

Stolen Hearts

FICTION AND THE 1990S' PATHOLOGY SCANDAL

Tim Marshall

Revised Edition



Critical, Cultural and Communications Press
Nottingham
2009

Stolen Hearts: Fiction and the 1990s' Pathology Scandal
by Tim Marshall

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First published in Great Britain by Critical, Cultural and Communications Press, 2007. This revised edition first published in 2009.

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Cover design by Andrew Dawson, from an idea by Ruth Richardson.

ISBN 978 1 905510 24 5 (UK)
978 1 60271 011 5 (USA)

Second edition.

Printed by Tipografia Guerra, Viseu, Portugal.

FOR RUTH RICHARDSON

We must learn the lessons of Bristol. Even today it is still not possible to say, categorically, that events similar to those which happened in Bristol could not happen again in the UK; indeed, are not happening at this moment.

That said, we must not lose a sense of proportion. Every day the NHS provides a service to hundreds of thousands of patients, with which patients are satisfied and of which healthcare professionals can justifiably be proud.

Learning from Bristol (2001)

(Report of the Public Inquiry into Children's Heart Surgery at Bristol Royal Infirmary 1984-1995, chaired by Professor Ian Kennedy, QC.)

The bodies of the newly dead are not debris or remnant, nor are they entirely icon or essence. They are, rather, changelings, incubates, hatchlings of a new reality that bear our names and dates, our image and likenesses, as surely in the eyes and ears of our children and grandchildren as did word of our birth in the ears of our parents and their parents. It is wise to treat such new things tenderly, carefully, with honour.

Thomas Lynch, *The Undertaking: Life Studies from the Dismal Trade* (1998)

To turn a blind eye to the incompetence of other doctors is a denial of the Hippocratic oath; its consequences are harm to the sick, and death to some, among them babies, as has been seen in recent cases. Every doctor I have spoken to believes that any criticism of a professional colleague could get them into disciplinary trouble. It is not what the GMC rulebook says but it appears to be what many doctors fear. Whistle-blowers are frequently pilloried for doing their ethical and professional duty in exposing malpractice and incompetence. If the profession does not voluntarily agree to address this issue urgently, the government should consider taking regulation away and giving it to an independent body. Such cover-up is not only immoral and unethical, it may well be criminal conduct.

John Batt, *Stolen Innocence: The Story of Sally Clark* (2004)

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ACKNOWLEDGEMENTS

I want to thank several people for their support during my work on this book: Vic Sage, Cathie Carmichael, Michael Robinson, Joad Raymond, Robert Clark, Mark Currie, Lyndsey Stonebridge, Jacqueline Fear-Segal, Kate Campbell, Jean Boase-Beier, Dawn Manners and Joyce Dunbar. I owe thanks to Macdonald Daly, my editor, who commissioned a reader's report that helped improve my case; to the anonymous author of that report, my thanks. I thank Patricia Hollis, Colin Clarke and Roger Sales for their encouragement to me early in my academic career. The missing person is Roger Fowler, whose death while I was working on the book lost me a friend and mentor. The historical research published by Ruth Richardson, to whom the book is dedicated, has begotten other books, including this and an earlier effort of mine; it is an inspiration and in the academic community and elsewhere I am not alone in thinking this. To my son Thomas, and Alison, with my love, I owe more than it is possible to put into words.

I thank Denise Green for permission to use reproductions of the artwork she produced as a result of her parental involvement in the 1990s' organs scandal. The artefacts by her that appear in my text were first displayed in May 2003 in the 'Never Again' exhibition at the Bolton Museum, Art Gallery and Aquarium. 'Never Again' was a memorial exhibition on behalf of the children involved in the organ retention scandal throughout the UK.

CHRONOLOGY

This chronology gives the main events of the disclosures made in the 1990s about Bristol Royal Infirmary and Alder Hey Children's Hospital in Liverpool. It includes the publication dates of the fiction and life-writing examined in this book and other relevant events, and is adapted from the timetable given in The Daily Telegraph, 31 January 2001.

1824 In his article 'The Use of the Dead to the Living' in *The Westminster Review*, Dr Thomas Southwood Smith recommended that the bodies of those dying unclaimed in workhouses and hospitals should pass legally to surgeons for anatomical dissection. He argued on the grounds of an urgent need to improve medical knowledge of the human body. He wanted to halt the widespread practice of newly buried bodies being taken from graves and given, in exchange for payment, to anatomists. He was also fearful that people might be murdered and their bodies passed to the medical profession for money.

1828-9 Southwood Smith's worst fears were confirmed when it was discovered in Edinburgh that two murderers, Burke and Hare, had passed the bodies of sixteen of their murder victims to Dr Robert Knox, receiving payment in return. Every member of Parliament subsequently received a copy of 'The Use of the Dead to the Living' for urgent consideration. Burke was convicted at the men's trial when Hare turned King's Evidence against his confederate, escaping free in the process. Burke was executed and publicly dissected.

1831 Copycat killings took place in London for the benefit of surgeons. The two men involved, Williams and Bishop, acquired the nickname the 'London Burkers', in reference to Burke's part in the Edinburgh scandal. The London killings intensified the need to pass legislation that would bring to an end the very damaging association between the medical profession and murder scandal.

1832 The utilitarian philosopher Jeremy Bentham died; his body, on his request, was dissected in a London anatomy school in front of a select, invited audience of his associates. The 1832 Anatomy Act was passed, permitting the unclaimed bodies of people dying in workhouses and hospitals to be dissected. The Act repealed previous 1752 legislation that had made dissection the punishment for murder. Bentham's dissection was performed by Southwood Smith. The Anatomy Act represented the acceptance of his call in 1824 for dead poor people to be requisitioned for dissection. In the meantime, however, Southwood Smith had had a change of mind, and moments before commencing Bentham's dissection, made a speech advocating the need to encourage people to donate their bodies for dissection after death. He did not regard it as fair that dissection, a fate previously reserved for murderers, should henceforth

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be the fate of society's poorest people. What had to be faced, he argued, was society's prejudice against dissection and the way to do this was to encourage body donation. Southwood Smith's appeal notwithstanding, his original recommendation passed into law. Not much notice was taken of this fact because the nation's attention was caught by the drama of the passing of the First Reform Bill.

*

1983 *Waterland* by Graham Swift, close to the moment of Dr Janardan Dhasmana's sabbatical at Great Ormond Street, London, where he observed the 'arterial switch' heart operation on babies; *Autobiography* by Harriet Martineau, originally published in 1877, republished.

1987 *Lifting the Latch* by Sheila Stewart.

1991 *The Kindness of Women* by J.G. Ballard.

1992 *Poor Things* by Alasdair Gray.

1993 *The Waters of Thirst* by Adam Mars-Jones.

1995 On 6 April the BBC breaks the story of disastrous paediatric heart surgery at Bristol Royal Infirmary: Helen Rickard discovers her baby's heart was retained there after unsuccessful surgery.

1996 *Liza's England* by Pat Barker.

1997 *Ingenious Pain* by Andrew Miller; *Not Entitled* by Frank Kermode.

1998 *The Rings of Saturn* by W.G. Sebald; *The Giant O'Brien* by Hilary Mantel; the artist Anthony-Noel Kelly is arrested for stealing body parts from The Royal College of Surgeons and is convicted of theft; Rodney Ledward, many of whose gynaecology patients nearly died after his incompetent surgery, struck off by the GMC (his patients later received compensation).

- **May** The General Medical Council convenes to look at fifty-three operations on babies at Bristol RI, twenty-nine of whom were left brain-damaged.
- **June** The General Medical Council strikes off James Wisheart; it bans Janardan Dhasmana from operating on children for three years; it strikes off John Roylance, Chief Executive of the United Bristol Health Care Trust, ruling that he should have ordered a stop to the disastrous surgery.

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1999 *The Dress Lodger* by Sheri Holman; Bristol Royal Infirmary admits it retained the hearts of more than one hundred and seventy dead children after operations in the twelve years up to 1995; the British Medical Association votes in favour of ‘presumed consent’ legislation for organs-for-transplant procurement.

- **7 September** The Inquiry into the Bristol heart scandal is told by Professor Robert Anderson, the President-Elect of the British Paediatric Cardiac Association, that Alder Hey Children’s Hospital has ‘probably the biggest and best collection of hearts’ in the UK.
- **6 October** It emerges that other organs have been stockpiled in a University of Liverpool laboratory. Hospital bosses claim that many were removed by Professor Dick Van Velzen. The then Health Secretary, Frank Dobson, orders a country-wide investigation into organ retention by the Chief Medical Officer.
- **14 October** Joan Wheeler, who lost her baby son Karl twenty-seven years before, sets up a support group for families affected. About fifty parents meet in November.
- **3 December** The Liverpool Coroner Andre Rebello agrees to open an inquest into the death of an eighteen-week-old North Wales girl whose organs were allegedly removed without her parents’ consent. He says the family of Kayleigh Valentine has been ‘brutalised by a system’. Later that day, the new Health Minister, Alan Milburn, announces an Independent Inquiry into the organ issue at Alder Hey as the support group Pity II (Parents Interring Their Young Twice) hold their second meeting in the glare of the country’s media. Rebello describes the organ scandal as ‘absolutely outrageous’.
- **21 December** Alder Hey admits in an internal report that previous practices were ‘unacceptable’ and calls on the Coroner and bereaved families for help.

2000 *Bad Blood* by Lorna Sage; *Martha Peake* by Patrick McGrath; *The House of Sight and Shadow* by Nicholas Griffin; the Royal College of Nursing votes against the adoption of ‘presumed consent’ legislation for organ procurement; Margaret Atwood gives the Empson Lectures at the University of Cambridge; the ‘Spectacular Bodies’ exhibition takes place at the Hayward Gallery, London (October).

- **15 January** Alder Hey defends its decision to take microscopic samples before returning retained organs to parents, but families condemn its response as ‘insensitive’.
- **7 February** The Independent Inquiry, chaired by Michael Redfern QC, starts.
- **16 March** Alder Hey admits the organs of Stephen White have been accidentally disposed of just days before his parents were due to hold

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a second funeral. The Health Secretary demands the resignation of the Trust Chairman, Frank Taylor.

- **23 March** The Chief Medical Officer, Professor Liam Donaldson, publishes guidelines on dealing with bereaved parents and post-mortem operations.
- **18 April** Alder Hey sets up a special board to deal with the scandal and invites parents' representatives to participate.
- **12 May** Alder Hey says the organs of Simone Robinson, who died aged three, were mistakenly 'disposed of'. Her parents, who were initially told the hospital did not have their daughter's organs, are appalled.
- **15 August** Parents talk of being 'battered by new disasters' when a store of brain tissue is discovered. A further sixty-two families, previously given the all clear, are told their children's organs have been removed.
- **21 September** One of Alder Hey's two heart surgeons, Roger Franks, says he has ceased operating on children with cardiac problems due to increasing publicity about his work.
- **5 October** The post-operative death rate of the surgeon Roger Franks for the complex 'switch' operation is revealed to be almost three times the national average.
- **30 October** The British Medical Association issues guidelines to doctors on how to obtain consent for the removal of organs from dead patients.
- **13 November** There is a fresh twist to the organs controversy after it emerges that up to four hundred fetuses were stored in a University of Liverpool laboratory without parental permission.
- **28 November** Parents are dismayed when Alder Hey sends out letters detailing how to carry out 'do-it-yourself-burials' of their children's body parts returned by the hospital.

2001 *Learning from Bristol*, the Report from the Bristol RI Inquiry, chaired by Professor Ian Kennedy, is published (on 18 July).

- **11 January** It emerges that the organs of three thousand five hundred children have been removed without parental knowledge or consent.
- **26 January** Alder Hey admits that thymus glands removed from living children were passed to a French pharmaceutical firm in return for cash.
- **29 January** On the eve of the publication of the Redfern Report, Health Minister Milburn pledges to ensure that in future informed parental consent is secured before organs are removed from children.
- **30 January** The Redfern Inquiry Report on events at Alder Hey is

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published; the Donaldson Report into general organ retention in the UK published.

2002 *The Body* by Hanif Kureishi.

2003 *Things You Should Know* by A.M. Homes; *Bodies* by Jed Mercurio; ‘Body Art’ by A. S. Byatt.

- **11 May** It is disclosed that in the second part of the twentieth century thousands of brains were taken after death from mentally ill people without their relatives’ permission.

2004 Denise Shorter is awarded damages (on 26 March) of £2,750 for the removal without her consent of her stillborn baby’s brain. This ruling opens the door to thousands of potential compensation claimants.

2005 *Never Let Me Go* by Kazuo Ishiguro; *Untold Stories* by Alan Bennett.

INTRODUCTION

BRISTOL ROYAL INFIRMARY AND THE 1990S' PATHOLOGY SCANDAL

'The heart is the beginning of life...it is the household divinity.'
William Harvey, *The Motion of the Heart and Blood in Animals* (1628),
quoted in Sheri Holman, *The Dress Lodger* (1999).

In his 1991 autobiography *The Kindness of Women* the novelist J.G. Ballard recalled his early ambition to be a doctor. Ballard in 1950 was a freshman at Addenbrooke's Hospital in Cambridge and attended the opening address by the Head of Anatomy, Professor Harris:

Welcoming us to his profession, Harris took us through a brief history of medicine from the days of Vesalius and Galen, stressing its craft origins and low social standing – only in the present century, in response to the emotional needs of his patients, had the physician's status risen to that of the older professions, and Harris warned us that in our own lifetimes its status might fall.¹

The Kindness of Women went into paperback in 1994 and after April 1995 those informed of events had reason to be brought up short by Ballard's sentence. A story that broke on the BBC on the 6th of April 1995 invested Harris's words with a prescience visible now as uncanny. 'Harris warned us that in our own lifetimes [the status of the profession] might fall': the doctors of Ballard's student generation, working towards retirement in the mid-1990s, did indeed see their profession fall in the embroilment of a scandal that led to the largest medical inquiry ever convened in Britain, headed by Professor Ian Kennedy QC, which reported in July 2001.

The events Kennedy reported on concerned the paediatric cardiac unit at the Royal Bristol Infirmary in England and were some years in the making. In 1986 Janardan Dhasmana, an Indian-born doctor, became a consultant at the hospital. In the early 1980s, on a sabbatical leave at the Great Ormond Street Hospital for Children in London, he had observed the 'arterial switch' operation performed on babies' hearts. This operation, a technically challenging one, corrects a heart defect by swapping the aorta and pulmonary arteries. Dhasmana and a senior colleague of his, James Wisheart, the Medical Director, were soon to introduce the operation at Bristol, mindful of the need to keep a good reputation and attract funding for their prestigious unit. The result was the death of 35 babies and many others left brain-damaged. When

¹ Ballard, 1994, 78.

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the story broke it appeared that Wisheart and his team between 1988 and 1995 had risked babies' lives by continuing with heart operations even though the death rates were twice the national average.

The arterial switch operation accounted for many of the deaths, but hole-in-the-heart surgery also failed. One of the latter fatalities was eleven-month-old Samantha Rickard, and because Samantha died in the operating theatre a post-mortem was performed. In a 2003 interview, Samantha's mother Helen Rickard recalled how before the operation Wisheart 'reassured' her and her partner Andy of 'the Bristol RI's excellence in carrying out this type of children's heart surgery'.² In 1994 Andy Rickard, unable to cope with his daughter's death, committed suicide. The subsequent news about Bristol RI led Andy's widow to uncover a fact that changed her life:

My blood just ran cold. Samantha's surgeon was at the centre of the allegations of malpractice. I immediately demanded a copy of her medical records from the hospital. I found myself staring at a letter from the pathologist who performed the post-mortem to her surgeon, stating that he had retained the heart. I was horrified and felt bitterly angry that this had happened without my knowledge. Organ retention without consent was routine practice and I didn't know who my daughter's heart belonged to – me or the hospital's pathology department.

The hospital promptly returned her heart, five years after she had died, but it felt like she had died all over again. I wasn't alone. Thousands of other families were affected and as the scandal snowballed in the media, I gave up work to find out exactly what had happened. The heart scandal monopolised my life.³

This finding resembles the start-of-story situation common in Gothic fiction where a document or bundle of papers comes to hand unexpectedly and sets into train a sequence of events. Rickard at the time thought that hers was a one-off case. But as she became involved with the Bristol Children's Heart Action group, it dawned on her and others that hearts might have been removed at the hospital from other dead children. These suspicions were confirmed in February 1999 when Bristol RI disclosed that it had retained the hearts of more than a hundred and seventy children after failed operations in the twelve years up to 1995, including those of fatalities of the arterial switch operation. And in September of that year Professor Robert Anderson, President-Elect of the British Paediatric Cardiac Association, revealed to the Kennedy Inquiry that some eleven thousand hearts were stored nationwide.

² Rickard, 2003.

³ *Ibid.*

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For years the public heard no word of the disastrous surgery at the United Bristol Healthcare Trust (UBHT). To insiders at the hospital, however, the children's heart surgery unit was known as 'the killing fields'. In their account of the Bristol RI disaster, Dr Phil Hammond and Michael Mosley observe that 'numerous [cardiac surgeons, cardiologists and anaesthetists] knew about Bristol... but none saw it as their responsibility to go to the General Medical Council (GMC).'⁴ There is no clearer example of 'a culture of unwillingness'⁵ to report failing doctors. Dr Stephen Bolsin, the anaesthetist who blew the whistle on the scandal, before doing so 'spent six years going through all the right channels.'⁶ Were it not for Bolsin's persistence – and his eventual decision to speak out in *Private Eye* with Phil Hammond as his mouthpiece – the story may never have broken. The title of Kennedy's report, *Learning from Bristol*, indicated that the events investigated held meanings for the NHS as a whole.

One, if not the, fundamental failing of the doctors involved was a serious abuse of the relationship between doctor and patient – the key relationship that Harris back in 1950 spoke of as investing the profession with both status and potential vulnerability. The reassurance Wisheart gave to Helen and Andy Rickard was typical of the way many parents were not openly appraised beforehand of the risks involved. One case, that of Joshua Loveday, is particularly revealing because it shows that parents continued to be unaware of the risks even as serious doubts were gathering in the minds of those close to the work. Joshua was to die in the operating theatre:

One of the final cases was a little boy called Joshua. On the eve of Joshua's operation, nine clinicians got together to discuss if it should go ahead in view of the vehement opposition expressed by Dr Bolsin, the doubts of Professor Angelini, an adult cardiac surgeon, and the unease of Dr Doyle from the DOH [Department of Health]. At no stage did they consider inviting Joshua's parents into the meeting or telling them it had taken place. At 11 p.m., Mr Dhasmana gained consent for the operation. At 8 a.m. the next morning, he was carrying it out.⁷

⁴ Hammond and Mosley, 1999, 60.

⁵ The expression is from a much later report in 2004 that drew attention to the persistence of this problem. Dame Janet Smith, Chairman of the Inquiry into the doings of the serial murderer Dr Harold Shipman, wrote that 'the culture of unwillingness to report doctors is still there. It must go.' Harold Shipman received fifteen life sentences in January 2000; his case was the most extreme instance of several 'untrustworthy doctor' stories in the media in the post-Bristol RI period.

⁶ Hammond and Mosley, 1999, 55. Close to the story's disclosure, Bolsin moved to Australia to work. Speaking to *The Independent* on 19 July 2001, he said: 'I decided I didn't have a future at Bristol, with threats to my employment and ill feeling.'

⁷ *Ibid.*, 1999, 60.

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At this meeting those conscious of the arguments not to proceed were unaware that Wisheart and Dr John Roylance, the UBHT Chief Executive, were minded at the time to commission an independent review of the Paediatric Cardiac Service (PCS). Kennedy in his report found it 'a serious error of judgement' that Wisheart failed to tell the meeting of this fact. 'When the question of whether to proceed or not was in the balance, we have little doubt that if the meeting had learned of the proposed review, the clinicians would have decided not to proceed with surgery but to make other arrangements'.⁸ In this loop-within-a-loop situation those most excluded were those who consented to the operation, Joshua's parents.

In *Learning from Bristol* Kennedy said 'it is in the formative years of undergraduate education that attitudes are forged and skills imparted which shape the quality of engagement with patients for years to come'.⁹ For this reason it seems appropriate to introduce the Bristol scandal within the frame of Ballard's memory of his first day as a medical student; and Ballard's voice as a medical apprentice will be heard again in this book. The passage in his autobiography that catches the eye because of Bristol describes an initiation ritual, the formal welcome to the profession, the start of a lifetime of work. The predictive force of Harris's warning – that 'in our lifetimes [the profession's] status might fall' – manifestly applies to Bristol RI in 1995. But rather than suppose Harris had gazed into a crystal ball, it is better, I think, to see in his remark an early sensitivity to difficulties that arguably are intrinsic to surgery and which became worryingly apparent in the 1990s when the Bristol story broke. The difficulties concern the element of risk involved in innovative surgery and the need for truth-telling in the asymmetrical relationship between doctor and patient.

It is worth taking a close look at the technique Dhasmana observed at Great Ormond Street Hospital. The *British Medical Journal* in the Spring of 2000 published a report detailing the experience of doctors working in the paediatric surgery unit at that London hospital in the period 1978 to 1998. The report was for a specialist audience and is technical,¹⁰ but a summary of its findings is given by the American surgeon Atul Gawande in his book *Complications* (2003):

The doctors described their results in operating on three hundred and twenty-five consecutive babies with a severe heart defect, known as transposition of the great arteries, over a period (from 1978 to 1998) when its surgeons changed from doing one operation for the condition to another. Such children are born with their heart's outflow vessels transposed: the aorta emerges from the right side of the heart instead of the left and the artery to the lungs emerges from the left instead of the right. As a result,

⁸ *Learning from Bristol*, 2001, 169, para. 36.

⁹ *Ibid.*, 325, para. 10.

¹⁰ See *British Medical Journal*, 320 (2000), 1168-73.

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blood coming in is pumped right back out to the body instead of first to the lungs, where it can be oxygenated. This is unsurvivable. The babies died blue, fatigued, never knowing what it was to get enough breath. For years, switching the vessels to their proper positions wasn't technically feasible. Instead, surgeons did something known as the Senning procedure: they created a passage inside the heart to let blood from the lungs cross backward to the right heart. The Senning procedure allowed children to live into adulthood. The weaker right heart, however, cannot sustain the body's entire blood flow as long as the left. Eventually, these patients' hearts failed, and although most made it to adulthood, few lived to old age. Then, by the 1980s, a series of technological advancements made it possible to do a switch operation safely. It rapidly became the favoured procedure. In 1986, the Great Ormond Street surgeons made the change-over, and their report shows that it was unquestionably a change for the better. The annual death rate after a successful switch procedure was less than a quarter that after the Senning, resulting in a life expectancy of sixty-three years instead of forty-seven.¹¹

In William Harvey's words, the heart is the 'household divinity', the intersection of the human with the divine. The switching of arteries restores to working order an awesome entity – there surely is no better illustration of medical empowerment. Gawande goes on to comment forthrightly on what has been called 'the most controversial concept in surgery today – the learning curve':¹²

But the price of learning to do it [the arterial switch operation] was appalling. In their first seventy switch operations, the doctors had a 25 percent surgical death rate, compared with just 6 percent with the Senning procedure. (Eighteen babies died, more than twice the number of the entire Senning era.) Only with time did they master it: in their next hundred switch operations, just five babies died.

As patients, we want both expertise and progress. What nobody wants to face is that these are contradictory desires. In the words of one British public report, 'There should be no learning curve as far as patient safety is concerned'. But that is entirely wishful thinking.¹³

Reviewing the findings of some studies in learning curves, Gawande spells out their application to medicine: '...no matter how accomplished, surgeons trying something new got worse before they got better'.¹⁴

¹¹ Gawande, 2003, 27-28.

¹² Horton, 2003, 434.

¹³ Gawande, 2003, 28.

¹⁴ *Ibid.*, 30.

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To Gawande, this unavoidable state of affairs argues the need to forge a new covenant between doctors and patients, without which there is no future for surgery. The learning curve is a reality and doctors have to be honest with patients about expectations of perfection that cannot be fulfilled. Risk assessment must be shared if informed consent is to be freely given. Healthcare at best should be co-produced: patients and their families must be regarded as partners by the experts, for the sake of better care and better education. The watchwords should be trust, openness and accountability; the door would then be open to manage claims of negligence in appropriate ways. This is a noble vision, but one that even the best-intentioned will not find easy to deliver. Richard Horton, the editor of *The Lancet*, writing in 2003, welcomed Gawande's 'call to arms' for honest dealing but was uneasy about its possible consequences:

...the recent history of medicine's relations with our wider culture suggests that transparency, shone through the lens of an aggressive media, breeds mistrust, not confidence. And with mistrust comes profound anxiety. The dangers of litigation and professional humiliation for the surgeon who takes risks will simply become too great. And so we will arrive at a moment that could truly be called the end of surgery.¹⁵

The events at Bristol matter, and need to be reflected upon, because they gave hostages to fortune in this negative direction. It is only conjecture, but perhaps when he warned Ballard's student generation all those years ago Harris had in his sights the intrinsic limits of surgery.

The Bristol story, as told in Kennedy's report, can fairly be described as a nightmare negation of covenant. Kennedy blamed incompetence, arrogance and secrecy for the death of the babies and its cover-up. The tragedy was the result of a 'club culture' of doctors more concerned to protect its own members than the health of those placed in its care. And Kennedy, following the findings of the General Medical Council in 1998, gave no ground to the doctors' attempt to rationalise their conduct by claiming they were on a learning curve. Not so, countered the report: the doctors failed as scientists to admit, or even welcome, any evidence that ran counter to their beliefs. Furthermore, Dhasmana on occasions told parents they had an eighty per cent chance of success, but the reality was different. Of thirteen babies operated on, nine died and one was left brain-damaged. Dhasmana in the meantime persisted in his belief that this was all part of his learning curve, a defence he later presented to Kennedy's Inquiry. It is true that he attended courses in an attempt to improve his skills, but Kennedy judged that his and his superiors' appeal to a learning curve was an excuse and indeed an abuse of the empiricism that ought to prevail when new techniques and procedures are

¹⁵ Horton, 2003, 441.

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introduced. Furthermore, no system was in place to monitor the hospital's performance against other institutions. Collation of data from the unit, when compared with similar operations elsewhere, would have raised concerns and prompted the authorities to investigate. In the event, the truism that 'doctor knows best', and the parents' continuing ignorance of malpractice, allowed the denial to persist.

The burden of the Bristol story, as Kennedy put it, was that 'too many children died'. Some, on the other hand, did not. My collection of press cuttings includes a letter from a parent stating, with profound thanks, that James Wisheart twice saved his young son on the operating table. The letter occupies about an inch and a half of column space, while Kennedy's report is voluminous. It puts me in mind of the words the playwright Samuel Beckett used when he was once asked to explain the meaning of his play *Waiting for Godot*. Beckett obliged, not very helpfully, by quoting the words of St Augustine on the thieves sent for crucifixion beside Christ: 'Do not despair, one of the thieves was saved. Do not presume, one of the thieves was damned'.¹⁶ True enough, but the point about Bristol RI was that, relative to other hospitals, far more were damned than saved.

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In September 1999, Kennedy's Inquiry was told by Professor Anderson that Alder Hey Children's Hospital in Liverpool held the largest collection of hearts retained on an unpermissioned basis. The following month news emerged that other organs from some 800 children had also been stockpiled at Alder Hey. The focus fell on the activities of Professor Dick Van Velzen, the head of the pathology department at the hospital. Van Velzen, it was revealed, had accumulated a huge collection of children's organs taken during post-mortem examinations and had done so using gross dishonesty and deception in relation to many of the parents involved. After this disclosure Frank Dobson, the Health Secretary, ordered a nationwide investigation into organ retention. The subsequent report by the Chief Medical Officer (CMO), Professor Liam Donaldson, showed that practice at Alder Hey was not unique. Many hospitals in the UK, going back as far as fifty years, had routinely retained all manner of organs, from adults as well as children, on an unconsented basis – though some, since the Bristol RI and Alder Hey news, had moved to introduce informed consent procedures. The estimate was that some one hundred and five thousand body parts were stored in UK hospitals. Donaldson affirmed that, as the law stood, it was entirely legal for hospitals to remove organs from bodies without the explicit knowledge of relatives. Hospitals needed only to ensure that relatives 'do not object' to a post-mortem, which can include the removal of 'tissue' for diagnosis, research or education. But doctors were not

¹⁶ Quoted in Esslin, 1968, 52.

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required to get written consent, only verbal, and Donaldson acknowledged that most parents were unlikely to know that the word 'tissue' legally meant entire organs and organ systems.

The law in this way supported an assumption in medical culture, criticised by Donaldson as 'paternalistic', that the research value of the organs outweighed any obligation to obtain them through genuinely open means. In a BBC interview on the 4 December 1999 Donaldson admitted that many parents had not understood the 'full implications' when giving consent to a post-mortem examination.¹⁷ After Alder Hey, hospitals nationwide had to admit that subterfuge and euphemism ('tissue') had been used on a routine basis, and the belated way the parents learned of the deception gave an appearance of theft on a grand scale. Donaldson's report lent support to this perception when he said that many of the organs had been taken illegally. 'Something went seriously wrong in some institutions in the way the health service and the medical profession sought to secure...advances in medical science and standards of care. Despite the fact that there is legislation governing the conduct of post-mortems and the retention of tissue and organs there appears to have been little understanding or application of the law'.¹⁸ Of the one hundred and five thousand total, some sixteen thousand organs were taken between 1970 and 1999 after coroners' post-mortem examinations – which accounted for ninety per cent of all post-mortems – despite rules stipulating that organs could only be removed for diagnosis of the cause of death and had to be replaced before burial (unless specific consent was sought). Donaldson pointed to cases where 'relatives were lied to' or misinformed: 'some parents were explicitly told that organs had been returned to the body before burial when this was not true'.¹⁹ He noted that ten per cent of post-mortems were carried out by hospitals with no coroner, and that these were far more loosely regulated. In many cases, he said, the scale of the retention was 'disproportionate and unnecessary'.²⁰ He rejected as 'inadequate and unnecessary' the profession's defence that it had kept to the law by getting relatives to sign consent forms: '...in some places there is clear evidence that custom and practice has departed from the legal framework'.²¹ Summing up, Donaldson called for the 1961 Human Tissue Act to be amended 'to enshrine the concept of informed consent'.²²

¹⁷ Reported in *The Observer*, 5 December 1999.

¹⁸ Opinions are divided on the legality question. Jeremy Laurance, the medical correspondent for *The Independent*, referred on 31 January 2001 to hospitals 'taking and keeping organs for decades...with scant regard for the law'. On the other hand Raymond Tallis maintains that 'in fact no laws were broken' (Tallis, 2005, 317). My understanding of the legal position, given in chapter eight, is from Salter, 2004, 125.

¹⁹ Donaldson, quoted in *The Independent*, 31 January 2001.

²⁰ *Ibid.*

²¹ *Ibid.*

²² *Ibid.*

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As with the Bristol RI events, the shocked public reaction to Alder Hey led to the setting up of a formal inquiry, chaired by Michael Redfern QC. In the period leading to January 2001, when Redfern reported, the public learned of the efforts many parents made to claim back retained organs. The piecemeal manner in which some hospitals returned the organs reflected an understandable lack of preparedness for the crisis, but bad record-keeping was also a factor. It meant that some parents had to exhume and re-bury their children more than once. Like Donaldson, Redfern identified a policy of paternalism that denied to parents – in their and society's supposed best interest – the opportunity to object to organ retention. He found that inadequate management and record-keeping systems had allowed the maverick Van Velzen to accumulate his collection without control or scrutiny. Van Velzen himself, Redfern said, was guilty of:

Order[ing] the unethical and illegal retention of every organ in every case for the overriding purpose of research... ignoring written consents to limited post-mortem examination... lying to parents about his post-mortem methods and findings...[and] causing an unnecessary excessive, illegal and unethical build up of organs following post-mortem examination, ostensibly for research but with no likelihood that the bulk of the organs stored in containers would ever be used for research.²³

Other offences included lying to doctors and hospital managers, and falsifying statistics and reports and encouraging other staff to do the same. Redfern concluded that this behaviour over seven years at Alder Hey made Van Velzen unfit to practice anywhere in the world. He also criticised the hospital for failing to supervise and monitor Van Velzen's activities, a process that would have revealed the organ retention; and he found that the hospital failed to communicate properly with parents after the organ hoard came to light.

Some of the parents directly involved found Redfern's report insufficiently penetrating. 'We are very disappointed...' said Geoff and Liza Harris, who lost their day-old son James in 1990, that 'the report did not look at all the evidence and it did not cover a wide enough time-frame. There is not enough information for people whose children died after Van Velzen left'.²⁴ Others thought Redfern concentrated overmuch on Van Velzen and placed insufficient emphasis on the culpability of others. May Allen, whose daughter

²³ Redfern, 2001, para. 4. Even Raymond Tallis, otherwise a staunch defender of the medical profession in relation to the pathology episode, concedes that Van Velzen's behaviour was 'utterly disgraceful'; see Tallis, 2004, 189. Himself an experienced doctor, Tallis's is the best apologia I've read of organ retention procedure in the long days before the Liverpool disclosures, but it relies on an eloquent vanguard defence of the 'doctor knows best' premise.

²⁴ 'Parents demand belated apology', *The Guardian*, 31 January 2001.

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Kathleen died at Alder Hey in 1991, said:

the government has simply used Van Velzen as a scapegoat, but that man was not a law unto himself... The government themselves are to blame for all of this, they let it go on. Van Velzen is evil, he went along with what was passed down to him, but he was not the only one to blame, this was going on ten, twenty, thirty years before he was at Alder Hey. They took forty-seven of my daughter's body parts and I have still not got them back and I want justice for that.²⁵

This charge that 'they let it go on' is supported by a family story that I report in chapter two. In this case, Derek and Joan Bye long suspected their daughter's brain had been removed, but in twenty-one years of trying to get answers they found politicians and doctors unwilling to break rank and speak out. In the long timetable of organ retention, as now known, no doctor, it seems, ever saw fit to 'blow the whistle' – to ask publicly whether what was legally permitted was ethically acceptable. This silence reflects a remarkable unanimity in medical culture on 'the way things are done', but what is striking about the pathology crisis is the intensity with which the parents rejected this culture and asserted their ownership of their children's bodies. Donaldson, speaking to the way post-mortems nationally had been done hitherto, said that the process was 'out of step with public expectations'.²⁶ He did not, however, comment on what cannot have been lost on many doctors in these years – the fact that, legal as their actions may have been, these nonetheless were essentially secretive actions, excluding parents from real knowledge. There surely must have been some who were uneasy on the point, but the ranks stayed closed. Kennedy was to observe in his 2000 Interim Report that the property law regulating the removal, retention, use and disposal of human materials is 'obscure, uncertain and arcane'.²⁷ In the event, many parents expressed their perception and ethical view in their own language. One family spoke for many. They buried their son believing his body was intact. When she learned otherwise, his mother, Daphne Ford, said her son's heart 'felt to me as if it was stolen. For it to be taken and used without our knowledge was immoral'.²⁸

In the paternalist view criticised by Redfern, the research imperative outweighed any need to treat those close to the dead as adults with a view to express; by extension, society itself was not adult enough to participate actively in helping to advance medical science. After her ordeal, Helen Rickard worked

²⁵ *Ibid.*

²⁶ *Ibid.*

²⁷ A point made by Kennedy, addressed to Donaldson, in *Bristol Royal Infirmary Inquiry Interim Report: Removal and Retention of Human Material*, 2000, opening notes.

²⁸ 'The Pain of Learning Your Child was Buried without His Heart', *The Independent*, 17 March 1999.

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with the legal team in litigation with the NHS for the retention of organs. She explains why consent is important. 'Consent for organ retention is essential because it allows families an informed choice to reclaim what is already theirs.'²⁹ This Rickard proceeded to do. Having received her daughter's heart back, she donated it for research for two years and then, on the anniversary of Samantha's birthday, buried it alongside the body in the grave. This, as I understand her account, was a compromise. Had she been asked in the first place, she would have said no. And undoubtedly other parents also, if asked, would have declined, but a survey done by Ruth Richardson suggests that a good number, as much as fifty per cent, would have donated.³⁰ When Daphne Ford said of her son's heart that 'it felt to me as if it were stolen', she added that the family was not opposed to research. Had they been asked, they would have delayed the burial until the tests were complete in order to return the heart to the body. The attitudes of these two mothers suggest that no essential harm to research would have been done if permission had been sought and the wishes of those declining respected. Nor, as Richardson observes, would the NHS have had a national scandal on its hands with weeks of headlines and so many parents needlessly traumatised.

History Research

The 1980s and 1990s saw the publication of the first fully researched accounts of the history of anatomy in Britain, several of which appeared when the Bristol RI narrative, then unknown, was under way or close to exposure. This is true of three major studies: Richardson's *Death, Dissection and the Destitute* appeared in 1988; Peter Linebaugh's *The London Hanged* in 1991; and Jonathan Sawday's *The Body Emblazoned: Dissection and the Human Body in Renaissance Culture* in 1995. Other studies³¹ appeared in the aftermath of Bristol and Alder Hey, for example Lilian Furst's study of power relations between doctors and patients in history in *Between Doctors and Patients* (1998); Rachel Holmes in *Scanty Particulars* (2003) portrayed the Victorian surgeon James Barry; Richard Horton examined doctor/patient relationships in a wide variety of contexts in *Second Opinion* (2003); Kate Berridge laid bare the twentieth-century taboo on death in her book *Vigor Mortis* (2001); Sarah Wise presented the 1831 London murderers, Bishop and Williams, in *The Italian Boy* (2004); and, as noted, Atul Gawande in *Complications* (2003) pointed the way for a wholesale re-examination of modern surgery's doctor/patient relationships. Furthermore, Susan Lawrence in 1998 – on the cusp of the Liverpool disclosures – explained

²⁹ Rickard, 2003.

³⁰ See Richardson, 2001, 416. Richardson's work, since her 1988 study *Death, Dissection and the Destitute*, has greatly influenced my thinking in this book.

³¹ The list in this section is very selective; I am referring only to those studies that have been essential to my project. For a larger list, see the bibliography.

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the historical origins of modernity's human body part cosmology (see bibliography). Another valuable study, appearing in 1996, was a collection of essays entitled *Organ Transplantation: Meanings and Realities*, edited by Youngner, Fox and O'Connell. These academic studies are, so to speak, 'fellow travellers' of formal reports such as those by Kennedy and Redfern – they are profoundly informative about the history that clings to the Bristol RI and Alder Hey narratives, and belong to the literature relevant to the pathology crisis. My intention is to use these historical studies to interpret the fiction that spoke to the 1990s' pathology story.

Fiction

This book is not an evaluation of the Kennedy and Redfern reports. It is a task for future historians of the NHS to assess whether or not the authors of these reports laid the basis for sustained reform. Kennedy, Redfern and Donaldson have given us the formal record and their voices will be heard in my analysis. But the formal text is only one version of a story that has other manifestations. Between the late 1970s and 2005 – between the start of the Great Ormond Street Hospital paediatric-surgery narrative and the aftermath of *Learning from Bristol* – another body of writing supplemented the retrieval of history. In an uncanny proximity in time to events in Bristol and Liverpool, a number of novels, some of them prize-winning, visited the medical past. This work imaginatively reconstructed the mid-eighteenth and nineteenth-century world of anatomical science and in particular its bodysnatching underworld. These fictions put the search today for organs for research and transplant purposes into a revealing historical perspective and are complementary to the historical research and the post-Bristol formal overviews.

Robert Coles in *The Call of Stories* (1989) argues that the reading and discussion of fiction by students training for a medical career can open up greater sensitivity in relating to others – not least future patients.³² It is hard to imagine this contention being taken seriously in the days when J.G. Ballard received his medical training, but the post-Bristol era brought about a reconsideration of what might have a place in the training of future doctors. *Learning from Bristol* makes this observation:

An understanding of science may be a necessary condition for entry to medical school, but it cannot be sufficient. The future doctor must also have demonstrated other qualities, not least a capacity to be open-minded, comfortable with uncertainty, free of pre-conceived views and capable of recognising and responding to ethical issues.³³

³² See Furst, 1998, 243.

³³ *Learning from Bristol*, 2001, 335, para. 36.

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In 1998, three years before Kennedy, this view was anticipated in Trisha Greenhalgh and Brian Hurwitz's book *Narrative-Based Medicine* which enlisted 'literature', fictional and otherwise, into the medical training curriculum. As their title suggests, Greenhalgh and Hurwitz argue that medicine itself is, and always has been, narrative-based in the sense that the biological events it deals with are mediated by language and cultural frames – 'stories' entertained consciously or unconsciously. Greenhalgh and Hurwitz suggest that the doctor/patient dialogue would be therapeutically enhanced if training curricula were to promote a greater understanding of the narrative nature of illness – the facts on the table in the clinical encounter are embedded in complex life stories that need attention and interpretation. It is argued that the study of an appropriate kind of literature, fiction included, would help develop an awareness of this narrative element in medicine. To this end Greenhalgh and Hurwitz identify some 'core text' requirements:

[Such texts]... should tell us something about the practice, history or epistemology of medicine, illuminate the experience of illness, parenthood, disability or 'otherness', highlight the importance of cultural factors, or offer insight into the character, education, daily life or decision making skills of medical practitioners.³⁴

The texts I examine in this book meet these criteria. For example, Sheri Holman's *The Dress Lodger* (1999), acclaimed when it first appeared, is an outstanding example of 'core text' requirements and the fact that it is fictional in no way reduces the impact of its arguments. The story visits Britain in the early nineteenth century to remind us how doctors in the past obtained bodies for dissection by lending encouragement to grave-robbing. In a fictionalised version of actual history, *The Dress Lodger* dramatises the commencement in 1832 of a debate about the need to encourage a body-bequest culture. That debate, which is voiced in the novel by a character called Audrey Place, holds vital lessons now in the search for organs for transplantation. Those today who remain persuaded that fully consensual organ donation is the way forward will take heart from the brave stand on the matter taken in Holman's narrative. Those in favour of the solution known as 'presumed consent' (or the 'opt-out' system) will find a substantial challenge to their convictions. Particularly in the chapters on Holman and Charles Dickens, a debate about the acceptable ethics

³⁴ Greenhalgh and Hurwitz, 1998, 273. A good example of the power of fiction to illuminate medical practice appeared, as if on cue, at the same time as Greenhalgh and Hurwitz's proposal. In 1998, Richard Selzer, an American doctor, published *The Doctor Stories*, a volume of short stories that portray the interaction between doctors and patients in the treatment of major illness. 'In telling these stories,' writes Selzer in his introduction, 'I have applied the lamp of language, especially metaphor, to tetanus, radiation sickness, autism, and so forth in order to illuminate the sufferer and the one who tends him'.

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of consent will be heard. Holman's text appeared in 1999, the same year in fact that the British Medical Association voted in favour of a move to presumed consent legislation; and it is no less notable that in 2000 the Royal College of Nursing rejected any such move and voted by a large majority to retain the current system of free donation. In 2003 more than six thousand people in the UK were on the waiting list for an organ transplant and in the previous nine months more than four hundred had died waiting for a suitable organ to become available.³⁵ In the same year, amid growing concerns about an international black market trade in organs, some senior doctors argued that the NHS should be allowed to buy organs from live donors. They noted the pressure on the NHS from incompetent transplant operations conducted abroad and the frequent fate of impoverished donors abroad dying after selling one of their kidneys. A state-controlled trade in organs, they argued, would enable transplants to be done safely.³⁶

The Dress Lodger is the story of a baby that urgently needs life-saving heart surgery. The surgeon who aspires to perform this work has a defective grasp of the principles of consent, as the baby's mother learns to her cost. The mother's cultural disadvantage to the doctor, his education and decision-making authority – these are the determining factors in a doctor/parent, doctor/patient relationship that moves towards tragedy in Holman's narrative. The doctor eventually betrays the mother's every trust and when her son dies she and an angry public learn that he has retained the baby's heart for research purposes. When *The Dress Lodger* appeared in 1999, Bristol RI added to the 1995 disclosures of botched paediatric surgery the admission that it had retained one hundred and seventy babies' hearts for pathology research. Anyone mindful of these disclosures will find Holman's story invested with an uncanny resonance.

My intention, then, is to read Holman's text and other fiction using insights available from the academic studies of anatomy produced within the BRI and Alder Hey timetable. In the chronology provided as preliminary material to this study a list is given of the texts examined and their publication dates in relation to events. It is necessary to read some texts in detail; in other readings the narrative context will be explained and attention given to select passages. My study of these materials includes commentary on some art exhibitions held in Britain close to the moment of the Kennedy and Redfern reports: 'Spectacular Bodies' at the Hayward Gallery in London in 2000, and the 'Body Worlds' exhibition, also in London, in 2002.

The sequence in which I take these materials reflects, I hope clearly, a theoretical perspective. The context of Bristol Royal Infirmary and Alder Hey Children's Hospital is given in this introduction and in the first three chapters, where I suggest how fiction from the 1990s and from the nineteenth century

³⁵ *The Independent on Sunday*, 3 December 2003.

³⁶ *Ibid.*

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can deepen our understanding of these events. The examination in chapters four and five of Victorian attitudes to the workhouse, where the focus is on Charles Dickens, is positioned in my commentary to make visible a residue in the Bristol RI and Alder Hey narrative of what the socialist critic Raymond Williams refers to in his analysis of culture as a 'structure of feeling'. It is true that Williams never claimed complete theoretical satisfaction with his concept. Nevertheless, in my view, it remains a usable structural principle in the investigation of interrelationships between society, history and literature. The 'structure of feeling' theory provides an account of the art considered here not merely as sociology, or as a source of historical detail, but as a mediation of continuing ideological and ethical concerns.³⁷ The general idea, as Tony Bennett puts it, 'is that of a shared set of ways of thinking and feeling which...form and are formed by the "whole way of life" which comprises the lived culture of a particular epoch, social class or group'. A 'structure of feeling' is culture as it is lived by groups of individuals who share the same experience and social and historical situation.³⁸ The notion is apparent in Williams's own words when he speaks of the work of art as:

...the articulate record of something which [is] a much more general possession. This was the area of interaction between the official consciousness of an epoch – codified in its doctrines and legislation – and the whole process of actually living its consequences. I could see that here might very often be one of the social sources of art. The example I then worked on was the contrast between the formal ideology of the early Victorian middle class and the fiction its writers produced.³⁹

For my purposes of textual analysis, in particular my reading of Holman, Ishiguro and Barker, one salient piece of legislation is one that Williams never mentions, despite his close focus on the early Victorians and the 1840s: the 1832 Anatomy Act.⁴⁰ This legislation legalised, for the purpose of anatomical dissection, a supply-line to the medical profession of thousands of unclaimed dead bodies from workhouses and hospitals. I argue in chapter seven that this legislation and the resistance to it in the 1840s is a sub-text of Ishiguro's novel *Never Let Me Go*. The 1832 Anatomy Act was implemented within the bureaucratic framework of the 1834 New Poor Law Amendment Act. Pat Barker's 1996 novel *Liza's England* explores historic fears of the Poor Law

³⁷ I am grateful to Sean Matthews for suggesting this formulation to me.

³⁸ Bennett, 1981, 26.

³⁹ Williams, 1979, 159.

⁴⁰ For example, no mention is made of this legislation in Williams's reading of Elizabeth Gaskell's *Mary Barton* (in Williams, 1958); this is for the likely reason that when Williams was writing in the 1950s little was known about this legislation, unlike today (see Richardson, 2001). I have given a reading of *Mary Barton* in relation to the 1832 anatomy reform (Marshall, 1995).

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workhouse through the mindset and memories of an elderly proletarian woman; the interaction between official consciousness and 'the process of living its consequences' is expressed in the novel's title.

The middle-class utilitarians who enacted the 1832 Anatomy Act provide a good illustration of a 'shared set of ways of thinking and feeling' characteristic of a 'structure' of feeling because they framed the legislation on the assumption that it was ethically acceptable to presume rather than expressly solicit the consent of those who went for dissection. This assumption was accommodated comfortably in the mindset of the Victorian 'dominant culture', in Williams's term, and did much to retard the emergence of a 'subordinate' culture of opposition which recognised the social inequality of the 1832 reform and started the argument for an alternative and fairer body donation system based on express consent. In Holman's *The Dress Lodger*, which is set in 1831 in Sunderland, the impending 1832 Anatomy Act is resisted by two characters, both women, who (to recall Williams's formulation of 'actually living the consequences' of legislation) campaign for an alternative donation system. This culture eventually came into being around the time of the setting up of the Welfare State after World War Two, but where history's search for whole bodies for dissection has given way to today's search for human organs for transplant, the idea of freely expressed consent has not prospered. The 'structure of feeling' associated with the early Victorian ethical and medical culture came back in 2007 when the Chief Medical Officer, Liam Donaldson, advocated doing away with the donation system and replacing it with 'presumed consent' procurement:

Everyone should be seen as a potential organ donor on their death unless they expressly request not to be, England's Chief Medical Officer says. Sir Liam Donaldson wants a system of 'presumed consent' to be introduced in England to tackle organ shortages. His Scottish counterpart rejected the move. One person a day dies after failing to find a suitable donor, data suggests.

The Tories opposed the move, saying it would be better to increase the number of people on the donation register. Shadow Health Secretary Andrew Lansley said: 'The state does not own our bodies or have a right to take organs after death'. He said the Conservatives were committed to enhancing organ retrieval teams in hospitals and appointing more donor liaison nurses as the best way to combat any 'transplant crisis'.

Sir Liam's Scottish counterpart, Harry Burns, rejected the idea for Scotland, saying there was no evidence that the public would support such a move. A system of 'presumed consent' was rejected by MPs when they voted on the Human Tissue Act in 2004. Both the then Health Secretary John Reid and Health Minister Rosie Winterton declared it was not up to Parliament to make decisions about what became of people's bodies when they died. But Liberal Democrat MP Dr Evan Harris – who chairs

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Parliament's all-party kidney group and introduced the Human Tissues Amendment, said on Tuesday that it was time for the government to back a change to presumed consent. Sir Liam said that efforts to persuade more people to either carry donor cards or sign up to the NHS Organ Donor Register had failed. The move has been welcomed by transplant campaigners and has been endorsed by the British Medical Association (BMA).⁴¹

On 20 September 2007 the British government agreed to set up a committee to examine the feasibility of this proposal. Early in 2008 the Prime Minister Gordon Brown signalled his support for Donaldson's proposal. Previously an opponent of the reform, Brown wrote in the *Sunday Telegraph*: 'A system of this kind seems to have the potential to close the aching gap between the potential benefits of transplant surgery and the limits imposed by our current consent system.'⁴² He called for a public debate on the subject prior to any Government action.

To help us to hear the history inhering in Donaldson's proposal, I have retrieved some Victorian voices that are representative of, in Williams's words, 'the official consciousness of an epoch', hence the appearance in chapters five and seven of statements from Harriet Martineau and Charles Dickens. In Williams's account, the 'structure of feeling' is governed by the value system and the behaviour and attitudes of the dominant social group, and Martineau and Dickens provide good exemplifications of this where the question of bodies for dissection is concerned. As Bennett, paraphrasing Williams, puts it, 'cultural analysis' – of the kind I attempt here – 'is an interpretation and an attempted reconstruction of dormant or partially dormant lived cultures undertaken for and from within the interests and values of the present'.⁴³

That Martineau and Dickens played significant roles in the long suppression of arguments for a donation culture is one point I make. I also want to try to characterise the way the questions that surfaced publicly in the wake of the Bristol RI and Alder Hey events enable us to re-read writers such as George Eliot and Dickens as speaking on medical matters as much to our day as to their own. This emphasis will play its part in my reconstruction of the cultural space opened up by the 1990s' pathology scandal. Williams speaks to the difficulty and challenge involved in the reconstruction process: 'the most difficult thing to get hold of, in studying any past period, is this felt sense of the quality of life at a particular place and time: a sense of the ways in which the particular activities combined into a way of thinking and living'.⁴⁴ Conscious as I am of the unavoidable selectivity of one's material, I have

⁴¹ *The Guardian*, 17 July 2007.

⁴² Reported in *The Guardian*, 14.1.2008.

⁴³ Bennett, 1981, 27.

⁴⁴ Williams, 1975, 63.

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nonetheless tried to meet this difficulty by letting a range of voices from the 1990s speak, including newspaper columns and letters to the press. As reaction mounted to events after 1995, the press filled with a lively debate, particularly on the subject of consent procedures in medical practice; and some contributions from journalists and lawyers, interpreting the medical, legal and political meanings of what was happening, are worth hearing again. Even where I have not agreed with them, I have learned much from Jeremy Laurance, Joan Smith, Deborah Orr, Mary Riddell, Mary Dejevsky, John Batt and others. My aim has been to integrate their insight into the reading of fiction's commentary on unfolding events.

A significant influence on Williams as he refined the 'structure of feeling' argument was the work of the Russian theorist of language, V.V. Volosinov. In the realm of linguistic theory Volosinov argued against the structural linguistics of Saussure for its concept of language as an abstract and static system: for its view of the sign as clear and unambiguous, and for its view of discourse as monologic, as presenting a single point of view. In place of Saussure's scheme, Volosinov argued that language and language use is dynamic and contains multiplicity of voice, tension and contradiction. For Volosinov the key term is what he calls the multi-accentuality of the sign – the fact that a word (or other sign) does not have just one meaning, but is inherently double-valued:

Each living ideological sign has two faces, like Janus. Any current curse word can become a word of praise, any current truth must inevitably sound to many other people as the greatest lie. This *inner dialectic quality* of the sign comes out fully in the open only in times of social crises or revolutionary changes. In the ordinary conditions of life, the contradiction embedded in every sign cannot fully emerge because the ideological sign in an established, dominant ideology is always somewhat reactionary and tries, as it were, to stabilise the preceding factor in the dialectical flux of the social generative process, so accentuating yesterday's truth to make it appear today's.⁴⁵

Scaling down Volosinov's terms (or Marxism) for my more limited purposes I prefer his stress on 'social crisis' rather than larger 'revolutionary changes'. The pathology scandal was a social crisis and we will see how in fiction and other discourse words such as 'trust', 'consent', 'ownership', and even 'death' became, to use Volosinov's metaphor, arenas of contested meaning or accentuation. It was with anguish that one set of parents, as we will see in chapter five, experienced the power of the sign to be uni-accentual – the tendency in official discourse to use words as if they have only one meaning. The parents of Joshua Petrou expressly requested that their child's organs be 'retained', understanding the word to mean the organs would remain in his body, but were later to learn that 'retained' in the formal parlance of procedure

⁴⁵ Volosinov, 1973, 23.

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meant that the surgeons in fact removed a long catalogue of the child's organs.

In Brian Salter's view the pathology scandal erupted as an intense contest of ownership:

Lay and medical cultures confronted each other in a previously quiescent area of the doctor-patient relationship where medical authority had always been *taken for granted* so the nature of consent had not been an issue... Since the retention of body parts without the fully informed consent of the relatives was soon shown by the Chief Medical Officer's subsequent inquiry to be common practice in many NHS hospitals as opposed to an exceptional incident, the issue served to illustrate dramatically the assumptive nature of the cultural divisions... Both sides considered they had the right to the use of the dead body.⁴⁶

Here at a micro-level is another formulation of a dominant culture versus a subordinate (or insubordinate) culture – the dramatically visible existence of other patterns of thought and ways of feeling in opposition to the 'taken for granted' view. Official ideology prefers a monologic discourse where discord and tension are smoothed away, but critical and creative practice can restore multi-acculturality. Following Williams and Volosinov, the fiction I examine is a significant 'carrier' of structures of feeling in conflict with each other.⁴⁷ In my main example, Holman's *The Dress Lodge*, the historical origins of the 'taken for granted' are explored as Holman portrays England in 1831 and the impending anatomy reform. This exploration opens up a space in the text in which a baby's mother contests the claim on the child's defective heart by the doctor, who acts after the baby's death on an automatic assumption of ownership. A contest is joined and for most of the story nothing is reduced or resolved in only one direction: the doctor's word does not suppress the mother's. At the level of the plot, however, the doctor's word does ultimately prevail, leading to betrayal and tragedy.

The same terms, betrayal and tragedy (the latter was Kennedy's word) apply to the Bristol RI events. In Kennedy's analysis, the core problem was a 'club culture' in which younger doctors, alarmed at developments in the death rate of babies, found no opportunity to question or have dialogue with the monologic authority of their superiors. Elsewhere in the late 1990s a single authoritative viewpoint was brought to account. In the realm of unpermitted organ retention, Kennedy in his Interim Report on Bristol RI regretted the long continuance of 'standards [that] were the product of a small group of professionals talking to themselves... But that is how things were done... That was the culture of the times.'⁴⁸ Likewise, as I argue in chapter

⁴⁶ Salter, 2004, 63 (emphasis added).

⁴⁷ 'Carrier' is Williams's word. See Williams, 1975, 65.

⁴⁸ Cited in Salter, 2004, 125.

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three, an insufficient contestation of expert witness authority in 2000 undoubtedly helped to convict for the murder of her two sons the solicitor Sally Clark. At her trial, the paediatrician Sir Roy Meadow said the probability of two natural unexplained cot deaths in the family was 73 million to one. Only later was this testimony discredited, an instance of the force of Volosinov's observation that 'any current truth must inevitably sound to many other people as the greatest lie'. For the reasons given in chapter three, Mrs Clark was eventually freed in 2003, but not as a result of Sir Roy's discredited testimony.

Following the organ scandal, Donaldson recommended 'a programme of public education to ensure that there is general understanding of what is involved in the post-mortem process and its value to maintaining standards of patient care and medical science'.⁴⁹ This initiative prompted me to write *Stolen Hearts* so that fiction and life-writing might have a voice in the educational project. Notably, this initiative came from the same Chief Medical Officer who, as we have seen, proposed in 2007 the change to 'presumed consent' policy for organ procurement and whether this policy is the desirable ethical way forward, consistent with public education about pathology, is a question I take up in this book. The initial idea to write about these matters came before Donaldson's call for consciousness-raising. When the Bristol RI story broke, I was completing a study of Mary Shelley's *Frankenstein* – the story of a creature made using organs stolen from the dead – in relation to the bodysnatching era of the eighteenth and early nineteenth century. The ensuing news about the retention of the children's hearts, followed by the Alder Hey revelations, put the imprint of the past on the evolving 1990s' pathology story. The 'stolen hearts' headlines sounded distinctly like history recurring, a story of attitudes and actions unchanged from the days when surgeons, aided by grave-robbers, obtained dead bodies for research purposes with little regard for public feeling. The constant talk of a need for the profession to put its house in order to avert a crisis of public distrust seemed like a repetition of perceptions back in the 1820s, similarly prompted by major bodysnatching scandals. The re-enactment of this history in the fiction published close to the moment of the Bristol RI and Alder Hey narratives (including, as we will see, some re-writes of Shelley's story) was timely. It put into the public domain a pertinent historical narrative that Donaldson did not refer to in his 2001 report on the national situation regarding organ retention. In something of an understatement Donaldson said that 'it is the extent to which this [system for the retention of tissues and organs] has fallen out of step with public understanding and public expectations which is at the heart of the present controversy'.⁵⁰

In Donaldson's terms 'public understanding', as in the statement just given, seems to be a given, but, as we have seen, elsewhere 'public understanding' is defective and in need of 'a programme of public education'. It remains in this

⁴⁹ Quoted in Holmes, 2002.

⁵⁰ Quoted in Salter, 2004, 62.

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introduction to speak about the function of art in the programme Donaldson declared necessary. The fiction examined in *Stolen Hearts* does not only explain in layman terms the purpose of pathology research, important as the explanation is. Nor are the texts best regarded as merely tracts or documents about the history of pathology. They are art works that locate routine pathology work within a much broader context of sensitive cultural activity, and not least the relationship of the living to the dead.

The artwork from Denise Green's 'Never Again' exhibition in 2003 (see pages 162-163) spoke to this relationship. Green was a parent involved in the pathology scandal. Her work was intended to raise public awareness of what had happened.

In a timely way, indeed as if in response to Donaldson, a commentary on the role of art in the conduct of this relationship was given in 2002 by the Canadian novelist Margaret Atwood. In that year her William Empson lectures given at Cambridge University in 2000 'to an audience composed not only of scholars and students, but also of the general public'⁵¹ were published under the title *Negotiating With The Dead*. With this suggestive title, Atwood contended that 'writing of the narrative kind...is motivated, deep down, by a fear of and a fascination with mortality – by a desire to make the risky trip to the underworld, and to bring something or someone back from the dead'.⁵² Atwood linked this proposition – initially a rather strange one perhaps – to an observation that 'societies...have ways of devising rules and procedures – 'superstitions', they're now called – for ensuring that the dead stay in their place and the living in theirs, and that communication between the two spheres will take place only when we want it to'.⁵³ However, in art, if not in society as well, the dead have a way of never vanishing completely – the famous example is the ghost of Hamlet's father returning to the land of the living with demands on his son. This ghost demands revenge and justice, but, as Atwood observes, the returning dead can exercise benign power as well, as in Cinderella's dead mother's gift of ball gowns and glass slippers to her daughter – the point is there is a traffic process between the dead and the living involving the latter in a give-and-take situation, in short, a negotiation.⁵⁴ As often as not, Atwood notes, what is given is food, to satisfy the hunger of the dead. The visitants from the world of the dead have a variety of demands and needs – revenge, justice, food, but Atwood's emphasis fell on 'a word that encompasses life, sacrifice, food and death – the word 'blood''.⁵⁵ 'And this is what the dead most

⁵¹ Atwood, 2003, xv. It was fitting that Atwood's talks were given as the Empson Lectures. Volosinov's notion of the multi-accentuation of the sign, which is suppressed for the most part in ordinary speech and official discourse, can be compared with Empson's insistence on the multiplicity of meaning in poetry (see Empson, 1930).

⁵² *Ibid.*, 140.

⁵³ *Ibid.*, 143.

⁵⁴ *Ibid.*

⁵⁵ *Ibid.*, 147.

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often want, and it is why the food of the dead is often, though not always, round, and also red. Heart-shaped, more or less, and blood-coloured, like Persephone's pomegranate.⁵⁶

One starting-point for *Stolen Hearts* was an observation made by a pathologist at a conference I attended in Oxford in 2002.⁵⁷ He said that the living learn from the dead. What among other things we get from the dead, as Atwood notes, is knowledge, knowledge that is otherwise unobtainable. The hearts taken from the dead at Bristol RI and elsewhere – 'stolen' in Daphne Ford's perception – were not, pure and simple, pathology specimens. They were elements in a ritual transaction the proper or improper conduct of which is a subject often taken up by art – and the example I will concentrate on in chapter eight is A.S. Byatt's 2003 short story 'Body Art'. The fact that the heart was the *first* organ found to be purloined invested the 1990s' pathology scandal with a poignancy that belongs to myth, ritual and art. The heart-shaped food given to the dead is part of a transaction that sees the dead, as if alive, giving something back – in this case knowledge of how the human heart works. The scale of the shock involved in the public response to the hearts scandal is not easy to account for, but an element of it seemed to be an apprehension that the surgeons' act of stealth represented an impropriety, a failure of attention to the delicate exchange process between the living and the dead. Not given to pathology on a consented basis, the hearts were not properly given over to the dead.

Atwood supports this notion of a transaction or exchange process by pointing to vestiges of cultural narratives in which the dead are regarded as still part of the community, at least intermittently.⁵⁸ Rituals of propitiation exist to pay respect to the dead in order to secure something back from them – their help. Atwood gives the example of Halloween, the vestige of the pre-Christian Celtic night of the dead:

The spirits are abroad, and you need protection, so you make a pumpkin with a goblin face and a light inside it, to act as the guardian of your threshold. The dead are represented by children wearing masks and costumes. It used to be ghosts, witches, and goblins, but today it's just as likely to be Elvis Presley, Superman, or Mickey Mouse, whom we have apparently now claimed as ancestral spirits. These come to your door and demand food. 'Trick or treat' is one of the verbal formulae – which means that unless the ancestral spirits get food, you'll get the mischief. Again, giving food to the dead is supposed to propitiate them and bring luck to the living...⁵⁹

⁵⁶ *Ibid.*

⁵⁷ 'The Business of the Flesh' conference was held in Oxford in November of that year.

⁵⁸ Atwood, 2003, 144.

⁵⁹ *Ibid.*, 145. Atwood's examples of modern day ancestral spirits reflect the extent to which Halloween is now a North American festival.

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In chapter two we look at how the medical narrative in George Eliot's 1871 novel *Middlemarch*, which is set in 1831, reads in a new way given the Bristol RI events – and in particular a passage that sees the people in the poor quarter of Middlemarch very apprehensive about a still topical case of multiple murder. The 1828/9 Burke and Hare case revealed that the bodies of murder victims had passed, in a relationship of collusion, to an Edinburgh surgeon for anatomical dissection. There is a rich symbolism in a small but salient fact: Burke and Hare killed the last of their sixteen victims on Halloween night, 31 October.⁶⁰ The next day, careless in their hiding of the body, they were found out in the deed by some people returning from an all-night Halloween party. It is an ironic adjacency: this murder case, the most notorious in the history of anatomy, came to light in the space of a cultural ritual designed to negotiate a relationship of proper give-and-take between the living and the dead. The killers' deeds were a gross violation of the human investment in this relationship, one face of which is humanity's investment in medical knowledge.

The Burke and Hare case spawned copycat killings in London in 1831 and obliged the government to prevent further violations by passing the 1832 anatomy reform which requisitioned the workhouse unclaimed dead for the anatomy slab. The recreation of history in Holman's *The Dress Lodger* visits precisely this sequence of events, as the impending Anatomy Act hangs over the oppressed and cholera-afflicted poor in the town of Sunderland in 1831. One convention of Gothic fiction is the *doppelgänger*, or double, and in Holman's text the young mother whose baby has a potentially fatal heart defect is shadowed – followed and watched – by a mysterious and elderly one-eyed lady called the Eye. The identity of this 'hideous' figure is the subject of 'a hundred different stories', in one of which she is a projection of the rumour-mongering that was rife after the 1828/9 scandal – she is thought to have 'sold the recipe for human meat pies to the body snatchers Burke and Hare'.⁶¹ She is repeatedly described as 'a shadow', as the *doppelgänger* often is, and is associated with death: this shadow 'is with you from the hour of your birth to the day of your death and beyond, following you even where no one else will, into the wooden box as they hammer down the lid'.⁶² It becomes apparent late in the story – as the sentence just quoted hints at – that the Eye's function in the story is to patrol and draw the reader's eye to the boundary between the dead and the living. All-seeing, the Eye however is not all-powerful. On the boundary of life and death, the Eye's real object of solicitation and concern, it is finally revealed, is for the baby and his ailing heart. She cannot in the event prevent that heart being retrieved from the grave by the doctor who intends to make it a special pathology exhibit. The resource of Gothic convention figured

⁶⁰ George Eliot does not mention this fact, but the historical record does. See Richardson, 2001, 133.

⁶¹ Holman, 1999, 15.

⁶² *Ibid.*, 12.

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in the power of the *doppelgänger* fails to avert, in Volosinov's term, the final uni-accentuation of the sign.

In the literary-medical archive relating to anatomy, the paradigm narrative of mis-negotiation with the dead (not mentioned by Atwood) is Mary Shelley's *Frankenstein*, a narrative full of *doppelgänger* relationships, not least the relationship between Victor Frankenstein and his Creature. The third edition of *Frankenstein* appeared in 1831 when, as noted, the Burke and Hare case was still topical.⁶³ Victor Frankenstein's Creature is made from different bits of many dead bodies – he is the incarnation of today's organ transplant technology. He is another instance of the dead returning, with a burden of demands, to the world of the living. The improper conduct in the story is the act of theft involved when Victor Frankenstein visits graveyards at night to gather the materials for his creation – this is a distinct echo of the bodysnatching underworld that serviced the surgeons in the years that saw the first three editions of the story. In the event, the creation, when galvanised into life, turns in his maker's first-sight projection into a 'monster' – monstrosity in this text is the ubiquitous sign of a violation, a breach in the delicate cultural relationship of the living with the dead.

Frankenstein's nocturnal visits to graveyards are a metaphor for the journey – there and back – that the artist of narrative makes to the Underworld. In Atwood's proposal, writing is motivated 'by a desire to make the risky trip to the Underworld' and come back. The writer 'doesn't just visit the Other World. He partakes of it. He is double-natured, and can thus both eat the food and return to tell the tale'⁶⁴ – and Mary Shelley's authorship of *Frankenstein* reminds us that female artists also possess this dual identity. 'The dead get blood... In return, the poet gets clairvoyance, and the completion of his identity as a poet. It's an old arrangement'.⁶⁵ Embedded in this narrative motivation, Atwood suggests, are strands of traditional folk-tale narratives in which body-parts and products such as blood, bones and hair acquire a power to speak or sing.⁶⁶ Atwood's commentary on this vocalisation process reminds us that art and anatomy have long been twinned activities:

Modern stories about forensic pathologists, such as Patricia Cornwell's thriller-heroine Kay Scarpetta, or forensic doctor-anthropologists such as the protagonist of Michael Ondaatje's latest novel *Ani's Ghost* are firmly of this tradition... When the blind old man in the Ondaatje novel 'reads' a skull with his fingers, it's a recap of a very ancient scene. The premise is that dead

⁶³ For a full examination of the resonance of the Burke and Hare case in *Frankenstein*, see Marshall, 1995.

⁶⁴ Atwood, 2003, 156. Atwood draws on Rilke's *Sonnets to Orpheus* to illustrate this proposition.

⁶⁵ *Ibid.*, 159.

⁶⁶ *Ibid.*, 146. For an example of this genre published around the time of the pathology scandal, see Greenhalgh and Hurwitz, 1998, 266-272.

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bodies can talk if you know how to listen to them, and they *want* to talk, and they want us to sit down beside them and hear their sad stories. Like Hamlet laying a death-scene narrative injunction on his friend Horatio – ‘in this harsh world draw thy breath in pain/To tell my story’ – they want to be recounted. They don’t want to be voiceless; they don’t want to be pushed aside, obliterated. They want us to know.⁶⁷

If the dead can speak to the living, there is a complementary sense in which the genre of historical fiction – and Holman’s work in particular – can make the past speak to the present. The journeys into medical history undertaken by several of the writers examined in this book are acts of reclamation. The past, like the treasure of knowledge held by the dead, is brought back to enter time once again, for the benefit of the audience, the living.

The psychological feeling that the new millennium put the 1990s somehow further back in time was another prompt to write *Stolen Hearts*. That decade is indeed gone and is another underworld of a kind that needs visiting and narration, not least because there is also a political narrative. In my final chapter, where I draw again on Atwood’s findings, I discuss how New Labour sought to make political capital out of the Alder Hey scandal by siding with ‘public understanding’ (Donaldson’s phrase) against the doctors. As Salter notes, ‘such was the intensity of the conflict’ between lay and medical cultures, the government, ‘after some prevarication and attempts at neutrality, felt obliged to establish an official position’.⁶⁸ In a statement accompanying the publication of Redfern’s report, Alan Milburn, Frank Dobson’s successor as Health Secretary, insisted on a redefinition of the profession’s relationship with patients and parents:

We can no longer accept the traditional patronising attitude of the NHS that the benefits of medicine, science or research are somehow self-evident regardless of the wishes of patients or their families. There is a simple principle at stake here. The health of the patient belongs to the patient, not the health service.⁶⁹

Salter’s gloss on this pronouncement indicates the contest at stake – ‘whether the majority of consultants would agree with such a bold re-fashioning of their traditional relationship with patients is debatable.’⁷⁰ Milburn’s was a call to the profession to relinquish its long taken-for-granted authority in the doctor-patient

⁶⁷ *Ibid.*, 146, citing Ondaatje, 2000, 87. There is a long history of collaboration between artists and anatomists, the latter dissecting the body, the former, on the basis of the dissection, making wax models of it. See http://www.janewildgoose.co.uk/projects_and_publications/zones_of_morbidity.html.

⁶⁸ Salter, 2004, 62.

⁶⁹ *Ibid.*

⁷⁰ *Ibid.*

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relationship – involving an intellectual and cultural ‘learning curve’ no less challenging than any operation in theatre, and no less urgent than Donaldson’s public educational programme. With its ‘simple principle’ the government unequivocally took the layman’s view against medical culture in a highly publicised conflict of claim on the dead body. And as the pathology scandal unfolded, fiction provided the history lesson. An unacknowledged history is a history likely to repeat itself and, after 1995, the repetition became visible. In the event, the revelations of botched surgery, secrecy, organ theft and medical paternalism reactivated a submerged but not remote older narrative of negative perceptions of hospitals as places to be feared and distrusted.

Sympathetic as I am to the Alder Hey parents or the ‘lay’ view, I hope I neither demonise the doctors nor understate the vital need for pathology research. On the latter point, the fiction was very clear. In 2000, Patrick McGrath’s *Martha Peake*, some months before Milburn’s ‘simple principle’ declaration, voiced the need for pathology research; in this, as I will show, it anticipated concerns expressed by consultants that the strictures on consent in the then envisaged Human Tissue Bill were too strict and overly influenced by the Alder Hey parents’ views. The fiction of the period, as if standing between the medical and lay culture, debated the implications of the pathology scandal both before and as it unfolded – and therefore raised an intriguing question: was fiction getting its word in before Kennedy, Redfern, Milburn and Donaldson? The first text I consider, Andrew Miller’s 1997 novel *Ingenious Pain*, suggests it was indeed the case. In advance of Donaldson’s call for a better understanding of medical matters, Miller’s story opens with a scene in which two surgeons and a layman discuss the purpose of the post-mortem process.