The Inquiry into the management of care of children receiving complex heart surgery at The Bristol Royal Infirmary

Interim Report

Annex A and Annex B

The Bristol
Royal Infirmary
Inquiry

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Removal and retention of human material:

Annex A and Annex B

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These Annexes are published separately from the main Interim Report. The Interim Report includes Recommendations; an explanatory note on references and footnotes; and an Appendix containing details on the people referred to in these Annexes and a glossary of acronyms.

Annex A

An account of the evidence to the Inquiry on the removal and retention of human material at post-mortem

Introduction

Summary of evidence

1 The Inquiry received evidence, both orally and in writing, as to the national context in which both Coroners' post-mortems and hospital post-mortems were conducted throughout the period of the Inquiry's Terms of Reference, as to the particular practice in Bristol and as to the events in Bristol once widespread retention came to public attention. Evidence was taken, in particular, from parents, clinicians, the Coroners Society, the Coroner for Avon, the Home Office, the Royal Colleges of Pathologists and of Physicians and from other relevant United Bristol Healthcare Trust ('UBHT') employees.

2 In Bristol, between 1984 and 1995, 265 post-mortems were carried out on children who died following paediatric cardiac surgery.

3 Throughout the period, of the post-mortems conducted, 220 were Coroners' post-mortems carried out at the direction of HM Coroner in order to establish the cause of death and subject to the Coroners Rules[1] ('Coroners' post-mortems'); another 45 were hospital post-mortems carried out with the consent of parents, pursuant to the Human Tissue Act 1961, section 2(2), ('hospital post-mortems'). Human material removed at hospital post-mortem may also have been used for medical education and research, section 1.

4 It was common practice, in Bristol and elsewhere, for human material removed during a post-mortem to be retained for long periods of time by pathologists.
In a large number of cases, parents appear to have been unaware of this practice.

5 Once the extent of the retention of human material was made public, many parents of the children who had been the subject of the post-mortems were very distressed.

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[1] See Annex B

Part I

The national context

Hospital post-mortems

6 Professor Michael Alan Green, consultant pathologist to the Home Office, confirmed that, in the past, when obtaining consent to hospital post-mortems, the prevailing culture was not to go into details with the family of the deceased about precisely what was involved in a post-mortem. He charted the changes in attitude, as he saw them, from the time that the Human Tissue Act 1961 (the 1961 Act) was passed. He told the Inquiry:

> ‘I qualified in 1960. The Human Tissue Act was passed in 1961. My generation were, therefore, taught by those who had always themselves been taught that there was no property in a dead body and the general lesson that was drilled into me as a medical student was: be courteous, be polite, explain that you are asking for permission for this autopsy because it will help others, both in learning and in the treatment of disease, but do not go into any more detail; it will upset the relatives and they might refuse consent. This was the attitude on which my generation was brought up.’[2]

7 Even when the notion of consent to a hospital post-mortem became more widespread in the medical profession, parents were still given few details either of what a hospital post-mortem actually involved or about the possibility or likelihood of the retention of human material after the hospital post-mortem. Parents were not told, or at least did not understand, that they would not be ‘burying all of their child’. Professor Green told the Inquiry:

> ‘The Human Tissue Act was passed [in 1961]. At first it made little difference. I think everybody, both hospital management and clinicians, said “But we are doing all this anyway. We have a consent form which we always have witnessed”, and in those days there were no such things as bereavement counselling officers. It was usually the senior house officer (SHO) or the Registrar who saw the relatives and got permission, and you simply had a bald consent form which said “I, being [the wife, husband, et cetera] of … hereby agree to an autopsy being carried out. I understand this will help advance medical knowledge”, or words to that effect.
>
> ‘There was nothing organ specific and equally, there was no option of a limited or restricted post-mortem…’ [3]

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[2] T42 p. 56
[3] T42 p. 57

8 The traditional attitude of the pathology profession was described by Professor Green as:

‘The general feeling when the Act was first passed that it did not make all that much more difference, you only needed one extra sentence in the consent form. The realisation that specific agreement to the retention of organs and tissues [was needed] I think crept on the profession more generally and, I think, the profession in general over those early years of my involvement with it – and I admit it freely and I think most doctors of my age do – is that we were generally rather paternalistic. We knew what was best for the patients and the relatives and did not want to upset them and this was the attitude which was inculcated.’[4]

9 Professor Green explained how, prior to the period with which the Inquiry is directly concerned, the prevailing professional attitude towards the authorisation of hospital post-mortems had begun to change. He said:

‘As I say, immediately after the passing of the Human Tissue Act it did not make very much difference. Then I suppose in the 1970s people started talking about “informed consent”, which in my view is an Americanism which has crept into English law; I was always taught to talk about “valid consent”, but the realisation dawned on the profession that fully informed consent involved rather more than just using the old-fashioned bald one-paragraph consent form … I got the feeling that there was a gradual swing to them either verbally or in writing incorporating, “I understand that it might be necessary to retain certain tissues for further examination”; but, as far as I know, it is only in the last few years in this present decade[5] that people have then carried it forward and started making what I call the organ-specific consent form, which is the thing that is now recognised, and by the time the book which you have before you was published in 1991 I had said, and I quote from memory, “under no circumstances should this issue be fudged”, and emphasised the point that to comply with the Human Tissue Act, …

‘Even so, I think from the early 1980s onwards I, certainly in my teaching, was emphasising to medical students and to young doctors, “Look, distasteful though you might find it, you must get used to the idea of asking relatives specifically for retention of an organ or tissues”… we really had to get our act together and start being more specific.’[6]

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[4] T42 p. 63
[5] The 1990s
[6] T42 p. 57

Coroners' post-mortems

10 Mr Michael J C Burgess, Secretary of the Coroners' Society of England and Wales[7], told the Inquiry about the present practice in respect of Coroners' post-mortems, for which consent is not required.

> 'The information that is given to a family depends very much on their ability or perceived ability to receive it. There is no point in information overload, so I am sure most of us, and our officers, will inform the family of the examination taking place; that it will be made by a pathologist, a doctor who is qualified in a particular field or expertise; very often the timing of the examination; sometimes the venue, if it is not obvious from the way in which the exchanges have at that point taken place; and the expectation as to a result, in other words, that we are hoping that this examination may establish for us what it is that happened that gave rise to the death that has happened.'

11 However, Mr Burgess told the Inquiry that a Coroner is instructed in the *Practice Notes for Coroners* ideally to give the family of the deceased the following information:

> 'concerning the intended examination in writing, if necessary; if they desire to be represented at the examination then their nominated medical practitioner should be told of the examination arrangements. The family should be told if there is any delay and, in due course, the result of the examination. It might be appropriate to offer that the result of the examination be forwarded to their nominated medical attendant so that this can be explained to them.'[8]

Purposes of a post-mortem

12 Professor Berry, Consultant Paediatric Pathologist at Bristol since1983 and Professor of Paediatric Pathology at the University of Bristol since 1990, saw several purposes of post-mortem examination. He was of the view that it:

> 'should take place and that the examination should be part of formal audit and review, fed back as appropriate to parents, providing information, and the autopsy should be carried out according to the parents' needs and giving them choice and information including, if the coroner is not involved, their right not to have a post-mortem examination and, if they choose, their right not to know what goes on.'[9]

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[7] T43 p. 12–13

[8] WIT 0039 0014

[9] T55 p. 140

13 The post-mortem examination also aids the surgeon. Mr Janardan Dhasmana, Consultant Cardiac Surgeon at Bristol from 1 January 1986 to 9 September 1998, said that it is

> ‘a necessary requirement to improve one’s knowledge and also to check on one’s technique and learn from post-mortem examinations.’[10]

14 Mr Burgess, as a Coroner, saw the post-mortem examination in a wider context as a public policy issue. He said at the Inquiry that

> ‘getting better general health for the public [is an aim], so there is an undercurrent suggesting that if the post-mortem information can be improved, then there will be a corresponding improvement for general health purposes’.[11]

Further, in the case of hospital post-mortems, another purpose is that:

> ‘major errors come to light and steps are taken to prevent them occurring again.’[12]

The prevailing view of the value of post-mortems and subsequent retention, use and disposal of human material

15 The benefits accruing from and the consequent importance of the post-mortem examination were emphasised in the evidence to the Inquiry.

16 Professor Robert Anderson, President elect of the British Paediatric Cardiac Association, Professor of Morphology at Great Ormond Street and Joseph Levy Foundation Professor of Paediatric Cardiac Morphology, University College, London, explained the benefits of retention of human material:

> ‘we examine them for the purposes of our research. We demonstrate them. We make them available for others to study….[but] to a certain extent they become damaged … which is why I believe it is essential that we keep on adding to these collections so that we have the capability of teaching tomorrow’s surgeons and tomorrow’s paediatric cardiologists better than we have been doing at the present time.’[13]

17 As to longer-term retention, in the case of cardiac surgery the Inquiry also heard evidence from Professor Anderson regarding the benefits of retaining hearts for the purpose of study and teaching. He considered that one of the many reasons for improvements in mortality in centres of excellence for cardiac surgery was the knowledge that had accrued from the study of retained hearts.[14] He gave evidence

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[10] WIT 0084 0105

[11] T43 p. 33

[12] T55 p. 110

[13] T45 p. 109

[14] His letter to the Inquiry of 25 January 2000, WIT 0546 0001

as to the scale of the retention of congenitally malformed hearts in this country.[15] He estimated that the largest collection was at Alder Hey Children's Hospital with approximately 2,500 hearts; he himself had built up a collection at the Royal Brompton Hospital of some 2,000; there were collections at Great Ormond Street of 2,000, at Birmingham Children's Hospital of about 1,500 and other, smaller collections, in Leeds, Bristol, Southampton, Newcastle and Manchester.

18 He explained that, in the case of a congenitally malformed heart, it was thought necessary to retain the whole organ in order to study and demonstrate it[16]. 'In the case of a heart, no two organs are ever identical, and, for proper study, it is essential to retain the entire organ.'[17]

19 The Inquiry was also told by Professor Berry:

> 'one of the benefits of the widespread practice of retention of tissue and organs is to increase understanding of medical diagnosis, disease processes and surgical practice to help future patients. This has been of particular value in the field of paediatric cardiac surgery, a high risk and relatively new speciality.'[18]

20 Professor Berry emphasised the importance of removal and retention of the heart when undertaking a post-mortem on a patient who had undergone cardiac surgery. A period of retention may be necessary to understand the individual case. He said:

> 'the heart is always removed during the course of the post-mortem examination. It depends what level of examination is required. It would be very easy just to look at the heart and say congenital heart disease is present, surgery has been performed, and to return it to the body. But if one wishes to try and approach what really happened and provide useful information, then I believe the heart has to be retained for a period for proper examination in a quiet place with good light, proper instruments and so on, separate from the actual mortuary itself.'[19]

21 Professor Berry also emphasised the potential utility of longer-term retention:

> 'many of these conditions are rare and no two hearts with a given condition are quite the same. So by keeping quite a large number (a very large number to people who are not pathologists), it is possible to provide somebody who wishes to study a particular anomaly a range of examples that would take them many years to see in their own practice.'[20]

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[15] T45 p. 104–106
[16] T45 p. 108
[17] WIT 0546 0001
[18] WIT 0204 0024
[19] T55 p. 59
[20] T55 p. 141

22 As a consequence, Professor Berry said of the retention of human material at Bristol that:

> 'this represented best practice as seen by doctors at the time, and that what I was doing and my colleagues were doing was entirely usual.'[21]

Parents' knowledge about the removal and long-term retention of human material

23 The necessity of removing the heart at post-mortem may well not be understood by many parents. One parent told the Inquiry:

> 'whilst I accept that a post-mortem can be ordered by a Coroner, that does not mean that organs need to be removed or indeed should be removed.'[22]

24 Parents were not informed about the practice of retention after the examination, where a Coroner's or hospital post-mortem, was concluded. Professor Roderick MacSween then President of the Royal College of Pathologists, said in his witness statement:

> 'if organs were to be retained for use as museum specimens etc, it was felt that "doctor knows best" and that relatives should not be further distressed by being presented with a list of organs which might be retained.'[23]

25 The removal and then retention of the heart for a period of time for the purpose of the post-mortem itself would very often mean that the heart could not be returned to the body before a funeral was carried out. This was also the case if the heart was retained for other purposes. Many parents were unaware of this.

26 Professor Robert Anderson told the Inquiry that, until recently at least:

> 'When I then came to the Royal Brompton and started to build up my own collection of hearts, because I was not a pathologist – and I am not trying to deflect the decision-making in any way here – but because I was not a pathologist, the pathologist would remove the organs at autopsy, for which we had received consent, so unless it was a Coroner's case and *we presumed that the consent given for the autopsy permitted us then to retain the organs*, we never asked the question; had the parents been asked if it was appropriate for us to retain the organs? We presumed that appropriate permission had been given. But I think we were wrong in that respect. I do not think we asked the question. I think we should have asked the question because I think that had we explained – and I think we did explain, we always explained to the parents why we wanted to do the autopsy. We explained to them that we wanted to gain from examining the organs of what we recognised was for them a tragic loss, and we hoped

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[21] T55 p. 55

[22] T2 p. 109, Michael Parsons, father of Mia

[23] WIT 0054 0026

that from this tragic loss we could prevent such things happening in future. I think that huge advances we have made over that period have been testimony to the justification of what we were doing. But I do not think that we explained to the parents that we were going to retain the hearts. I think we should have done. I think we were wrong to presume that we had that right.'[24]

The clinician's understanding of the entitlement to remove and retain human material at a post-mortem

27 Professor Green told the Inquiry that, in respect of hospital post-mortems:

'the view that was generally taken was that in hospital permission cases, the consent which the relative had given for the retention of tissues or organs allowed one to take whatever one felt may be useful for medical research.'[25]

28 Professor Anderson's evidence contained the following exchange with Counsel to the Inquiry:

'*Q.* If you were asked for your view as to what legal or moral right pathologists, and morphologists like yourself, had to retain and examine hearts, looking back at it, what would you say?

A. I think in terms of the legal view, I would have to say that we did not ask that question. I still do not know the answer. I think from the moral view, I am convinced that *morally we were right to do that* [take the hearts], because I think that the advantage we have gained from the study of those hearts totally substantiates the fact that the organs were retained, *perhaps incorrectly*. But I think the advances that we have made in diagnosis and treatment would not have been possible had we not retained the hearts and had we not built up these collections.'[26]

29 Professor Berry was, however, at the least aware that the entitlement to retain human material taken at a coroner's post-mortem was legally and ethically complex. He recognised that:

'whilst carrying out a post-mortem examination for HM Coroner, the pathologist is an independent practitioner not acting for the hospital or Trust. The grey area arises because of course most [pathologists] work out of hospitals and so the tissues usually, but not always, come on to NHS premises … So to what extent a Trust becomes responsible for tissues which may have been removed from one of their patients who may or may not be lying in the same hospital at that time is a difficult one.'[27]

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[24] T45 p. 100–1, emphasis added

[25] T42 p. 72–3

[26] T45 p. 102, emphasis added

[27] T55 p. 66–7

The clinician's understanding of the entitlement subsequently to use human material removed at post-mortem

30 As regards hospital post-mortems, Professor Green was asked about a passage in the Royal College of Physicians' 1990 guidelines to the effect that:

> 'the anonymous use for research of tissues genuinely discarded in the course of medical treatment … and of tissues removed at surgery or at autopsy is a traditional and ethically acceptable practice that does not need consent from patients or relatives.'[28]

31 Professor Green was asked whether this view was the understanding then common amongst pathologists. He replied:

> 'It was the understanding that was common amongst pathologists and it was the understanding that was common amongst clinicians as well, particularly surgeons, of course.'[29]

32 As regards coroners' post-mortems, the Inquiry heard evidence from Professor Green that during the period of the Inquiry's terms of reference the understanding of the pathology profession in respect of the subsequent use of human material removed during a Coroner's post-mortem pursuant to Rule 9 of the Coroners' Rules was:

> 'Our understanding was and I think still is – and this, as I say, has been confirmed repeatedly by the different coroners I have spoken to – the Sheffield Department serves a total of 15 Coroners, full- and part-time, and in the course of my career I consulted with all of them – that you can only take material to establish the cause of death under Rule 9 (Coroners' Rules 1984); but once the cause of death has been established and the coronial process has been completed, fixed tissue in particular can be used for research purposes … throughout my career, putting it shortly, we always understood – and the coroners for whom I worked always understood – that although you could only retain tissue to confirm the cause of death, once that had been done you could use that tissue for research and teaching purposes.'[30]

33 Professor Berry concurred with the prevailing view that human material removed during a Coroner's post-mortem could be retained and used by the pathologist once the Coroner was *functus officio* (had discharged his legal duty), having established the cause of death. He considered such a practice to be in accordance with the law and with the ethics of his profession. He told the Inquiry:

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[28] WIT 54/978
[29] T 42 p. 85–6
[30] T42 p. 82–3

> ‘our views are based on common practice, the law and ethics … I think our view was that tissue which was lawfully obtained and was no longer required for its original purpose could ethically be used for the greater good, if you like.’[31]

34 Dr Michael Ashworth’s understanding was that human material removed at Coroners’ post-mortems could be used for research purposes so long as the primary purpose for which they were removed was not research. (Dr Ashworth was appointed to a post as a consultant paediatric pathologist at the UBHT in 1993.) Dr Ashworth agreed with the Royal College of Physicians’ 1990 guidelines, and then was asked, in relation to Coroners’ post-mortems:

> ‘So tissues removed at surgery or at autopsy could be used for research purposes?’

He replied:

> ‘Provided they were not taken primarily for the research purpose.
>
> *Q.* So if they were taken for Rule 9 purposes originally?
>
> *A.* Yes.
>
> *Q.* Once a Coroner has finished, they could be used for research purposes …?
>
> *A.* Yes.’[32]

35 Professor Green told the Inquiry, in respect of Coroners’ post-mortems:

> ‘once the Coroner has discharged his function and he is *functus officio,* that piece of tissue is in effect *the property of the pathologist* and the department which has processed it. It has had something done to it and *therefore it is perfectly licit to use … for research purposes; it is perfectly licit to use that organ for teaching purposes, museum purposes*.’[33]

36 Whether the view advanced by Professor Green concerning a Coroner’s post-mortem is correct as a matter of law is addressed elsewhere[34]. For present purposes, it is necessary to note only that: (a) the pathologist carrying out a Coroner’s post-mortem does so as the Coroner’s agent; (b) the question arises, once the Coroner is *functus officio,* of the legal basis for continued retention of human material by the pathologist; (c) the question of whether or not the human material becomes ‘the property of’ the pathologist is problematical; and (d) it is by no means clear that, even if that pathologist is entitled to retain the human material, he has a right, as Professor Green claims, to use it for teaching or research purposes.

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[31] T55 p. 68

[32] T54 p. 72–3

[33] T42 p. 80–1, emphasis added

[34] Refer to Annex B

The practice in relation to disposal of human material taken during a Coroner's post-mortem

37 The Inquiry was told by Professor Berry that:

> 'the Coroner did not give any specific instructions about the release or disposal of tissues and organs. It was presumed in practice that custodial responsibility for retained tissues remained with the pathologist once the Coroner had accepted his report, and a reasonable time for any queries from interested parties had passed … this was the standard practice across the whole country.'[35]

Guidance to the medical profession in existence in the period of the Inquiry's terms of reference, 1984 to 1995 and later

Removal of human material

38 In August 1977, the Department of Health and Social Security ('DHSS') published Health Circular (77) 28 *Removal of Human Tissue at Post-mortem Examination – Human Tissue Act 1961.*[36] It stated, in respect of hospital post-mortems, that:

> 'the removal of tissue may be authorised only if, after having made such reasonable enquiry as may be practicable, the person lawfully in possession of the body has no reason to believe that the deceased had expressed objection or that a surviving spouse or other relative objects. Specific *consent* is not required by the Act.'

This was sent to all coroners[37] 'in view of the widespread publicity given recently in the national press to the considerations governing the removal of organs after death'.[38]

But the Inquiry heard no evidence that this advice on hospital post-mortems had any bearing on Coroners' approach to Coroners' post-mortems.

Removal – Coroners' post-mortems

39 In 1985 Professor Bernard Knight, Consultant Pathologist to the Home Office since 1965 and Professor of Forensic Pathology, University of Wales College of Medicine since 1980, wrote and published in the *Bulletin of the Royal College of Pathologists* an article entitled 'Legal considerations in the retention of post-mortem material.'[39] He discussed the retention of human material after a Coroner's post-mortem and stated:

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[35] WIT 0204 0009

[36] WIT 0043 0119

[37] WIT 0043 0118

[38] WIT 0043 0124

[39] Knight, Professor B H 'Legal considerations in the retention of post-mortem material', *Bulletin of the Royal College of Pathologists* 1985; 52:3–4

‘the retention of tissue for teaching and research is not covered by the Coroner’s permission and “the Coroner cannot grant such permission”, as it is not within his remit to do so.’

This article was drawn to the attention of Professor Berry in a letter dated 24 December 1985.[40]

40 In the course of his exchange with Leading Counsel to the Inquiry, it became clear that there were problems over the meaning of the word ‘retention’. Professor Berry understood Professor Knight’s use of the word ‘retention’ to be referring to the retention of human material other than that lawfully removed during a Coroner’s post-mortem in order to establish the cause of death:

‘*Q.* So what Professor Knight appears to be saying is – whether he is right or wrong is beside the point – what he appears to be saying is that you cannot keep tissue after a Coroner’s examination, except for the purpose of establishing the cause of death?

A. That is correct. But I think pathologists and I think – I will not try and speak for lawyers and I look forward to the opinion that you receive, sir – but I think it is a generally held view that, if tissue has been legally and properly retained during the course of a Coroner’s post-mortem examination, then it may be further retained for the legitimate processes such as medical audit, clinico-pathological review and so on.

As you have seen from my statement, I have modified my views about how this should be done with information given to relatives and consent sought where appropriate, but at that time, and until really quite recently, the view was that, if it was legally and properly retained during a Coroner’s post-mortem and the Coroner had finished with it, then rather than destroying it, it would perhaps be better to retain it and try and get some good from it.

Q. You say that is the view. Here is Professor Knight, who was himself a pathologist, saying the opposite?

A. I think – no, I do not think so, because the word “retention” to us at least, and I appreciate that pathologists live in their own world, but to us retention is the matter of holding something back from the body and allowing it to be closed and returned to the relatives. That is what we mean by retention.’[41]

41 In seeking to clarify Professor Berry’s understanding and interpretation of Professor Knight’s article, the following exchange took place between the Panel, Professor Berry and Leading Counsel:

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[40] UBHT 0308 0001

[41] T 55, p. 75–7

Q. (from the Panel) Do I take it that Professor Berry is really saying that the word “retention” in the sixth line could, in layman’s language, be described as the initial taking?

A. That is how I think pathologists understood it, sir.

Q. (from the Panel) Whether it was intended to be read that way, we can only find out if we ask Professor Knight.

Q. (from Leading Counsel) Yes. What I think, Professor Berry, you are telling us is the understanding that pathologists in general had, no doubt informed by your own reaction to the article?

A. Yes.’ [42]

42 Professor Berry told the Inquiry that he thought that Professor Knight was not addressing the question of further retention of material removed and initially retained pursuant to Rule 9, but the different question of the removal and subsequent retention during the Coroner’s post-mortem of material other than that required to help to establish the cause of death. Professor Berry told the Inquiry:

‘I am not sure that pathologists at that time were fully aware that, during the course of a Coroner’s post-mortem, you could only retain, initially or long-term, tissues for the purposes of establishing the diagnosis. It may be in the early 1980s pathologists might have been retaining [ie “removing” in Professor Berry’s understanding] tissue over and above what was required for diagnosis, and I think that is what [Professor Knight] is warning us against in 1985.’ [43]

43 Dr Ashworth told the Inquiry that he understood of Professor Knight to be arguing that retention of material other than Rule 9 material was probably ‘not illegal but that it may come under media scrutiny’.[44]

44 Mr Burgess told the Inquiry that the Coroners’ Society agreed with the view that Professor Knight was referring essentially to the retention of non-Rule 9 human material. Mr Burgess told the Inquiry that:

‘although a post-mortem examination may offer the *opportunity* for wider research or investigation, the coroner has no power to authorise any such extension to the examination to be made, and those wishing to avail themselves of this opportunity will have to resort to consent under the Anatomy Act or Human Tissue Act.’ [45]

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[42] T55 p. 79
[43] T55 p. 77
[44] T54 p. 74
[45] WIT 0039 0014, Mr Burgess, emphasis added

45 In October 1989, a Home Office circular was sent to all Coroners[46] advising them that no human material should be taken for teaching or research purposes when conducting a Coroner's post-mortem examination. In Bristol, Mr Hawkins, the then coroner, drew the circular to the attention of all the pathologists within his jurisdiction[47].

46 Mr Robert Clifford told the Inquiry that the Home Office:

> 'reminded Coroners of the limitations on what might be done with material retained from a [Coroner's] post-mortem some years before as a result, obviously at that time of some complaints or information coming to our attention that the material was being retained for purposes which did not seem to be authorised under the legislation. But only since 1996 has the possibility of a problem in this area … really come to our attention.'[48]

47 The Inquiry was told by Mr Hugh Ross, current Chief Executive of the UBHT, that:

> 'different Coroners interpret their responsibilities in different ways. Some leave it to the discretion of the pathologist to retain tissues if they wish, others are more specific.'[49]

Retention of human material as part of Coroners' post-mortems

48 Professor MacSween of the Royal College of Pathologists in his statement told the Inquiry that:

> 'Coroners are now trying to address this sensitive issue. Until recently, very few [Coroners] informed relatives that organs had been retained. Indeed, many Coroners instructed pathologists to make no mention of such retention in the report which the relatives might receive. This policy has now been overturned in most jurisdictions. The Coroner is told by the pathologist immediately after the autopsy that a heart or brain has been retained. A letter is despatched forthwith to the relatives informing them of the fact and offering them the right to re-possess those organs when the enquiries have been concluded.'[50]

Disposal of human material

49 Professor MacSween's evidence on behalf of the Royal College of Pathologists was that, as regards Coroners' post-mortems:

> 'the Pathologist *must* retain any tissue, organ or fluid which in his opinion might have a bearing on the cause of death … What is unclear is for how long those

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[46] WIT 0043 0153
[47] WIT 0348 0007
[48] T42 p. 113, Mr Robert Clifford, Head of the Coroners Section of the Animals, Bye laws and Coroners Unit at the Home Office
[49] WIT 0054 0029
[50] T37 p. 25

tissues should be kept and what their ultimate disposal should be. Coronial practice varies widely. The vast majority of Coroners take the view that, once their enquiries are concluded, the disposal of tissue is a matter for the pathologists and for their departments.'[51]

50 There has been little, if any, guidance on the disposal of retained human material. As regards Coroners' post-mortems, Mr Clifford of the Home Office has stated:

'our perception is that the coroners generally do leave the arrangements for disposal to the pathologist. Again, we understand that how long or whether they lay down specific lengths of time for the material to be retained does vary, but we have no information as to whether there is a majority view of any particular length of time.'[52]

51 Professor Green stated that Coroners

'can tell you for how long you can keep it, but they tend not to tell you that you must dispose of it, or there is no disposal order. You are ordered to keep it, but disposal is left to the discretion of the pathologist.'[53]

52 In relation to hospital post-mortems, there was very little guidance throughout the period of the Inquiry's terms of reference on disposal of human material. In Professor Berry's 1989 *Code of Practice for Retention of Post-Mortem Tissue,* it states that 'in all cases where tissue is retained, the minimum required for diagnosis should be kept and disposed of as soon as possible.'[54] No mode of preferred disposal was mentioned. The revised version of this code in 1998 was more prescriptive in its recommendations about disposal.

Hospital post-mortems and consent forms[55]

53 It was standard practice at Bristol, and nationally, to seek consent by recourse to consent forms before a hospital post-mortem was carried out. The Inquiry received evidence[56] that, both in Bristol and elsewhere, the consent forms for hospital post-mortems:

'varied widely, and we are not aware of any central direction which specified their design or content.'

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[51] WIT 0054 0029

[52] T42 p. 117

[53] T42 p. 96

[54] WIT 0204 0034

[55] As mentioned above, the 1961 Act does not use the language of consent; but speaks of 'the person lawfully in possession of the body' …'may give authority' for the removal of body parts after making 'such reasonable enquiry as may be practicable' with a view to ascertaining whether any relative 'objects' (section 1(2))

[56] From Professor MacSween WIT 0054 0027

54 The Inquiry contacted the other hospitals that were designated as supra regional neonatal and infant cardiac surgery centres during the period with which the Inquiry is concerned and asked for samples of the consent forms for hospital post-mortems that were in use between 1984 and 1995.

55 The practice varied. Examples of the responses received by the Inquiry follow.

56 At Guy's Hospital in London (part of the Guy's and St. Thomas' Hospital Trust) the hospital post-mortem 'consent' form in use in the period 1984–1995 stated:

'I understand that this examination is carried out:

1. to verify the cause of death and study the effects of treatment;

2. to further the advancement of medical education, research and treatment.

I understand that tissue, organs, bones and eyes may be retained for the purposes set out in 1 and 2 above.'[57]

57 At the Killingbeck Hospital, Leeds (now part of the Leeds Teaching Hospitals, an NHS Trust), the form in use during the period of the Inquiry's terms of reference

'I understand that this examination is carried out…

to remove amounts of tissue for the treatment of other patients and for medical education and research.'[58]

58 There is no express reference to 'whole organs' and no opportunity for parents or next of kin to express an objection to a full-scale post-mortem while agreeing to a more limited post-mortem.

59 Mr David Moss, the present chief executive at the Southampton University Hospitals NHS Trust, told the Inquiry that:

'the standard practice world wide during the period of 1984 to 1995 did not include consent forms for the retainment [*sic*] of tissue or organs. During this time parents were not asked to consent to such procedures.'[59]

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[57] HOME 0007 0017
[58] HOME 0007 0032
[59] HOME 0007 0033

60 The consent form now in use at Southampton is very detailed and allows for limited and full post-mortem examination, and removal of human material for treatment of other patients, for medical education and for research purposes. It also allows for the hospital to retain the human material for an indefinite period or for long enough:

> ‘to establish the medical causes of death after which time they will be decently disposed of by the hospital/medical school.’[60]

61 The form in use at the Royal Brompton Hospital (now the Royal Brompton and Harefield NHS Trust) in the early part of the period of the Inquiry’s terms of reference was similar to that at Killingbeck. In the later part of the period, the Brompton’s form also made reference to human material being retained for genetic research’.[61]

62 Alder Hey Children’s Hospital, Liverpool (now part of the Royal Liverpool Hospitals NHS Trust), also had a form that was similar to that used at Killingbeck. Ms Karen England, the director of operational services at Alder Hey, told the Inquiry that:

> ‘the specific issue about retained tissues was probably not discussed in detail, if at all. It was assumed at that time that consent for [hospital] post-mortem included consent for retention of tissue….and that also included retention of organs for teaching, research and education purposes.’[62]

In a report into the status of retained organs at Alder Hey in 1999, Mr S J Gould, consultant paediatric pathologist, the John Radcliffe Hospital, Oxford, stated:

> ‘Over this last five years, however, there has been growing recognition (in paediatric practice) that parents may not have considered that consent granted for tissue retention included consent for organ retention.’[63]

63 At the Royal Victoria Infirmary (now part of Newcastle upon Tyne Hospitals NHS Trust), a form introduced in January 1998 gives parents the opportunity to decline to give consent to retention of organs rather than tissue and retention of tissue for research. The form states that:

> ‘this examination…
>
> a. may involve keeping whole organs for laboratory tests;
>
> b. may involve keeping tissue samples for research.’[64]

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[60] HOME 0007 0034
[61] HOME 0007 0013
[62] HOME 0007 0025
[63] Gould, Dr SJ, ‘Internal Inquiry Into the Retention of Organs at the Royal Liverpool Children’s NHS Trust’. 20 December 1999 p. 13
[64] HOME 0007 0024

Prior to this, the form only *referred to* ‘retention of tissues for teaching and research’ and did not specifically use the word organ.

64 The Chief Executive of Great Ormond Street Hospital, referring to the current consent form introduced in 1992, wrote to the Inquiry that:

> ‘it was common practice for tissue and organs to be retained without seeking permission of the next of kin both for hospital and Coroners’ post-mortems. Whilst we recognise the clear need to seek proper consent from the next of kin … there is a danger that retention is seen as some kind of unpleasant curiosity rather than in its proper legitimate and scientific context.’[65]

The decline during the period 1984 to 1995 in the number of hospital post-mortems as opposed to Coroners’ post-mortems

65 The Inquiry heard evidence that the number of hospital post-mortems has declined in recent years. Professor MacSween said:

> ‘Over the years the permission autopsy has fallen into decline. In many hospitals, very few permission autopsies are carried out. There seems to be an increasing reluctance amongst the medical profession to request them, and an increasing reluctance amongst the population at large to give permission. Even in teaching hospitals, the incidence of so-called permission cases is now frequently less than ten per cent of the autopsy load.’[66]

66 One explanation for the decline in the number of hospital post-mortems put forward to the Inquiry related to clinicians’ communication skills. According to Mr Burgess:

> ‘[clinicians’] skills in that direction are not as good, maybe, or as persuasive as they should be. Maybe they do not even try. I do not think that I have heard it from relatives that if they had been asked in a particular way then they would certainly have agreed, but if the request is not made in the first place, then they are not given the opportunity of agreeing.’[67]

67 Mrs Diane Kennington, Patient Affairs Officer (PAO) at the Bristol Royal Infirmary (BRI) also noted that there are now fewer hospital post-mortems than when she started her present job in 1983. She thought there were several reasons for this:[68]

> ‘One of them is that I feel that the junior house officers are not really given enough training in dealing with bereaved people.’

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[65] Mr Robert Creighton, Chief Executive of the Great Ormond Street Hospital for Children NHS Trust, HOME 0007 0002

[66] WIT 0054 0027

[67] T43 p. 49

[68] T43 p. 93

She suggested a further reason for the decline:

> ‘we have now taken on responsibility at the BRI, since the city mortuary closed, for more Coroners’ cases, and that means that they take precedence over hospital post-mortems.’[69]

68 Mrs Kennington’s first point, on lack of training, was reflected in the evidence from the other supra-regional centres. Mr Mark Taylor, the current chief executive of the Royal Brompton & Harefield NHS Trust, told the Inquiry that:

> ‘no formal training was given for [the consent-taking] procedure.’[70]

69 Mrs Kennington gave evidence that she was given no guidance as to what she should or should not say to relatives of the deceased when going through the consent form with them.[71]

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[69] T43 p. 94

[70] HOME 0007 0004

[71] T43 p. 103

Part II

The Bristol Story

The hospital post-mortem consent forms used at Bristol

70 In a letter dated 15 February 1985 from J K Oliver, senior administrative assistant, to Professor G M Stirrat, Department of Obstetrics and Gynaecology, Bristol Maternity Hospital (BMH), there was a postscript addressed to Professor Berry stating that the hospital post-mortem consent form then in use at the BMH did not contain a clause about the removal of human material for research purposes.[72] Later that year, on 18 September 1985, Professor Berry wrote to A B Missen at the Medical Defence Union asking for advice on changing the hospital post-mortem consent form. He wrote:

> ‘Our local ethics committee have insisted that specific written consent must be given before tissue can be taken at post-mortem for research purposes. I am therefore caught between my clinical colleagues’ understandable wish to protect parents from further distress, and my wish to co-operate with other colleagues by supplying small samples of tissue for their research.’[73]

71 Professor Berry suggested a revised consent form in 1985 which gave the option of retention of human material for diagnosis, medical education and research.[74] As he told the Inquiry:

> ‘the idea was to increase parental choice, but also information so they had a better idea what it was they were consenting to, or at least, I could be sure that some sort of explanation had been gone into.’[75]

72 The consent forms for hospital post-mortems then in use at Bristol Royal Hospital for Sick Children (BRHSC) and BMH were different from those in use at the BRI.[76] Although they came under the umbrella of the United Bristol Hospitals Trust (UBHT), there was not at that time a corporate approach to this matter. Thus, a variety of different consent forms were in use within the district.

73 Professor Berry told the Inquiry that one reason was that it was not possible to have a single consent form for use in the different hospitals which are now part of the UBHT, which could deal with infant, child and adult deaths, which would be:

> ‘suitable for people who have lost very young or stillborn children [and also] for adults.’[77]

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[72] UBHT 0322 0150
[73] WIT 0204 0054
[74] WIT 0204 0041
[75] T55 p. 99
[76] UBHT 0322 0150
[77] T55 p. 104

74 Mrs Diane Kennington, the PAO at the BRI, has, since 1983, been responsible for obtaining consent to the hospital post-mortem at the BRI. Her recollection was that all of the cases involving children at the BRI were Coroners' post-mortem cases, for which no consent form was required. As such, Mrs Kennington had not seen the form which Professor Berry and Dr Ashworth said was then in current use at the BRHSC and BMH.[78] The consent form that she had always used was for hospital post-mortems performed on adults and was provided to the Inquiry.[79]

75 The Bristol and Weston Health Authority's (BWHA) legal advisers at the time did not appear receptive to the revised consent forms for hospital post-mortems that Professor Berry suggested. In a letter dated 2 December 1985, Mr R I Johnson, of Osborne Clarke, Solicitors, wrote to Mr V Harral, District Administrator, BWHA, stating that the problem was:

> 'the level of loss involved in the bereavement. I think that this is particularly so at the Maternity Hospital where one is asking a mother of a newly dead baby for consent to cut it up in the interests of medical science.'[80]

76 A subsequent comment from Mr Harral on Professor Berry's proposed form was that:

> 'I do not know that it confers any benefit in terms of being more sympathetically worded and, therefore, likely to be more acceptable to parents.'[81]

77 Professor Berry, however, remained of the view that consent[82] was required in order to remove and retain human material for the purposes of medical research or organ donation[83]. He understood that this applied to coroners' post-mortems and hospital post-mortems alike. This is demonstrated by a letter of 28 August 1986 from Professor Berry to Dr Robert Parker, the head of the Homograft Department at the National Heart Hospital, in which Professor Berry wrote:

> 'our Coroner in Bristol will *quite properly* not allow us to take tissues from cases in his jurisdiction without consent of the relatives which can usually not be obtained. Secondly my clinical colleagues have not allowed me to change the form of our hospital post-mortem request form to include permission for removal of tissues for teaching, research or organ donation.'[84]

Professor Berry appears to be referring here to human material other than that required during a Coroner's post-mortem to establish the cause of death.

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[78] UBHT 0014 0278

[79] WIT 0214 0035

[80] UBHT 0322 0160–1

[81] UBHT 0308 0085–6

[82] The point that the 1961 Act does not use the language of '*consent*' has already been made

[83] Though the position in relation to the subsequent retention of tissue removed pursuant to Rule 9 of the 1984 Rules was less clear to Professor Berry

[84] UBHT 0308 0050

78 Mr Paul Forrest, HM Coroner for Avon since 1992, confirmed that this was Mr Hawkins' approach in relation to Rule 9 of the Coroners Rules.[85]

79 Throughout 1986 and 1987, Professor Berry continued in his efforts to amend and standardise the hospital post-mortem consent forms in use in Bristol to include reference to the removal of human material for research.[86] The revised hospital post-mortem consent form had been with the hospital lawyers for 'over a year',[87] and it had been two years since Professor Berry had first raised the matter at the Division of children's services.[88] This was a cause of frustration for Professor Berry as he:

> 'was unable to help parents collaborate with ethical research and I was unable to take maximum advantage of the privilege of the post-mortem examination to help other people.'[89]

80 Finally, at a meeting of the division of children's services on 20 October 1987, the consent forms were approved on the advice of the District Solicitor.[90] The forms came into effect in 1988.[91]

Development of paediatric pathology in Bristol

81 Until 1971 there was no specialist paediatric pathology service at the BRHSC. Post-mortems on children, whether Coroners' post-mortems or hospital post-mortems, were carried out at the BRI or the city mortuary.

82 Between 1978 and 1992, Mr Donald Hawkins was HM Coroner for Avon. Local practice in relation to coroners' post-mortems under Mr Hawkins was:

> 'that deaths following operations to correct medical conditions were deaths arising from natural causes and as such only referable to the Coroner if the cause of death was unknown, or unknown without a … post-mortem examination.'

However, he did require that he be informed of deaths that occurred on the operating table.[92]

83 In 1983, Professor Berry was appointed consultant paediatric pathologist at the BRHSC.[93]

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[85] T 65 p. 117

[86] UBHT 0308 0066

[87] UBHT 0322 0145

[88] UBHT 0322 0129–30

[89] T55 p. 103

[90] UBHT 0211 0016–7

[91] In August 1996, after the end of the period of the Inquiry's terms of reference, the hospital post-mortem form used by UBHT was again revised to make it clear that a hospital post-mortem might lead to the retention of the whole brain or heart and giving parents a wider range of possible options to which they could consent (UBHT 0014 0278) (WIT 0204 0016)

[92] WIT 0348 0002

[93] WIT 0204 0002

84 Mrs Kennington was appointed to the position of Patient Affairs Officer (PAO) at the BRI in 1983. She was previously the cashier at the BRI. All of her previous employment had been finance-related. She was approached and asked if she wanted to become the PAO. Her duties have not changed significantly since her appointment:[94]

> 'My role, really, was a facilitator for the families, the bereaved families that came to see me.'

85 In a review dated 21 September 1990, the Department of Health (DoH) set out minimum standards for a perinatal pathology service. It recommended the establishment of a second paediatric pathology post in Bristol and the development of a professorial unit of paediatric pathology at the University of Bristol.[95] In 1990, the University of Bristol won a grant to establish a university chair and Dr Berry (as he then was) was appointed Professor of Paediatric Pathology.

86 Professor Berry was at this time particularly concerned with funding as

> 'several paediatric regional services have become established without provision for Paediatric Pathology back up. For example, paediatric cardiology and cardiac Surgery required 37 detailed examinations in 1988 which were unfunded'.[96]

Professor Berry wanted these services to be included in contracts[97] as, in 1991, cardiac surgery accounted for

> 'one quarter of [Professor Berry's] post-mortem workload, and I have already performed around 20 necropsies this year on these patients. Each post-mortem takes at least two hours of my time excluding histology and monthly meetings. These examinations are well worth doing as our recently published audit showed errors of diagnosis or surgery in nearly 40 per cent which probably contributed to death in about 17 per cent of cases. Over the last three years, I have pointed out in increasingly strident terms to all the paediatric cardiologists and cardiac surgeons that this is an unfunded service, and that they should make provision for their 10 per cent surgical mortality when agreeing contracts. This has not resulted in any apparent action on their part.'[98]

87 The South Western Regional Health Authority's (SWRHA) policy was set out in a report of 9 April 1991, which stated that:

> 'all children who die in the peri-operative period should have a post-mortem.'[99]

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[94] T43 p. 93
[95] UBHT 0308 0126–7
[96] UBHT 0308 0146
[97] UBHT 0308 0144–5
[98] UBHT 0308 0144
[99] UBHT 0212 0009–11

Bristol practice on retention, use and disposal of human material

88 The SWRHA report emphasised that:

> ‘retention of tissue for purposes other than to establish the cause of death is subject to the Human Tissue Act, 1961. The constraints apply equally to clinical autopsies and those performed for the Coroner.’

89 This report was prepared by Dr Charles Shaw,[100] Director of the Bristol clinical audit unit, and others following a meeting of the National Confidential Enquiry into Peri-operative Deaths. It is the

> ‘amended version of the general conclusions of the surgery on children discussion document.’[101]

Surgeons at the BRI were asked to comment on it before it was submitted to the regional health medical audit committee.

90 In 1991, Professor Berry issued Bristol paediatric pathology department’s first Code of Practice.[102] The evidence suggests that Professor Berry was in the vanguard in national terms in this development.

91 The Code of Practice advised that human material could normally only be retained as part of a Coroner’s post-mortem ‘for the express purpose of establishing the cause of death for HM Coroner’ or ‘when civil or criminal litigation is in prospect’. The Code of Practice continued:

> ‘in post-operative cardiac cases, the pathologist must make his own judgement in each case whether further examination of the heart is strictly necessary to determine the cause of death’.

92 However, it seems that the references in the code to ‘retention’ in fact were intended to refer to the initial removal of the human material from the body and its subsequent retention beyond the funeral date. The code does not appear to have addressed difficulties as to the *continued* retention of human material initially removed during a coroner’s post-mortem in order to establish the cause of death, after the cause of death had been established and the Coroner was *functus officio*. It was this practice which led to the retention of the great majority of the hearts from paediatric cardiac surgery patients and to the subsequent public concern about practice in Bristol and elsewhere.

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[100] See Appendix
[101] UBHT 0142 0016
[102] WIT 0204 0034

93 As to this practice, the long-term retention of Rule 9 material, Professor Berry's initial view appears to have been that shared by his profession generally. He told the Inquiry:

> 'Our understanding and the understanding of pathologists in general is that if tissue was legally retained for the purpose of diagnosis under Rule 9, when it was no longer required for that purpose it was ethical, legal for us to retain it for other purposes.'[103]

94 In May 1996 (after the TV programme 'Dispatches' had been broadcast) Professor Berry amended the Pathology department's Code of Practice to state that, in Coroners' post-mortem cases, as regards whole organs if not tissue, they would only be retained:

> 'if essential for completing the report to the Coroner' or 'if the clinician wishes an organ to be retained and has discussed the retention of the organ with the child's parents and recorded their consent in the case notes.'[104]

In relation to disposal, the code as revised stated that:

> 'where there are no forensic or medico-legal issues, whole organs will be disposed of by incineration after one year unless we have been made aware that the parents wish to make their own arrangements for disposal…'[105]

95 Professor Berry again amended the department's Code of Practice on 23 November 1998. Dr Ashworth agreed that the amendments were required, as by that stage there was more public awareness of the issue of organ retention and 'perhaps some antagonism to it.'[106] The code, as then amended, was more specific in its requirement for documentation and stated that:

> 'if the pathologist considers that retention of a whole organ is important for audit, educational or other reasons … then permission to retain it should be obtained from the parents by the clinician involved in the care of the child.'[107]

96 Dr Ashworth told the Inquiry that the Bristol Coroner had never given instructions as to what could be done with material removed during a Coroner's post-mortem under Rule 9. Mr James Wisheart, consultant cardiac surgeon, said:

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[103] T55 p. 69–70
[104] WIT 0204 0035
[105] T55 p. 72
[106] T54 p. 10
[107] WIT 0204 0036

> 'There was a clear distinction in this area of whether or not one needed consent to retain tissue, in our minds at that time, be it right or wrong, between a Coroner's post-mortem and a hospital post-mortem. In the latter, we understood clearly that it was necessary to have consent for everything specifically. In the Coroner's cases, our perception of things was that it was not so necessary.'[108]

Mr Forrest disputed this and said that he continued the previous practice of Mr Hawkins.[109]

Professor Berry and liaison with the Bristol clinicians concerning Coroners' post-mortems

97 Professor Berry was plainly troubled by the question of retention of human material removed pursuant to Rule 9 of the Coroners' Rules during a Coroner's post-mortem. On 6 August 1992, Professor Berry sent a letter to the Bristol cardiologists and cardiac surgeons which stated that:

> 'in future we will not be able to retain the heart unless there is a signed statement in the notes from one of the doctors looking after the child that they have satisfied themselves that the parents of the child do not object to the retention of tissue during the course of the Coroner's post-mortem examination.'[110]

It is noteworthy that this letter refers to the retention of tissue 'during' the course of the Coroner's post-mortem. In the circumstances, it can only mean 'after' the post-mortems, but this lack of precision and clarity was an ever-present feature of all discussions.

98 Responses from the recipients of this letter varied:

a) Dr Rob Martin, consultant paediatric cardiologist at Bristol, recalled the letter but did not reply as he knew Dr Stephen Jordan, consultant paediatric cardiologist at Bristol, had replied and he, Martin, was still fairly new to the unit;[111]

b) Dr Jordan responded by saying that it was something that he would keep in mind;[112]

c) Mr Dhasmana responded to Professor Berry admitting an 'oversight' and added, 'on some occasions, some of the parents have not liked any discussion regarding the post-mortem examination:'[113]

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[108] T 94 p. 171
[109] See Annex B for further discussion.
[110] UBHT 0308 0018
[111] T77 p. 171
[112] UBHT 0308 0235
[113] UBHT 0308 0017

d) Mr Wisheart thought that the need for this had ‘eased under the jurisdiction of the new Coroner’.[114] Mr Wisheart told the Inquiry that ‘it has never been represented to me that this was a legal requirement … I very much felt that the advice given by Professor Berry was certainly far-sighted and prudent, but was in a sense more than was necessary in our practice at that time.’[115]

Discussing post-mortems with parents in Bristol

99 Mrs Kennington had been the Patient Affairs Officer at the BRI since 1983. Her role was confirmed at the hospital medical committee in June 1997 where:

‘it was generally felt that the Patient Affairs Officer was at present the best person for obtaining consent for post-mortems’;[116]

and again at the patient care standards committee (PCSC) in July 1997, where it was stated that senior staff:

‘felt that it was handled adequately already and displayed no enthusiasm for becoming more involved.’[117]

100 Mrs Kennington’s evidence was that relatives:

‘feel more at ease with me … they can discuss things that they probably would not like to discuss with the doctor, consultant or even the nursing staff and, also, that they could bring to me any problems that they might have which they would not feel that they could talk to a doctor about, a complaint or a comment that they would feel a lot easier talking to me about.’[118]

101 As noted previously, Mrs Kennington usually obtained consent to hospital post-mortems performed on adults as, in her recollection, all of the post-mortems on children at the BRI were Coroners’ post-mortems for which no consent form was required.

102 It was left to Mrs Kennington to decide what to tell relatives about post-mortems. She was of the view that, when the families said that they hoped the post-mortem would help other people, they were accepting the fact that human material might be removed. She never explained to relatives what was meant by ‘tissues’ even though she understood, without being told expressly herself, that it could mean an entire organ. She appeared to be left in no position adequately to explain to relatives the full implication of the document which she was encouraging them to sign.

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[114] UBHT 0308 0170
[115] T41 p. 116
[116] UBHT 0003 0012–15
[117] UBHT 0014 0151–5
[118] T43 p. 120

103 Mrs Kennington was not a clinician. As Mr Ross stated:

> ‘one matter which was raised was the fact that the staff in the BRI complex who obtained consent for post-mortem were not all fully conversant with the procedures in the pathology department and might be unable to answer detailed questions raised by relatives.’[119]

It is unclear whether Mr Ross is also referring to Mrs Kennington in saying this. Mrs Kennington’s role had been confirmed by the hospital medical committee in June 1997, after the commencement of Mr Ross’s tenure as Chief Executive of UBHT.

Doctors

104 Mr Dhasmana found discussion of post-mortems very difficult. He told the Inquiry:

> ‘This used to be a most difficult period… I was always emotional during this meeting and the only way I could really just, you know, express it was just quickly get to the point … and because it had happened in theatre or whatever, like that, I would then say that “A Coroner’s post-mortem will be carried out …” It used to be very difficult for me to communicate very well at that time.’[120]

105 Mr Dhasmana advised the Inquiry that, in his opinion,

> ‘training of medical staff should include bereavement counselling training, which would provide the skills required to obtain post-mortem consents. The death of a child, during or after surgery, is a very difficult period for the parents and for the treating clinical teams, and it is important that all aspects of the situation be dealt with sensitively and without hurting parents’ feelings.’[121]

106 Mr Wisheart said:

> ‘It was not my practice to seek consent for retention of the heart after a Coroner’s autopsy. I did not feel that it was appropriate to add to the anguish of the parents by asking for permission to keep their child’s heart for scientific purposes.’[122]

107 Junior staff were not comfortable with tackling the issue of post-mortems with parents either. Mrs Kennington is recorded as having told the PCSC in June 1997 that:

> ‘half the consultants were happy for [Mrs Kennington] to deal with post-mortems and retrieval consents; junior housemen were reluctant to approach families about this delicate subject…’[123]

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[119] WIT 0128 0026
[120] T87 p. 97–8
[121] WIT 0084 0106
[122] WIT 0120 0253
[123] UBHT 0014 0251

108 Further evidence of the difficulties experienced by clinicians was that on 10 May 1994, at a meeting of the division of medicine:

> ‘Dr Roberts reported that a number of junior staff had spoken to him concerning the difficulties being experienced in requesting autopsies.’ [124]

When Dr Clive Roberts, who was the clinical dean and consultant senior lecturer in clinical pharmacology and therapeutics, was asked to clarify this comment by the Inquiry, he said that the junior doctors had told him:

> ‘that it was often difficult to see relatives. This was because death certificates which had been written early in the day tended to be collected without the doctors being offered a chance to talk to the relatives… I think some [doctors] also tried to avoid this difficult situation.’ [125]

109 As regards hospital post-mortems, in particular, in 1991 a joint working party of the Royal College of Pathologists, the Royal College of Physicians and the Royal College of Surgeons of England stated in its report entitled ‘*The autopsy and audit’* that ‘great care should be taken in obtaining permission for hospital post-mortem. The responsibility lies with the consultant in charge of the case.’ [126]

110 Again, in the 1998–99 consultation paper of the Royal College of Pathologists, it was recommended that:

> ‘the most senior doctor who knew the relatives best during the patient’s last illness should obtain consent to the hospital post-mortem examination.’ [127]

111 These recommendations were not followed in Bristol during the period of the Inquiry’s terms of reference. Contrast UBHT 0212 0010 dated 9 April 1991 (‘requests to parents for permission should be made by consultants’) with the revised policy at UBHT 0025 0242–3 dated 19 September 1991 (’requests to parents for permission should *usually* be made by consultants’). The UBHT’s recent ‘Staff guidance on post-mortem examinations’ states that it is ‘intended to assist junior medical and nursing staff when they discuss the need for a post-mortem with the next-of-kin of a deceased patient.’ [128]

112 Professor Berry takes the view that the UBHT’s policy should be that:

> ‘when a child dies, parents should rightly expect that somebody senior should come along and explain what has happened and what is going to happen to their child. That has always been my view.’ [129]

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[124] UBHT 0321 0021–6
[125] WIT 0214 0079
[126] WIT 0054 0936–60
[127] RCPath 0001 0072. See now the guidelines issued in March 2000
[128] WIT 0128 0033–5
[129] T55 p. 105

113 Mr Ross gave evidence that it was common practice throughout the NHS for consent to a hospital post-mortem to be obtained by junior medical staff:

‘I think the answer is that generally that would be delegated to junior medical staff, but sometimes a practised and experienced patients’ affairs officer or relatives’ officer, someone like that, would undertake that task at the request of the consultant medical staff.’ [130]

The emergence of concerns in Bristol[131]

114 On 27 March 1996, the television programme ‘Dispatches’ examined paediatric cardiac surgical services in Bristol. Mrs Helen Rickard, whose daughter Samantha had died after open-heart surgery at the BRI in 1992, saw the programme. It prompted her to contact the UBHT about the care of her daughter. Mrs Rickard arranged to view her daughter Samantha’s medical notes.

115 Mrs Rickard knew that her daughter had been the subject of a post-mortem. She said:

‘[I was told] there would need to be a post-mortem because she died in theatre and I accepted that… I knew that they had to cut her open. I knew that is what happened in a post-mortem, that they cut the body open and they look at things inside. At that point, I do not think I thought any more of it.’[132]

116 On 15 April 1996, Mrs Rickard telephoned Mr Ian Barrington, general manager of the BRHSC, as she had discovered from the notes that her daughter’s heart had been retained at post-mortem.[133] Mrs Rickard visited the UBHT to view the heart with Mr Barrington and Professor Berry. At this meeting, on 8 May 1996, Mrs Rickard asked Professor Berry who had the responsibility of informing parents about the issue of retaining human material, and he recorded himself as saying:

‘in Coroners’ post-mortems there was probably no requirement in law, but that [he] would expect the clinician who reported the case to the Coroner to explain to relatives that there would be a post-mortem examination and what it entailed.’ [134]

117 Subsequently, Professor Berry spoke to the Coroner:

‘who confirmed that retention of the heart from cardiac surgical cases is appropriate, but that his responsibility for the tissue ceases once he has completed his investigation.’ [135]

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[130] T37 p. 27

[131] These events fall outside the period of the Inquiry’s terms of reference. They are dealt with here to bring the events in Bristol up to date and to put the recent developments in the practice in Bristol into context.

[132] T52 p. 147

[133] UBHT 0308 0014–6

[134] UBHT 0308 0205–6

[135] UBHT 0308 0205–6. See Annex B

118 In the period after Mrs Rickard saw Professor Berry in 1996, and after the broadcast of the ‘Dispatches’ programme and the publicity surrounding the General Medical Council’s proceedings against Dr Roylance, Mr Wisheart and Mr Dhasmana, many parents made enquiries of UBHT. Professor Berry dealt with parents’ enquiries about retention of human material on an individual basis as he:

‘considered it wrong to approach parents who might have come to terms with their loss and not wish to be confronted with this issue.’[136]

As Mr Ross said in evidence:

‘unless the Trust could identify the individual parents who wanted to know whether organs or tissue had been retained, it would be a gross intrusion on their grief to contact them.’[137]

119 Mr Barrington was aware that a small number of enquiries were made of Professor Berry between mid-1996 and the end of 1998. In discussion between Mr Barrington, Professor Berry and Mr Ross, it was ‘agreed that we could only await contact initiated by parents, recognising that some parents would find a direct approach from us both unwelcome and distressing.’[138]

120 In the meantime, the Bristol Heart Children Action Group (BHCAG) was formed and its members had meetings with the Rt. Hon. Frank Dobson MP, the then Secretary of State for Health, at which they requested an independent inquiry. The Inquiry was announced on 18 June 1998.[139]

121 On 2 November 1998, there was a meeting between the executive of the BHCAG and the UBHT. Mr Ross confirmed in a letter to Mrs Michaela Willis, chair of the BHCAG, on 6 November 1998 that the following approach was to be taken as regards retained human material:

‘(1) the BHCAG would write to all the parents who had expressed concern on this issue;

(2) BHCAG would ask parents to forward permission via the BHCAG to the Trust for their particular case to be looked into…;

(3) when permissions were received, the BHCAG would forward them … to Ian Barrington, general manager at the BRHSC;

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[136] WIT 0204 0066
[137] WIT 0128 0011
[138] WIT 0076 0015
[139] Hansard Columns 529–30

(4) UBHT would then reply to each parent/family… The letter would explain the individual circumstances of each case and also make reference to the benefits to research and future clinical practice that had accrued from the knowledge gained from post-mortems and subsequent tests, etc.'[140]

122 Professor Berry began the process of compiling a list of children who had died after cardiac surgery and had undergone post-mortem examination (whether Coroners' or hospital post-mortems) in the department of paediatric pathology.[141]

123 At a meeting on 4 February 1999, the UBHT told the BHCAG about the number of hearts that had been retained and that, in addition, other organs had been retained in some cases. Mr Ross told the Inquiry that:

'it was only relatively late that I found out myself the material retained was not only limited to hearts.'[142]

After this meeting Mr Ross asked Professor Berry to prepare a list of the retained hearts as a matter of urgency. Professor Berry stated that:

'to create the list requested…it was necessary for me to hand search approximately 2,800 post-mortem reports to identify all children who had had post-mortem examinations after undergoing cardiac surgery between November 1971 (when the department of paediatric pathology began) and the end of 1995.'[143]

124 There was a further meeting on 8 February 1999 at which Mrs Willis:

'informed the Trust that we could no longer await their further deliberations because we had been informed that the press had become aware of the story by a Trust leak. We further told the Trust that we were not prepared to allow our members to find out about the retention issue via the media as had happened in the past in relation to other revelations. As they were unready to write to the parents with an agreed letter, we intended to write to our parents immediately, issue a press release and hold a press call to make sure that, as far as possible, the full facts were presented. The reason for doing this was I would have been no better than what we accused the Trust of doing 'withholding' information and I could not be party to this.'[144]

Mr Ross, however, was particularly concerned about the information being released in this manner as:

'there would be a substantial number of … parents who would only find out through the media.'[145]

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[140] UBHT 0322 0051
[141] WIT 0204 0020
[142] T37 p. 67
[143] WIT 0204 0020
[144] WIT 0221 0003
[145] T37 p. 72

The Trust had by this stage prepared draft letters with the assistance of the BHCAG executive that were to go to the families. The UBHT letters had to be amended in light of the press release from BHCAG.

125 At a further meeting attended by the BHCAG executive and Mr Barrington on 15 February 1999, when Professor Berry had completed his investigations, it was agreed that:

> ‘the Trust would write a letter that would be given to the Heart Action Group so that they could send it out to their members; there could be a consent form included in that letter for them to send back … so we would know the parents that wished to know about their child’s situation.’[146]

126 Mr Barrington, who was responsible for liaising with parents, did not at first discover the correct state of affairs in all cases. He had told some parents that a post-mortem had not been carried out and then subsequently discovered that one had in fact been performed. He also told some parents that there was no indication that the heart had been retained although he later found records that it had been retained and then disposed of.

127 Mr Barrington informed the Inquiry that the total number of parents who made enquiries was 231 and, of those, the total number of children whose organs had been retained was 140.[147] The process was a time-consuming one for both Mr Barrington and Professor Berry. Professor Berry realised that:

> ‘parents often wanted much more information than whether or not we had their child’s heart. This further information included whether the whole or part of the heart had ever been retained, what other tissue samples had been retained, why tissues had been retained, and when they were disposed of. We tried to provide this information in subsequent letters.’[148]

128 Unfortunately, the information initially given to a small number of parents was inaccurate.[149] For example, Mrs Lorraine Pentecost stated that she had:

> ‘received a letter [in February 1999] from the UBHT telling me that they had my son’s brain, heart and liver. Previous to the letter arriving, I had had a telephone call from the UBHT telling me that they had my son’s heart, brain and lungs… [in September] I had a letter saying that they had kept Luke’s brain, heart, lungs, liver, kidney, spleen and stomach.’[150]

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[146] T37 p. 121

[147] WIT 0076 0066

[148] WIT 0204 0024

[149] Mrs Penelope Shipley, mother of Amalie, was one such parent: see WIT 0392 0021

[150] T95, p. 205–6

Despite Mrs Pentecost's queries in the period between February and September 1999, Mr Barrington did not confirm what human material had been retained until he had spoken to Professor Berry. There was a delay in relaying this information to Mrs Pentecost as Mr Barrington was on leave and busy with 'other work commitments' on his return.[151]

Professor Berry and changes to national practice from the mid-1990s

129 Professor Berry played a leading role in the review of his profession's approach to the removal, retention, use and disposal of human material at and after post-mortem. As chairman of the Royal College of Pathologist's specialist advisory committee on paediatric pathology, he oversaw the drafting of a document alerting paediatric pathologists to changing public opinion on the retention of human material. He was chosen by the Royal College of Pathologists to chair a working group with a view to producing guidelines. The draft guidelines were put to the patient liaison group of the Royal College of Pathologists in January 1999. Following media attention about events in Bristol in February 1999, he stood down from the working party.

130 In March 2000, the Royal College of Pathologists' paper entitled 'Guidelines for the retention of tissues at post-mortem examination' was published.[152]

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[151] WIT 0076 0062

[152] RCPath 0001 0088. See Report and Annex B

Part III

The parents' experience

Whether hospital post-mortems were carried out with 'consent'

131 A number of parents of children who died following heart surgery at Bristol suggested that they had not given consent to a post-mortem.[153] Plainly, if a hospital post-mortem was carried out without consent (or, more accurately after establishing that the parents did not object), this would be a very serious matter. Lack of appropriate consent would raise important concerns. The Inquiry therefore looked into the matter in considerable detail. On day 55 of the Inquiry hearings, Leading Counsel to the Inquiry reported the results of the Inquiry's investigations to the panel. He said:

'Professor Berry has a database of post-mortems which were performed in his pathology department which covers the Bristol Children's Hospital and St Michael's Hospital. There are 265 names on his list in relation to children who died following heart surgery or from a heart condition in the period 1984 to 1995. That is 265 names. Of those 265 cases that came to post-mortem, 45 were hospital post-mortems, and as we know from evidence we have already taken, hospital post-mortems require written consent before they may be performed.[154] The remaining 220 cases were Coroners' post-mortems which do not require, legally, any consent from any relative for their taking place. So, in percentage terms, 83 per cent of the cases that came to post-mortem were Coroners' post-mortems. That list does not include a further four cases of post-mortems which were performed at the Bristol Royal Infirmary rather than in Professor Berry's paediatric pathology department. He has assisted in the tracing of those four cases. They were all Coroners' post-mortems.

Of the 45 which required written consent, in all but four of those cases we have been able to locate either the original signed consent form or a copy of it, or a reference in contemporaneous documentation to written consent having been given. It is quite plain – and I shall come back to this – that the best recollection of a number of parents is faulty in that when they thought, on reflection, they had not given consent, in fact they had. Of those four cases, we know – and I am not at liberty, for the reasons that I have given, to reveal the name of the patient concerned – that in one case although there is an absence of any written record of consent, consent was in fact given because the parent has told us that she asked for a post-mortem to be conducted.

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[153] As already noted, the 1961 Human Tissue Act (the 1961 Act) does not use the language of consent, but refers to giving authorisation after such reasonable enquiries as may be practicable have been carried out to ascertain whether any relative objects

[154] Here Leading Counsel to the Inquiry was describing the practice in Bristol

The other three are cases in which there has been no suggestion from the parent or parents concerned that they did not consent. There is a double negative there, but it has to be put that way. There is, therefore, no evidence that there was a lack of consent or evidence that there was any objection by the parents concerned. There is positive evidence (at the moment in written form) from Professor Berry – and he will answer to this later today – that in every case in which he conducted a post-mortem, there was consent. We heard yesterday from Dr Ashworth that his practice was never to conduct a post-mortem without being assured to his satisfaction that there was written consent. Dr Russell, I think, in addition, in his statement confirms that position.

So the evidence before the Inquiry, in the absence of any contrary evidence from those three parents, is that consent was obtained [in those three cases], even although there is no documentary record of it.

… the evidence presently before the Inquiry is that, in every case in which there was a post-mortem, there was a consent for the post-mortem. I should emphasise that I say nothing about the position in respect of the retention of tissue following a Coroner's post-mortem, which has already been the subject of some evidence, and nothing that I say is intended to suggest that there was consent in any written form for any such retention. Whether it was required or not is a matter which you will, I know, later be considering, and have been considering this week.

The matter I said I would come back to is one of comment and therefore for you to make and assess and not for me to suggest, save that it is a matter for you to conclude, Panel, whether or not the fact (as it is) that a considerable number of parents did not think that they had been asked for nor had given consent to post-mortem when as it happens they had, says something about the process; whether it may suggest that the process was carried out at a time when inevitably concerns and thoughts and feelings were elsewhere, making it difficult to comprehend everything that was happening; whether it may be a reflection of any inadequacy – and if so, it will be a matter for you to identify – in the way in which parents were approached and told of the requirement and what it involved; and whether or not it might imply any need for written information or for a follow-up, counselling or informative service, or conversation, so that parents are aware of the sensitive issues. Nor does it necessarily resolve any question of whether or not the parent concerned had full information as to the length of time; nor whether they had a full description of the purposes for which any tissue or organ was retained.'

The parents' understanding of post-mortem and its necessity

132 Professor Berry said:

> 'It has become clear that there is a great range in what parents understand about the post-mortem examination, and this challenges us to increase the public's general knowledge about what post-mortem examination involves, and the contribution of post-mortem examination to health care. Some parents are naturally upset at what post-mortem examination involves and choose not to receive further information. It is important to respect their right not to know as well as their right to know. Their comments re-emphasise the need for very sensitive and careful explanation to parents at the time of their bereavement whether post-mortem permission is being sought from them or HM Coroner directs the examination.'[155]

Further,

> 'I think now our view would change and we would perhaps enter into a dialogue with parents to see what their wishes were and if they were prepared to delay the funeral, perhaps by a day or so, we would accelerate the examination of the heart so it could be returned to the body.'[156]

133 In relation to the amount of time required to fix a heart for the purposes of a post-mortem, Professor Green said:

> 'To fix a heart in formalin takes 10 days. There is experiment now with microwave fixation techniques but this can only be used on relatively small organs and it is not, in my view, anywhere near as satisfactory as conventional formalin fixation.'[157]

Professor Berry stated that, whilst pathologists are trying to reduce the period of fixation by use of microwave fixation, it was

> 'not my practice at that time [1984–1995] and was not a practice that is used in the United Kingdom, so far as I know.'[158]

134 The parents who gave evidence to the Inquiry, written and oral, presented a diverse range of views of their experience in relation to the retention of human material and post-mortems generally.

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[155] WIT 0204 0050
[156] T55 p. 61
[157] T42 p. 51
[158] T55 p. 58

135 The emotions experienced range from anger:

> ‘I remained adamant that her organs should not be available for donation, so why did they assume they could donate her organs to the hospital for medical audit and training? I feel that the staff of the BRI let me down even after my daughter’s death. They have now left me with the horrible task of burying my daughter (or, at least, parts of her) again.’[159] Diana Hill, mother of Jessica.

136 To shock:

> ‘If they had asked us whether they could have retained Lewis’s heart for whatever reason we would have said no because we believe that the heart is the soul of the person.’[160] Janice Wilcox, mother of Lewis.

137 To bewilderment:

> ‘I could not accept that I had not buried Joseph whole, nor that his organs would have been taken without our consent. What makes their action even more baffling is that we actually offered Joseph’s organs for transplant after he died but were told that they would not be of any use.’[161] Angela Good, mother of Joseph.

138 To a feeling of loss of control:

> ‘The worst aspect, I mean, it is an awful trauma having Bethan operated on. The one thing as a father one enjoys is having the sense of control over your child’s life, but then with the operation, you lose that control, but then to further lose that control after death in this way, it is so upsetting.’[162] Paul Bradley, father of Bethan.

139 To perceptions of a lack of sensitivity from clinicians:

> ‘If only people had been honest and open with parents. I realise that doctors have to be trained and only see organs as specimens. The distress which we have all felt could have been alleviated by treating parents and patients as human beings rather than an extension of specimens.’[163] Brenda Rex, mother of Steven.

140 To acceptance:

> ‘While I was in the waiting room, someone asked if they could do a post-mortem and I agreed. I thought that, as there was nothing that could be done for Scott, I might as well try and help others. I was not asked about donation or about organ retention.’[164] Josephine Player, mother of Scott.

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[159] WIT 0263 0016
[160] WIT 0509 0009
[161] WIT 0460 0012
[162] T53 p. 45
[163] T53 p. 107
[164] WIT 0258 0007

141 The Inquiry received little evidence from parents whose child died but did not undergo a post-mortem. Mr Malcolm Curnow, father of Verity, was one such parent. Without being asked, he refused permission for a hospital post-mortem. He said:

‘As a police officer, as you are well aware, I have attended, as many police officers do, a whole series of post-mortems, and I am more than well aware of what is entailed in them. I did not want to think that my daughter would have to undergo that procedure, and as a result of that, I made it absolutely and abundantly clear to the staff at the hospital upon her death that there was no post-mortem to be carried out, and I made that clear and abundant, and the reasons were given why I did not want it carried out. It is for that reason that I believe that the post-mortem was not carried out.’ [165]

142 Coroners’ post-mortems were very common in the cases (where death resulted) within the Inquiry’s terms of reference, because death often occurred during or shortly after surgery.

143 The Inquiry heard that the post-mortem report would not highlight the fact that human material had been retained, nor that it might be put to other uses later, such as teaching or research. Thus, many parents remained unaware.

144 Parents gave evidence of the conversations with clinicians or hospital staff when a Coroner’s post-mortem was to be carried out. For example:

‘I never gave permission for a post-mortem, I was simply told that one would happen.’ [166] Moira Haggerty, mother of Matthew.

‘The Hospital told us that there would be a post-mortem as this was the usual practice and we were sent the results of the post-mortem. On the subject of organ retention, this was not addressed at the time.’ [167] Erica Pottage, mother of Thomas.

‘We are not surprised that a post-mortem was carried out following Jessica’s death but we do not remember anyone specifically discussing this with us and informing us that one would take place.’ [168] Josephine Feloy, mother of Jessica.

145 In some situations, parents were told, accurately and clearly, that they had no choice about whether a Coroner’s post-mortem was carried out. For example:

‘They said he had to have a [Coroner’s] post-mortem because he died in the theatre. They wanted to find out if the doctor did his job right, so they had no choice … so he [her husband] signed it.’ [169] Ellen Sheridan, mother of John.

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[165] T3 p. 75
[166] WIT 0364 0010
[167] WIT 0260 0005
[168] WIT 0311 0007
[169] T4 p. 146

> ‘The lady told me that, if I tried to stop the post-mortem, I would not be able to bury Brydie for about six weeks, and that even then, the post-mortem would still be done. We agreed, very reluctantly, but did not sign anything. No mention was made of any possibility that some or all of Brydie’s organs might be retained after the post-mortem.’[170] Jacqueline Rathbone, mother of Brydie Kinsman.

> ‘I think it was the next day, 13 May, that a male charge nurse spoke to us about a post-mortem examination. We said that we did not want there to be one, but he said that it was a legal requirement, as Corinna had died shortly after surgery. When we were told this, we agreed. We felt we had no alternative, in any event.’[171] Sharon Tarantino, mother of Corinna.

146 One of the main causes of parents’ anger and anguish was the fact that, as they saw it, they were ‘kept in the dark’ about the ‘usual practice’ of retention of Rule 9 human material after a Coroner’s post-mortem. The following gives a flavour of a common theme of parents’ evidence:

> ‘I know for a fact that if many of the families had had their consent sought and had it explained to them that the conclusion of a post-mortem and the retention of their child’s heart for research would have assisted the saving of a life they may well have agreed.’[172] Michaela Willis, mother of Daniel and chair of the BHCAG.

> ‘I think the most important thing is that we were not asked at the time. I am a reasonable person and I am quite sure we would have said yes … But I know I felt if another baby could be helped by the retention and if that was the reason, then we would have said yes, but the fact that they were kept without our knowledge and presumably we were never ever going to be informed, came as a very, very big shock.’[173] Susan Francombe, mother of Rebecca.

> ‘We were quite keen that Kate’s organs should be used for transplant purposes, and I suspect that, had we been asked, we would not have minded her organs being used for educational purposes. We did not know, however, and it came as a terrible shock to me to learn that some of her organs were retained.’[174] Lynne Lloyd, mother of Kate.

> ‘I think they should have told us, but the fact that they did not does not surprise me … I do not think that they have any right to take tissue from a baby without the parents knowing, whether their baby has died under special circumstances or not. If the parents have not got the right to know, then who has?’[175] Douglas Bwye, father of Jason.

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[170] WIT 0433 0015
[171] WIT 0223 0014–15
[172] WIT 0221 0001
[173] T68 p. 24
[174] WIT 0225 0011
[175] T6 p. 44

> ‘We were specifically asked for our consent to the retention of Naomi’s heart and we said no. Regardless of our decision the hospital retained not only Naomi’s heart but part of her lungs as well. I can appreciate the need to retain tissue specimens but can see no reason to retain entire organs for such a long period of time.’[176] Nigel Dymond, father of Naomi.

How parents were approached concerning post-mortems

147 There was evidence that the timing and location of the conversation concerning post-mortem examination are important. Compare the following:

> ‘I mean, we had literally come out of ITU and got back into this family room, I mean, a matter of minutes, five minutes at the outside, and there was this junior doctor suggesting that we should agree to a post-mortem. This had never been raised with us.’[177] Linda Burton, mother of David.

> ‘While we were at the Laboratory the doctor on duty there said that he had received a call from Bristol Children’s Hospital and they had asked him to ask me if we would consent to the removal of Aaron’s heart for research purposes. The timing of this request I thought was inappropriate. At this time I thought that Aaron had been through enough.’[178] Philip Davies, father of Aaron.

148 The difficulty in assessing how and when parents were to be approached to discuss post-mortems is most clearly illustrated by the responses of two parents who gave evidence to the Inquiry. Paul Bradley, father of Bethan, felt that such a discussion should take place well before any surgery. He said:

> ‘If they had asked us [about a post-mortem] the night before Bethan’s operation, and also after her death, I would have said – well, first of all, before the operation, I would have been affronted that they would have been seemingly dismissive, even before the operation, that she was going to die, so I would not have liked that. That is why I feel that well before the operation, when one is in a sober mind, it is far better to approach that. But then after the operation, I would have found that difficult and I would have said no, but I do consider that well before we would have been in such a mind, in such a sensible mind, to have thought, yes, it would be a good thing if, in the enforced event of death, for some good to be achieved.’[179]

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[176] WIT 0310 0014–5
[177] T5 p. 43
[178] WIT 0475 0009
[179] T53 p. 46

149 Sharon Tarantino, mother of Corinna, on the other hand, would have found such an early approach distressing as the following passage of evidence indicates:

‘*Q.* At the time of her death, as any parent would be, you were terribly upset?

A. Yes.

Q. Would that have been the right time to mention [a post-mortem examination] or would it have had to have been a bit later?

A. Before she was buried. I mean, it would have to have been quite soon after the death, but I think it is better to ask then than to come this far down the line and find out, and then you have to go through a funeral again.

Q. We heard the suggestion again from Mr Bradley this morning that it might be sensible to discuss the possibility, when difficult surgery is contemplated, some time in advance – not the night before, for obvious reasons, but some time before – that if, God forbid, the worst should happen, a post-mortem might have to be arranged and tissues might be kept. What do you think of that? Would that have upset you very much in advance, to have that sort of discussion?

A. Yes. Definitely before an operation.

Q. So your reaction is that that would not be helpful to you?

A. No, not to me personally, no.’ [180]

150 A variety of reactions were expressed by parents, on the preferred way or timing of raising the question of a post-mortem. Medical staff were left to strike the delicate balance between knowing what to discuss with parents and when to discuss these matters with understanding, when parents wish to be left alone to grieve.

Witnesses’ suggestions for the future

151 Several witnesses offered suggestions on what and how parents should expect to be told, or not told, in the event of a post-mortem. For example:

‘I think the more channels of communication you use to inform one the better the information is going to be received, understood. Somebody mentioned a video earlier, book, diagram, face-to-face contact, to reinforce one another. There is no ideal method, you need to have them all.’ [181] Jonathan Mallone, father of Josina Millers.

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[180] T53 p. 74

[181] T95 p. 203

> ‘I would expect to be told that, in the case of a Coroner’s post-mortem, where I have no say in what happens, I expect to be told that that is the case and what powers the Coroner has and that it may well be that they retain a heart or brain or every organ in the body, but to be told that that is a possibility and then, if it is going to happen, to be told that it is going to happen.’[182] Helen Rickard, mother of Samantha.

> ‘It was explained to me that he would not be able to come back quickly because of the circumstances of the death, that somebody would have to look into it, which I assumed that is what they meant, the post-mortem. So that was fine, we understood that, that things had to happen before he could come back.’[183] Douglas Bwye, father of Jason.

152 Dr Ashworth gave his professional opinion, as a pathologist, of what information fellow clinicians ought to impart to parents prior to a hospital post-mortem:

> ‘I would expect the clinician to explain the reasons for the requesting of the post-mortem in the first place; the benefits that it might confer; and to give in very general terms what would happen, in other words, organs would be removed, the cavities would be inspected and the body would be sewn up afterwards in a proper manner.’[184]

153 Professor Berry’s view was:

> ‘Hospital post-mortem examinations, I think when parents are asked for consent, it should be specified if we wish to retain whole organs … we should be more specific about the purpose for which they are going to be retained … when parents give consent to autopsy, the question of retention of whole organs is specifically addressed with them … They also need to be told about the possible ways, the choices they have as to what should happen to the tissue at the end of the period of retention they elect for.’[185]

154 Professor MacSween, again referring to hospital post-mortems, told the Inquiry that it was:

> ‘important that in future consent for autopsy forms should incorporate a specific and separate block for completion where there is an intention to retain an organ. The purpose for that retention should also be made clear to the relatives … The person talking to the relatives should make clear – and this has always been taught – that bodies are handled reverently.’[186]

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[182] T52 p. 164
[183] T6 p. 41–2
[184] T54 p. 26
[185] T55 p. 151
[186] WIT 0054 0030

155 As Professor Green, addressing the issue of retaining human material for the purpose of research, said:

> 'The profession is anticipating that outside scrutiny by a neutral body like an ethical committee is now essential, whereas at one time everybody said…the clinicians must go to the REC [Research Ethics Committee], pathologists do not need to. I think we are anticipating public concern and responding to it before that concern is generally raised.' [187]

Did practice at UBHT differ from practice elsewhere?

156 According to Mr Ross, the practice at UBHT was no different from other Trusts in the NHS:

> 'I know that large quantities, large numbers of organs and other tissues have been retained over the years and the degree of knowledge that parents and relatives have had about that, I think, has been partial, to say the least. So I do not think the Bristol practice was different… rightly or wrongly, but I do not think the Bristol practice was different from practice elsewhere.' [188]

Recent information about the practice of other Trusts and, previously, health authorities, bears out Mr Ross's evidence.[189]

157 Professor Berry tried several times to change the practice at UBHT. In writing, as he did, to the clinicians advising that hearts would no longer be retained after Coroners' post-mortems unless there was a note from the doctor in the medical records stating that the issue had been discussed with the parents and that consent had been obtained,[190] he was going beyond what was normally considered necessary by the medical profession generally and pathologists in particular at that time.

158 As Professor Berry said:

> 'In about 1990–1, I became concerned that legal justification was insufficient for the retention of some tissues. These concerns arose from speaking to parents, and from occasional cases widely publicised in the press. At about this time I wrote a departmental code of practice for the retention of tissue at post-mortem … also at this time I raised this issue with our paediatric cardiologists and cardiac surgeons, and reminded them that hearts could only be retained for diagnosis under the Coroner's Rules, and that I thought they should be telling parents that hearts were generally kept.' [191]

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[187] T42 p. 88
[188] T37 p. 41
[189] See paras 17, 22–24.
[190] UBHT 0308 0018
[191] UBHT 0308 0219

Changes to the practice at UBHT

159 Mr Ross, in his evidence to the Inquiry, stated that several changes to practice at UBHT were planned. These may be summarised thus:

a) professional development and training sessions for medical staff who request consent;

b) development of a Trust-wide code of practice;

c) changing the BRI hospital post-mortem consent form to that used at the BRHSC/St Michaels;

d) producing an information leaflet for relatives; and

e) contacting the coroner with a view to developing a leaflet on Coroners' post-mortems.

160 Refering to recent practice, Professor Peter Fleming, Head of Division of Child Health, department of clinical medicine, University of Bristol, told the inquiry that:

'For the past four years, routine practice has been to retain samples of tissue, rather than whole organs, unless specific consent has been sought and given by the parents, and the need for retention of a whole organ explained to them.'[192]

161 The UBHT has encouraged a more pro-active relationship with the Coroner so that:

'if the relatives do have particular objections or particular worries, … the Coroner has it within his or her power to take those on board and to adjust or alter their decision about what instructions they give to the pathologist about perhaps even the undertaking of a post-mortem, but even more particularly about whether organ tissue should be retained or not.'[193]

Professor Berry said that the practice now is:

'to ask the Coroner's officer or the general practitioner or somebody to tell parents if we have retained a whole organ, so we can follow their wishes as to what should happen.'[194]

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[192] WIT 0505 0004
[193] T37 p. 10–11
[194] T55 p. 153

And in relation to hospital post-mortems specific requests about the examination and how it is carried out and what parts of the body are examined:

‘are becoming increasingly common within the context of hospital consent post-mortems, and we always accede to those requests, but also explaining to parents that we may not be able to answer some of their questions later if we are not able to carry out a complete examination.’[195]

162 On 25 February 1999, Ms Lindsey Scott, UBHT director of nursing, issued ‘Staff guidance on post mortem examinations’. This was intended to help junior medical and nursing staff to discuss post-mortem examination with families. (The reference to junior staff has already been commented upon.) It detailed what information should be given to relatives. However, it did not discuss the retention of human material except to say as its final two points:

- if organs or tissues are retained, this is usually for a short period of time to enable further tests to be carried out. Tissue or organs may be kept for a more extended period of time for teaching purposes.
- retained organs or tissue are disposed of by incineration, according to national guidelines.’[196]

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[195] T55 p. 157
[196] WIT 0128 0034–5