it is for us to meet the demand in the South West and to attract the work to UBHT. There will be further investment in cardiac surgery next year and we want purchasers to invest here! The intention is to avoid further waiting list initiatives if possible, and the key to this is to get our waiting times down overall. The Trust is actively planning to expand the service for this purpose in the coming year.'[45]

37 The Cardiac Surgery Management Board meeting on 29 March 1994 recorded that:

> 'Mr Dhasmana thanked everyone involved with the waiting list initiative for their help. A total of 39 patients had been treated on the scheme which was a great achievement.'[46]

45 UBHT 0179 0201; letter dated 3 December 1993
46 UBHT 0132 0055; minutes of the Cardiac Surgery Management Board meeting on 29 March 1994

38 Many of the clinicians involved in the paediatric cardiac surgical service felt that it lacked resources, such as theatre time and space and beds, in comparison to the adult service.

39 Dr Bolsin, consultant anaesthetist, said that: 'The major throughput of cardiac surgical cases on the BRI site was related to adult cardiac surgery. In 1988 3 paediatric cardiac surgical cases each week would be undertaken compared to twelve adult cases.'[47]

40 Dr Martin's evidence to the Inquiry included this exchange:

> 'Q. … it was certainly your perception from what you have been telling us that the fact of doing the two together, adults and children, sometimes meant children were delayed for longer … than they would have [been] delayed had it been one service for children at one place?
>
> 'A. That might have been a factor. Equally it might just have been the actual allocation of paediatric beds within the adult department was inadequate for the throughput. By increasing the numbers on transferring, I think with the transfer from the Royal Infirmary to the Children's Hospital you would have gone up from essentially what were three beds being utilised to five or six and that would immediately have an impact on waiting.
>
> 'Q. You told the GMC, did you not, that the need for children having to compete with the adult list for paediatric time in the theatre made the delays ensue, or at least that was your general impression?
>
> 'A. As I have said, it is difficult for me to judge exactly whether it was pressure on theatre, pressure on beds on the intensive care unit, but I was aware that certainly some patients were waiting at the Children's Hospital longer than I would have hoped for.'[48]

41 Mr Dhasmana also took the view that running the paediatric and adult cardiac surgical services in the same unit led to conflicting demands. His evidence included the following:

> 'Q. So the pressure on beds from adults and the pressure on operating theatres from adults had, did it, an effect upon the waiting list for children?
>
> 'A. On both sides, yes, sir.
>
> 'Q. And that meant that children were waiting longer for operations than they would have been if the unit had been solely a paediatric unit?

47 WIT 0080 0002 Dr Bolsin
48 T77 p. 29–30 Dr Martin

'A. We now know that is the case.'[49]

42 The Chairman of the Inquiry sought to confirm this in the following exchange with Mr Wisheart:

'Q. (The Chairman) … during all of the time that you were seeking to bring about the various developments, not least the appointment of another surgeon and the movement to another place, you were, were you not, chasing almost mutually incompatible goals, namely, making sure you had enough children treated through and looking at them, whilst at the same time meeting increasing adult waiting lists, always with the same, not only people, but physical resources, numbers of theatres. I imagine that is not atypical in the Health Service …

'A. I think you are correct to say it is not atypical. I think it was very typical. I am not sure that I ever had any other experience as a junior doctor or senior doctor in the Health Service.'[50]

43 However, the Inquiry heard evidence that when it was necessary to cancel operations, it tended to be the adult rather than the paediatric cases that were further delayed.

44 Kay Armstrong, Cardiac Theatre Sister, gave evidence that: 'When it was necessary to cancel elective surgery to fit in urgent cases it was adult, not paediatric cases which were cancelled on these occasions.'[51]

45 Sister Julia Thomas, Clinical Nurse Manager, Cardiac Unit, said:

'There were occasions when the intensive care beds were occupied by seriously ill patients and other cases had to be cancelled. The adult cardiac cases were sometimes cancelled because beds were occupied by paediatric cardiac surgery cases, who sometimes tended to progress rather slowly and tended to take priority.'[52]

46 Alison Riddiford, Surgical Service Manager (General), told the Inquiry:

'If there was an emergency operation, then it might be that an elective procedure was cancelled, although this would probably be an adult elective procedure.'[53]

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49 T84 p. 90–1 Mr Dhasmana
50 T94 p. 107 Mr Wisheart
51 WIT 0132 0034 Ms Armstrong
52 WIT 0213 0031 Julia Thomas
53 WIT 0262 0022 Ms Riddiford

47 However, Mr Dhasmana recalled having to perform some of his surgery at night. His evidence to the Inquiry included this exchange:

> 'Q. So what restrained the unit from doing the operation was first of all waiting lists; secondly staffing, if I can say shortages …; and thirdly, do I get the sense that if you operate on more neonates, there is less room for non-neonates, given the pressures on bed space and operating theatres caused by the adults?
>
> 'A. Well, it is an emergency operation. You cannot wait for the next period to operate, so you have to — I mean, if you look in my record of closed cardiac surgery, it was working at night and various things, so almost I was doing open-heart surgery every night and then other surgery next day. So this was adding something new which I do not think we were geared up to, really.'[54]

The impact of financial incentives/penalties on waiting lists

48 At a meeting of the Cardiac Surgery Management Board on 18 July 1994, Miss Salmon reported that:

> 'Somerset were applying a financial penalty of 20% of the procedure price for any cardiac surgery patient who waited over six months for treatment. Professors Vann Jones and Angelini expressed their concern about this clause given the difficulties with managing a number of purchasing pressures.'[55]

49 Although the concern related to adult and child patients, it provides a context in which to understand the management, in terms of waiting times, for paediatric cases.

50 On 21 July 1994 Ms Linda Williamson, Contracts Manager for the B&DHA, wrote to Miss Salmon, complaining that part of a waiting list initiative had not been implemented:

> 'As you can see in the enclosed documentation, UBHT agreed to perform 20 cardiac operations between 1 April 1994 and 30 June 1994. Clearly these have not been done and in fact the specialty is under performing against contract.
>
> 'One option would be for us to claw back the £127,000.00.' [56]

54 T86 p. 65 Mr Dhasmana
55 UBHT 0226 0085; minutes of the meeting of the Cardiac Surgery Management Board on 18 July 1994
56 UBHT 0295 0615; letter dated 21 July 1994

51 At a meeting of the Cardiac Services Management Board on 26 September 1994, Miss Salmon:

> '… drew to the attention of the meeting that an offer of £127,000 had been made by BDHA to ensure a maximum waiting time for all their patients of 10 months, by April 1995.
>
> 'The Board agreed that she should put together a proposal for BDHA's approval. The Avon GP Fundholding Group had also approached cardiac surgery about purchasing extra activity, but this would be discussed with individual practices.
>
> 'Waiting time management was becoming increasingly difficult and complex with different waiting times being agreed with some purchasers. Financial penalties were also beginning to be imposed; £3,000 for any South and West patient waiting over 12 months and 20% of the procedure price for any Somerset patient waiting over 6 months.
>
> 'The South and West Region definition of a longer waiter would reduce to 10 months next April, adding to the pressure.'[57]

52 At the meeting of the Cardiac Services Management Board held on 28 November 1994, in relation to waiting list management it was reported that:

> 'The letter to BDHA detailing how the £127,000 non recurring waiting list resources would be used (circulated with the agenda) was discussed.
>
> 'Cardiology are over performing on the BDHA contact.
>
> 'RCF[58] will identify the names of patients and find out whether these can be counted and funded as part of the waiting list initiative.
>
> 'The additional 15 CABGs[59] and 2 valves required cannot be performed until Surgery is achieving contract for BDHA. RCF will explore arrangements for these to be subcontracted to the Glen Hospital.[60] The Board agreed that if subcontracting was to be necessary on a regular basis, a standing arrangement for one or two cases each week would be preferable to performing several cases at the end of the financial year.
>
> 'It was noted that weekend work was particularly unpopular.

57 UBHT 0227 0026; minutes of the meeting of the Cardiac Services Management Board on 26 September 1994
58 Mrs Ferris, General Manager, Directorate of Cardiac Services, UBHT
59 Coronary artery by-pass grafts
60 The Glen BUPA Hospital, Durdham Down, Bristol

> 'It was noted also that the additional Friday morning operating session was proving unpopular and difficult to implement. The issues of anaesthetic cover/funding and pressure on Theatre staffing need to be discussed. RCF to review with Mr Dhasmana and Mr [*sic*] Monk.'[61]

Effect of the waiting list on patients

53 Evidence on the possible effect on patients of the timing of surgery and delays in surgery generally is set out in Chapter 13.

54 As to any effect caused by there being a waiting list, Mr Wisheart said that, whereas some adult patients may have died while on a waiting list for cardiac surgery, he did not think that many paediatric patients, 'if any', died while on the waiting list.[62]

55 However, he said it must be accepted that some paediatric patients were detrimentally affected by being placed on a waiting list. He said that it:

> '… is really quite variable as to the effect of [being on a waiting list] would have on the child. The ones, of course, who wait are those who are in the elective group, and most of those who would wait longer are those for whom the timing is less critical, but I would be unable to say that that was the case entirely. In other words, I cannot say to you that there were not some children who would have suffered, for want of a better term, from the extra delay.'[63]

56 Mr Wisheart said that as at 1991 there was very limited knowledge available about the effect of keeping a given patient or patients in general on a waiting list in terms of morbidity or mortality:

> 'I imagine there was some published information by that time, but I think there was quite a lot more in the years that followed this, in the early 1990s.'[64]

57 Mr Wisheart said it was possible to say that:

> 'If we set aside those children who need urgent or emergency treatment and consider those who are not in immediate need of surgical treatment, the congenital abnormality which they suffer from will have an effect that secondary changes will develop in the heart and in the lungs, and possibly in other organs, but in most children, in all of them in the heart, in many in the lungs also, and in some, elsewhere.

61 UBHT 0227 0023; minutes of the meeting of the Cardiac Services Management Board on 28 November 1994
62 T40 p. 101 Mr Wisheart
63 T40 p. 98–9 Mr Wisheart
64 T40 p. 102 Mr Wisheart

‘So that, if a child early in life has an abnormality of the heart but is relatively free of secondary effects, whereas N years later they may still be alive but in addition to the abnormality of the heart, they will have these secondary effects.

‘The importance of this is that whereas in the 1970s, say, and also in the early 1980s, people, surgeons and cardiologists, preferred to delay operations because they felt children would be operated on more safely when they were a little bit older, people came to realise and accept that, indeed, they should be operated on sooner in order to prevent the development of these secondary effects which, in essence, were complications — additional complications.

‘That, then, is the thinking underlying the trend towards earlier operating. …

‘So the effect of a child waiting, again, whether they are on a waiting list or not, is best understood within, I think, that set of ideas.

‘So, for some children, an extra wait will be of very little significance; for others it will be of some; for some it may be quite important, but whether or not they are on the waiting list is not the crucial factor; the crucial factor is that time is passing.’[65]

58 Mr Dhasmana said:

‘I think it was more obvious when you had a condition like VSD or AV canal, or similarly transposition, where the pulmonary or lungs are already subject to higher pressure. If you leave it longer, it could deteriorate. And of course, you know, I cannot prove it, but I had a feeling that the longer you leave it, post-operative recovery would be further prolonged.’[66]

65 T40 p. 103 Mr Wisheart
66 T84 p. 91 Mr Dhasmana. See Chapter 3 for an explanation of these terms