

## 2 *Res Nullius* – Nobody’s Thing

---

While the stories and hidden histories of the dead stand at the heart of this book, it is important to frame these narratives against the restrictions and permissions of the ‘laws’ that governed matters of consent, harvesting and research in modern British medical research. This seemingly simple endeavour is considerably complicated by the fact that as well as direct legislation on these matters, medical practice and the ‘rights’ of the dead and dying are shaped by legislation in other areas of criminal, civil and administrative law. Official and unofficial ‘guidance’ and long-established customs also have purchase on these matters. In turn, the fact that much ‘law’ merely clarified or amended previous legislation rather than repealing it, means that ‘the law’ becomes ‘the laws’. Thus, there is often considerable scope for differential interpretations of legal permissions at any chronological point. In this sense, law matters very much for the interpretation of the stories that we will go on to encounter in the rest of this volume.

A starting point for this process is the long tradition in English Common Law that: ‘A dead person cannot own the property of their body once deceased – the legal principle is *Res Nullius – Nobody’s Thing*.’<sup>1</sup> In many respects, this lack of a human identity set the tone for how medical science represented its dissection and research work to government, as we have already begun to see in previous chapters. The importance of this basic principle becomes apparent in the eighteenth century, when many European states were threatened by revolution and the mob, and preventing criminal behaviour became a matter of urgency. In Britain, central government decided by 1750 that the forces of law and order should link heinous crimes like murder to a system of extra-physical punishments. Murder thus became punishable by death and dissection. The thinking was that this double deterrent would prevent ordinary people from seeking the radical political change threatened in Europe. These new regulations drew on ingrained body taboos in northern European cultures. Popular opinion held that any interference with the integrity of the human body in death was a moral shame. For the soul to go to heaven, the dead body had to be buried intact. As this author has argued extensively elsewhere, the culmination of these cultural mentalities was the passing of new capital legislation called the Murder Act (25

Geo. 2 c. 37: 1752) in England.<sup>2</sup> Based on the Common Law principle of *Lex Talionis* – that the punishment must match the degree of offense committed – it had a biblical counterpart, ‘an eye for an eye’ of retributive justice, outlined in the book of Numbers, chapter 35. After 1752, if convicted of homicide in a court of law, the condemned faced a death sentence, was hanged on a public gallows, and then surgeons either dissected the criminal corpse or placed it on a gibbet to rot. The bodies thus released by the justice system became one significant strand of the supply that medical science required for its educational and research needs over the next eighty years. It relied on ‘Nobody’s Thing’.

It was not to be enough. There was meantime a corporate ambition amongst practitioners to gain full professional status from an expansion of European medical education. At Bologna, Padua and Paris, training doctors in human anatomy had been a national priority since the Renaissance. Now others, particularly in northern European countries and cities where Enlightenment values gained a strong intellectual foothold, like Edinburgh, followed suit. Yet, those in Britain faced a logistical problem. The murder rate lagged behind the expansion of human anatomy training. Not enough people were convicted of homicide to supply dissection tables, and medical students thus lacked enough corpses to dissect. Grave robbing soon became commonplace, and newspapers reflected public concern that the unscrupulous were indiscriminately digging up the dead for anatomical profit. Resurrection men sold the dead of the rich, middling-sort and labouring poor, disinterred for dissection. This class question of who owned the dead body and who should be charged legally for stealing human remains became a highly emotive one in contemporary British culture, until, that is, the controversial Anatomy Act (2 & 3 Will. 4 c. 75: 1832 (hereafter AA1832) changed the medical status quo. Two catalysts changed public debates about the need for more legal supply lines in human anatomy by the 1830s. First, the famous ‘Burke and Hare’ murders in Edinburgh revealed how the destitute who were killed for medical profit entered the supply chain of anatomists in Scotland. Second, the simultaneous death of an ‘Italian boy’ in London, murdered and traded for a similar dissection sale, caused public outrage. These scandals would result in the medical profession successfully lobbying for a better and more plentiful legal mechanism of supply but crucially one still based on class inequalities. AA1832 permitted the poorest in society to become the staple of dissection tables, supplied by asylums, infirmaries, workhouses and street deaths, amongst the homeless, friendless and nameless of society. In turn, key aspects of AA1832 were to remain in force until HTA2004, a remarkable 172 years. Officially, AA1832 was supposed to end when the New Poor Law closed in 1929.<sup>3</sup> In reality, as we shall see, its class ethos, tinkered with and rehashed a number of times, did not alter that much. This was because, as Richard Smith and Peregrine Horden have observed, early Welfare State council care homes were really just workhouse infirmaries

renamed. They still supplied the dispossessed for dissection.<sup>4</sup> In other words, in terms of body supply-mechanisms there was a great deal more continuity than discontinuity inside the healthcare system, a theme that runs throughout this book. Starting from this point, Table 2.1 summarises key statutes and important regulatory changes in British law on matters of consent, biomedical research regulation and the rights of the dead.

A full description of the technicalities of this legislative canvas is neither possible nor desirable in the context of this book. Broad trends are, however, important. Thus, prior to WWI a raft of intersecting changes influenced fundamentally public and legislative attitudes to the supply of the dead for dissection and research. The passing of the Third Reform Act (48 & 49 Vict. c. 3: 1884), the creation of County Councils (51 & 52 Vict. ch. 41: 1888), democratisation of the New Poor Law under the Local Government Act (56 & 57 Vict. c. 73: 1894) and the Liberal Welfare Reform Programme (1906–1911) encapsulated a growing sense that poverty and pauperism were not the fault of individuals.<sup>5</sup> Having the vote without the citizenship rights of healthcare and welfare provision was thus regarded as an empty political promise by the labouring poor, and no longer tenable in a modern society. The progressive extension of the franchise to women, the structural and cultural effects of the war, increasing political and economic assertiveness by the working class and the final demise of the New Poor Law in 1929, all signalled the increasing fragility of public support for the legislative base that underpinned the use of bodies for medical research and teaching. During the 1930s, however, the *modus operandi* of the medical sciences did not really alter that much. It was resistant to the direction of wider cultural shifts happening in British life, and continued to rely on Victorian legislation.<sup>6</sup>

Change when it came was from an ostensibly unusual angle. The growth of the Victorian information state had been a boon for the medical sciences by the early twentieth century.<sup>7</sup> In particular, the expansion of the Coronial Office proved to be an important stepping stone in the piecemeal regulation of dissection and its further research agendas by the 1930s. This was the culmination of fifty years or more of a strategic realignment of the professional classes inside the expanding Information State in which coroners sought to be pivotal to the development of forensic medicine and crime-scene evidence, working closely with the anatomical sciences, as well as pathologists. As this author has shown elsewhere, some coroners were so successful at expanding their official jurisdiction that by the turn of the century a medical school which did not cooperate with the Coronial Office risked losing an important source of supply in the dead.<sup>8</sup> It came therefore as less of a surprise to the medical profession as a whole that coroners were the first to lobby about the need for 'special examinations' (not just post-mortems) under the Coroners (Amendment) Act

Table 2.1 *The official boundaries of bio-security in modern Britain and Europe*

| <i>Timeline</i>              | <i>Legislation/regulations</i>   | <i>Main features of its remit</i>  |
|------------------------------|--|--|
| <i>Ancient Times</i><br>1832 | English Common Law – <i>Res Nullius</i> – <i>Nobody's Thing</i><br>Anatomy Act | A dead person cannot own the property of their body once deceased  |
| 1926                         | Coroners (Amendment) Act   | The dead must repay any welfare debt to society. Welfare costs paid from public taxation merit post-mortem.  |
| 1926                         | Registration of Stillbirths Act  | The individual dissected and dismembered for the purposes of anatomy teaching and medical research<br>Extended retention powers over post-mortems  |
| 1950s                        | Pituitary Gland Programme  | Stillborn children now constitute a potential 'living' person in law and as such their death and burial must be registered officially  |
| 1952                         | Corneal Grafting Act   | Extraction of Human Growth Hormone post-mortem by anatomists, coroners, pathologists   |
| 1960/1                       | Declaration of Helsinki  | Regulates the removal of eye material taken from cadavers post-mortem  |
| 1961                         | Human Tissue Act   | World Medical Association's new ethical framework for medical research<br>Human tissue from a dead patient considered in law to be an <i>unconditional gift</i> . In the case of material derived from fatal operations (organ, body part, tissue) provided the patient when living gave consent for the surgical procedure that led to that removal, once removed in law is <i>abandoned</i> . It hence becomes the legal property of the medical establishment, removed for the therapeutic benefit of the consenting patient before their death. Doctors need ' <i>only make reasonable enquiries</i> ' where human material originates |
| 1962/3                       | Medical Research Council (MRC) Annual Report                                   | Seen as a cornerstone of medical ethics in Britain. Future funding of research studies dependent on adhering to a new Ethical Code of Conduct. Has been revised many times, especially in 1979 (see below)   |
| 1977                         | National Health Service Act  | Section 25 – <i>where the Secretary of State has acquired: (a) supplies of human blood . . . or (b) any part of a human body . . . s/he may arrange to make such supplies or that part available (on such terms, including terms as to charges, as he thinks fit) to any person</i>  |
| 1979                         | Medical Research Council (MRC) Ethical Code                                    | Compulsory for scientific and medical research studies based in Britain  |
| 1984                         | Coroners' Rules  | Clarified post-mortems by coroners and the Preservation of Material. Rule 12 stated that: <i>A person making a special examination shall make provision, as far as possible, for the preservation of the material submitted to him for such period as the coroner thinks fit</i>   |

|      |   |   |
|------|---|---|
| 1984 | Anatomy Act   | Passed to repeal aspects of 1961 legislation but did not clarify adequately use of tissue and organs, and their ownership   |
| 1986 | Corneal Tissue Act  | Permitted the removal of eyes or parts of eyes for therapeutic purposes, medical education and research by persons who are not medically qualified, subject to appropriate safeguards. Amended parts of the HTA 1961 so responsibility for medical death resided with doctor(s) who had cared for the patient   |
| 1989 | Human Organ Transplant Act  | Passed to prevent the illegal trade in organs globally and to protect the vulnerable from becoming victims of organ harvesting  |
| 1988 | Anatomy Regulations   | A written record kept of all bodies and body parts retained by medical schools for human anatomy teaching and medical research  |
| 1989 | Human Fertilisation and Embryology Act  | Specifically regulates research into fertility and embryology research due to international concern about the future of designer babies   |
| 1998 | European Directive on the Legal Protection of Biotechnological Inventions                         | Directive 98/44/EC of the European Parliament and of the Council of 6 July 1998 and ratified under the Treaty of Rome – Harmonises the laws of Member States on patentability of biotechnological inventions, plant varieties (as legally defined) and human genes – under BREXIT review in the UK  |
| 2004 | Human Tissue Act  | It is a criminal offence to use or store human bodies or body parts without explicit consent. Human tissue can, however, be subsequently used in medical research under presumed consent provided it has been first removed for the benefit of a living patient being treated and they have not sought to object in person  |
| 2008 | Health and Social Care Act (Regulated Activities)   | Saying Sorry campaign of NHS Litigation Authority   |
| 2009 | <i>Jonathan Yearworth and others v. North Bristol NHS Trust</i> (known as the Yearworth Judgment) | Court of Appeal Judge warned that patients were entitled to compensation if their bodies generated sperm before undergoing chemotherapy and these a hospital mistakenly destroyed. It was not a defence in law that the hospital now owned that sperm and was not liable for its mistake. The case was an admission that Common Law may be no longer reliable, with regards to, the development of medical technologies and body/parts/products ownership |
| 2014 | Care Act (NHS)  | Duty of Candour – admission of errors is now a clinical responsibility to NHS patients  |

(16 & 17 Geo. 5 c. 59: 1926). For the purposes this chapter's legislative review, the part of the Bill ratified that mattered most to anatomists was *Sections 21–24*, which gave the coroner special powers for:

### **Post-Mortem and Special Examination**

21. Post-Mortem examination without an Inquest.
22. Power of Coroner to request specifically qualified person to make a Post-Mortem and Special Examination.
23. Fees to Medical Witnesses.
24. Power of Removal of body for Post-Mortem Examination.<sup>9</sup>

All of these slippery legal terms, notably 'Special Examination', created material ambiguities that were eventually repealed by HTA2004. Meantime, what the legal framework did was to extend the already extensive powers of the coroner and the nature of discretionary justice in their hands. This they made, and remade, during the modern era, and often to the benefit of their professional contacts in dissection rooms and pathology labs, as we shall see in Part II.

At the same time, central government passed the Registration of Stillbirths Act (16 & 17 Geo. 5 c. 48: 1926), alarming anatomists. They worried that their natural allies at the Coronial Office in sponsoring this new legislation might cut off dissectors from parts of their historic supply-lines. Previously a stillbirth – defined by the Victorians as the death of a fetus after the twentieth week of pregnancy – went unrecorded as an 'official' death. In English law, spontaneously aborted fetuses (accidental and unnatural) physically had to breathe independently when separated from their mothers or they did not exist legally as a human being. To save money, normally such grieving parents buried their dead offspring without paying a sexton's fee or covering a doctor's death certificate expenses.<sup>10</sup> Often when a mother and child died together, burying both in the same coffin was commonplace; families registered just the dead parent in the parish burial records of a local church. Anatomists could therefore ask coroners for their stillbirth cases without any official oversight and the promise of a small supply fee to those struggling to make ends meet in relative or absolute poverty. But after 1927, acquired human material now had to be recorded officially: '*“still-born” and “still-birth” shall apply to any child which has issued forth from its mother after the twenty fourth week of pregnancy and which did not at any time after being completely expelled from its mother, breathe or show any other signs of life*'.<sup>11</sup> Then the Births and Deaths Registration Act (1 & 2 Eliz. 2 c. 20: 1953) altered this stipulation again. The qualifying time span of official notification increased to '*within 42 days of the birth*'. This regulatory change meant that anatomists who acquired (or were supplied) with dead fetuses for the purposes of teaching and research could no longer do so unofficially, and without a time limit, as they had done for 200 years.<sup>12</sup> The outcome of the legislation was that it convinced the medical sciences of the vital importance of co-ordinating with coroners more

closely by the 1950s. The professional tensions that arose in this process are explored in Part II of this book.

By the early 1950s, a series of new laws and regulations about the use of the dead by the medical sciences became even more piecemeal. These generally reflected concerted public health campaigns that again had their roots in the late-Victorian era. Two in particular stand out because they were to have long-term consequences for disputed bodies, and issues surrounding them were to feature in public debates around the time of the NHS scandal at Alder Hey Children's Hospital. The first was the Pituitary Gland Programme (hereafter PGP) that began in the USA in 1958, extended to the UK under the auspices of the Medical Research Council (hereafter MRC). The aim of the initiative was to investigate whether children born with a shorter stature needed growth hormone treatment. The medical facts were that Growth Hormone Deficiency (GHD) appears on the pituitary gland, a pea-size gland at the base of the brain. Its function in the body is to be the 'master controller' to 'make hormones and control the function of other glands' efficiently.<sup>13</sup> Once it starts to malfunction, it 'slows down or stops from the age of two or three years onwards. It is often first detected through routine monitoring using growth charts although it can become more obvious when a child starts nursery or school and is much shorter than other children in the class.' Children characteristically display GHD by 'growing slowly' but crucially they do so 'in proportion', that is, 'the length of their arms and legs stay at the same ratio to their chest and abdomen'. Thus, 'their face may look younger than their actual age. They may also seem chubbier, more than other children, due to the effect of growth hormone on fat storage in the body. Puberty may occur later than usual or not at all.' By early adulthood, typical symptoms will have started to manifest, as:

- Increase in fatty tissue, especially around the waist
- Decrease in lean body mass (muscle)
- Decrease in strength and stamina, reduction in exercise capacity
- Decrease in bone density, increase in rate of fracture in middle age and beyond
- Changes in blood cholesterol concentrations
- Increased sensitivity to cold or heat
- Excessive tiredness, anxiety or depression
- Reduction in quality of life<sup>14</sup>

Medical science in Britain was therefore from the 1950s concerned to do new research on whether GHD had links to poor diet, a lack of sanitation or substandard housing: all social problems once familiar to the late-Victorians, exacerbated by the Wall Street Crash (1929) and the food rationing privations of WWII. The main diagnostic tool was to extract GH post-mortem in order to see 'if it could be manufactured in the laboratory and used to treat patients with hypopituitarism'.<sup>15</sup> This PGP initiative would expand exponentially in the 1960s, and by the 1980s it had grown into a commercial enterprise in northern



Europe, but one still reliant (in Britain) on the relatively cheap extraction of GH by anatomists, coroners and pathologists. The standard MRC payment for each post-mortem extraction was 1s 6d in the 1950s, increasing to £0.20p by 1985. As the amount of GH extracted each time was very small, multiple extractions happened until official approval for a more profitable, synthetic replacement for NHS use occurred in the 1990s. It was this hidden history that Professor Van Velzen exploited at Alder Hey Children's Hospital when he removed organs, including pituitary glands, as so-called 'bio-extras'. The standard means of harvesting GH was thus a classic case of 'going *around* the law while going *through* legal processes' overseen by the MRC and then supposedly the NHS.<sup>16</sup> And, it proved to be a pivotal catalyst for HTA2004.

Meantime a second post-war initiative involved the passing of the Corneal Grafting Act (15 & 16 George 6 & 1 Eliz. 2: 1952). This too had its roots in late-Victorian public health concerns about the welfare of the poorest children in England. Many suffered from common eye diseases and eye defects due to vitamin deficiencies and birthing problems associated with substandard medical practices before the establishment of the NHS. Professor Arthur Thomson, for instance, who ran the dissection program at Oxford University medical school from 1885, pioneered eye research and was funded by the MRC to do ophthalmology and its neurology from WWI. The new legislation in 1952 was hence the culmination of fifty years of research work, which seemed to justify expanding regulation of the removal of eye material from cadavers, post-mortem. As the *British Medical Journal* announced:

The use of cadaver material for medical purposes [has been] ... governed by the Anatomy Act of 1832 (2nd and 3rd William 4, cap 75.), which put a stop to the practices of the 'resurrectionists', and aimed at ensuring a legal supply of subjects for anatomical dissections from the bodies of unclaimed persons dying in public institutions. That Act did not help the provision of material for corneal graft surgery, since a complicated legal procedure has to be carried out before the body is available, and does not permit the removal of a fresh organ from the body since this is permissible only on a Coroner's order. Nor did the Act allow any person to bequeath his or her own eyes for graft purposes, as in law the dead body has no property. Legal opinion was that the removal of cadaver eyes for graft purposes, even with the consent of relations was, therefore, illegal. In addition, a large number of enlightened people in Great Britain who wished to bequeath their eyes for corneal grafts were, by law, prevented from doing so. It seemed, therefore, that if these obstacles could be removed the supply of donor material would be legally increased; surgeons would not run the risk of legal actions and the voluntary bequest of eyes would probably be sufficient for anticipated needs.<sup>17</sup>

Importantly, this legislation created two further initiatives that should have opened up a medico-legal space for donors and their families to enquire more about bodies and their body parts in their material afterlives. All the eye grafts were sent to a new eye-bank and cornea plastic units based at prominent hospital-based



eye units such as that at the Queen Victoria Hospital in East Grinstead Suffolk. Aware also of the sensitivities surrounding the gift of eyes, with many people feeling squeamish about donating them even after death, government launched a major publicity campaign. The BBC contributed, the press (both quality and tabloid newspapers) withheld sensational cases and emphasised instead the positive outcomes for NHS patients, and together the Women's Voluntary Service and the Royal College of Surgeons approached bereaved families in hospital emergency rooms for donations. In other words, in this specific context at the start of Queen Elizabeth II's new reign there seemed to be a concerted effort to be more engaging and open-handed. The confusion therefore about material afterlives came about after the passing of three amendments to AA1832: namely the Human Tissue Act (9 & 10 Eliz. 2 c. 54: 1961), Human Organ Transplant Act (Eliz. 2 c. 31: 1989) and Anatomy Act (Eliz. 2 c. 14: 1984).

In what follows in the rest of this chapter, these are styled HTA1961, HOTA1989 and AA1984 to avoid confusion. Before summarising their key features and explaining why they gave rise to disputed bodies by the late 1990s, it is important to set these cumulative legislative initiatives in the context of the history of international law. This is because what was happening in Britain did not occur in political isolation. Thus, as P. Sohl and H. A. Bassford explain: 'During the 1900s with the growth of complexity in both scientific knowledge and the organization of health services, the medical ethical codes addressed themselves to elaborate rules of conduct to be followed by the members of the newly emerging national medical associations.'<sup>18</sup> Then 'after World War II the World Medical Association was established as an international forum where national medical associations could debate the ethical problems presented by modern medicine'. Against this backdrop nonetheless concern was also being expressed that there was danger of seeing international consensus as 'progress' whilst ignoring its 'cultural relativism'. In reality, everyone welcomed the international framework of medical ethics, but it had to be applied in countries with 'different methods of financing medical services' and therefore differential socio-economic forces shaped doctoring and medical research cultures that were constantly evolving during the post-war era. In other words, we need to briefly engage with what the Hippocratic principle to 'first do no harm' meant in principle (the international foundation of medical ethics) before considering how it got applied in practice in modern Britain (the national imprint of HTA1961, HOTA1989 and AA1984).

### ***Primum Non Nocere – First Do No Harm – International Medical Ethics***

Once the Nuremberg Trials in 1945 exposed the atrocities of Nazi medical experimentation in the death camps of Auschwitz-Birkenau, there was an international effort co-ordinated by the Security Council members of the United

Nations to protect individuals from future exploitation.<sup>19</sup> The Nuremberg Code (1947) hence outlawed human experimentation of all descriptions that involved doing harm to the patient. Linked to the Declaration of Geneva (1948), this reflected widespread condemnation of war crimes in medicine, as well as a global commitment to monitor medical ethics to an international standard. The subsequent Declaration of Helsinki (hereafter DofH) in 1960/1, however, did not become international law. Instead, the UN ratified it as a code of practice, and monitored its uptake. One influential organisation to adopt its framework voluntarily in June 1964 was the World Medical Association (hereafter WMA). WMA consisted of a collection of voluntary national associations containing some eight million doctors worldwide, who signed up to self-regulate their commitment to medical ethics, education and the highest professional standards in patient-practitioner relationships. A crucial part of their commitment was that the WMA promised to remain politically neutral of the UN. At its 50th anniversary celebration in 2014, what was celebrated by WMA was the fact that their original DofH was now regarded as the cornerstone of human rights, a code of medical ethics that seeks to protect individuals against human experimentation in a global medical marketplace. It has unquestionably become *the* standard by which all ethical codes in individual nation states are judged in the human rights arena. It is not a code fixed in aspic: quite the opposite. Seven revisions happened since 1964, and that evolution is a creative process that keeps medical ethics valid in biomedicine today. In summary an overview remains:

The fundamental principle is respect for the individual (Article 8), their right to self-determination and the right to make informed decisions (Articles 20, 21 and 22) regarding participation in research, both initially and during the course of the research. The investigator's duty is solely to the patient (Articles 2, 3 and 10) or volunteer (Articles 16, 18), and while there is always a need for research (Article 6), the subject's welfare must always take precedence over the interests of science and society (Article 5), and ethical considerations must always take precedence over laws and regulations (Article 9).

The recognition of the increased vulnerability of individuals and groups calls for special vigilance (Article 8). It is recognised that when the research participant is incompetent, physically or mentally incapable of giving consent, or is a minor (Articles 23, 24), then allowance should be considered for surrogate consent by an individual acting in the subject's best interest. In which case their consent, should still be obtained, if at all possible (Article 25).<sup>20</sup>

The principal issue nonetheless with this important DofH codification is not its best intentions but, rather, its flaws. Few countries have queried the dignity of the human research subject. Most agree that an ethics committee should oversee scientific research that involves people (whether alive or dead). There is likewise consensus that good practice is what medicine is all about. Nation states do, however, differ on the degree of legal emphasis contained in

the original DoFH and its seven revisions. For the purposes of this book, there has been a great deal of contention about the meaning of 'informed decisions' (Articles 20, 21 and 22) and what system of consent (opt-in versus opt-out) should be adopted on location. In some countries like England, patients have to make a positive choice to enter a clinical study or donate their human remains to medical research in writing prior to death. Whereas, in the Welsh National Assembly, for instance, from 1 January 2015, an opt-out system of organ donation has been officially ratified because of organ donation shortages; that is, if you die it will be presumed in law that you intended to donate unless you took steps when living to state otherwise.<sup>21</sup> Recently, the Conservative government under Theresa May ratified new legislation in Parliament that followed the Welsh example in organ donation – though not without controversy. Thus, the fundamentals are the same but their resource management does differ, and this matters if historians are to trace their research threshold points and actor networks (discussed in Chapter 1), as well as their body disputes that have taken place in different places, at different times and for different reasons using donated bodies.

There has been, therefore, an increasing recognition in legal circles that translational medical ethics require good communication, an ongoing dialogue to reflect cultural change, and that in the modern world this has been a very complicated process since WWII. Some legislation succeeded, other bills did not. This was because in the recent past, civil servants who drafted government business in Britain were tasked with reconciling 'medical ethics, business ethics, professional ethics, and human rights considerations' as well as taking into account a doctor's 'fundamental fiduciary responsibility to the patient in the context of a growing secular, libertarian tradition'.<sup>22</sup> That complex and fast-moving bioethical backdrop started to expose the need for 'a fundamental reorientation' of issues of informed consent. Slowly, as legislation did not have the impact intended, patient groups began to argue that legal and ethical guarantees were not as robust as the medical sciences claimed. However, this often only became the focus of public attention after a number of body disputes came to press attention. This was because unless you can measure something, it is often difficult to manage it properly. Much modern medical research contained body parts, brain slices and tissue samples. It was consequently easier for those inside the system to evaluate international ethical policies translated to national contexts, rather than actual practices that were piecemeal locally. Approved policies also took time to be adopted, refined and applied by their intended users; continually these had the potential to result in multiple variables. It is therefore necessary to return to a discussion of keynote legislation and core medico-legal issues in the UK, since these ambiguities frame the research cultures in the rest of this book.

### A Toothless Tiger<sup>23</sup>

On 6 November 1967, the Right Hon. Julian Snow MP, Minister for Health in Harold Wilson's first Labour government (1964–1970), was asked by Cranley Onslow, MP for Woking, in the House of Commons: 'if he is satisfied that general practitioners are sufficiently aware of the provisions of the Human Tissue Act 1961; and if he will make a statement'.<sup>24</sup> The Minister replied that: 'My Department gave general practitioners guidance on the provisions of this Act in a memorandum issued in September, 1961 and I have no reason to believe that this has been generally overlooked. I am, however, glad to take this opportunity of again drawing attention to this guidance.' The matter, though, did not rest there. Over the next four years, there were numerous debates and discussions in Parliament about the efficacy of HTA1961. At issue was its implications for organ transplantation, and the degree to which it had placed more, not less, discretion in the hands of coroners, doctors, pathologists and transplant surgeons to decide on the material fate of donations from the dead and living donors in hospital care. So much so, that during a heated Prime Minister's question time in the House of Commons on 15 June 1971, Edward Heath (leader of the Conservative party) in reply to a question about the need to repeal HTA1961 and replace it with a new HTA statute at a forthcoming Queen's Bill, announced:

I realise that it is not only a question of opinion in the medical profession but that many hon. and right hon. Members have expressed the view that there should be legislation on this subject. Nevertheless, I think that if the hon. Gentleman studies the matter closely he will recognise that it is extremely controversial. What is required is a clear indication that legislation will improve the situation, and at the moment I think that that clear and convincing proof is lacking.<sup>25</sup>

At issue was that HTA1961 was supposed to have sorted out the class injustices of AA1832, but instead it had led to more ambiguity, confusion and misinformation. For the general public, what the legislation was supposed to have done was to set out what exactly informed consent meant in plain English, but it was flawed by the slippery civil-service speak of Parliamentary parlance. As Professor Margaret Brazier, Chair of Law at the University of Manchester, noted in the *Journal of Medical Ethics*:

The Human Tissue Act 1961 is a toothless tiger imposing fuzzy rules with no provision for sanctions or redress. Absent directions from the deceased . . . the act provides that the person lawfully in possession of the body (often the hospital where the body lies) may authorize removal of body parts for the purposes of medical education or research providing that having 'made such reasonable inquiry as may be practicable' [even though there is] . . . no reason to believe that the deceased had expressed objections to such a process or that 'the surviving spouse or any surviving relative of the deceased objects to the body being so dealt with'. Under the Human Tissue Act it may appear that

the requisite authorization, consent if you like, comes from the hospital. Hospitals permit themselves to remove organs and tissue which they desire to put to scientific or medical uses.<sup>26</sup>

Hindsight, she conceded, is a wonderful thing. Nonetheless, those who drafted HTA1961 should have been aware that although 'consent is such a simple word' it was also self-evident that a lack of clarity had resulted in many disputed cases. Helpfully, Brazier also elaborated on the legal position of the medical sciences:

A previous Master of the Rolls, Lord Donaldson, took a straightforward view of consent to medical treatment by living patients. He likened consent to a flak jacket. Once consent is obtained, the doctor is protected from legal gunfire. Consent protects his back. He cannot be sued. Academic lawyers, those rather precious creatures, dislike the analogy, ignoring as it does any analysis of the interests consent protects, avoiding even any mention of autonomy. Moreover, whether you like flak jackets or not, the crucial question remains of who has the requisite authority to provide the flak jacket to the doctor.<sup>27</sup>

There were essentially two medico-legal issues: 'Whose consent *should* have been obtained for organ retention? And whose consent *ought* to be obtained for organ return?' In other words, the main flaw in HTA1961 was exactly what the ethnographer Marie-Andree Jacobs identifies as a central problem with 'the law: how was everyone involved absorbing and using legal frameworks', and in what ways were those 'actors' going '*around* the law while going *through* legal processes?'<sup>28</sup> In many respects, these key ethical questions were not resolved by the raft of new legislation in the 1970s and set out in Table 2.1. This despite how widely the medical profession welcomed the Medical Research Council's new Ethical Code in 1979, which made MRC funding dependent on following new EC guidance. By the opening of the 1980s, there seemed to be an urgent need for yet more piecemeal legislation, tackling but never resolving discrete aspects of the consent issue.

The enterprise culture of Margaret Thatcher's Conservative government (1979–1990) saw the start of an unprecedented expansion of biotechnology in Britain.<sup>29</sup> In part, this reflected just how much early transplant surgery had benefitted from improved surgical training techniques, as well as the development of the next generation of drug-rejection therapies by the pharmaceutical industry. There were public health campaigns organised by the Department of Health to get more of the general public to carry organ donation cards, but still sociological studies found that half of those bereaved were prepared to give and half were not. As transplant lists grew longer, and patients' expectations rose, wanting to push past the dead-end of life, more and more parliamentary questions reflected on the need to deal separately with human organ transplantation. The result was the passing of HOTA1989. It had been preceded by

AA1984, and the Anatomy Regulations Act (1988) (hereafter ARA1988). HOTA and ARA were in principle about better accountability. The first prevented the illegal trade in organs and protected the vulnerable from becoming victims of organ harvesting. The latter made it compulsory for a written record to be kept of all bodies and body parts retained by medical schools for human anatomy teaching and medical research in Britain. This second medico-legal guarantee was heralded as a major ethical step forward, but it was nothing of the sort because the original AA1832 had a very robust system of tagging bodies to paperwork at each stage the corpse was moved on or changed hands.<sup>30</sup> It was, therefore, reintroducing an old law that HTA1961 had watered down, reviving it again to mask that HTA1961 was flawed. Because no official body had oversight of the entire process of medical research and its various hidden histories of the dead, older standards could be recycled in the belief that this was progress. It was clumsy and careless to reverse AA1832 legislation that was not fit for purpose in its HTA1961 form.

Focussing on the central aims of the various pieces of legislation passed in the 1980s to protect patients and facilitate further medical research, one aspect of AA1984 stands out. Amendments to statutes dealing with the legal use of organs and human tissue did not clarify who owned human material removed from its source. Moreover, it was clear that the issue of informed consent in a whole variety of contexts was very complex indeed. This was because it involved a balancing act of four sorts of agency: the patient, scientific research, medical doctors and public scrutiny. Thus, in letters to the *British Medical Journal* (hereafter *BMJ*) at the time the new AA1984 became law, some clinicians were asking uncomfortable ethical questions. What would happen to vulnerable patients with mental ill-health, manipulated into clinical trials by virtue of their vulnerability, and would those that committed suicide be automatically handed over by coroners for medical research post-mortem? Of concern were those patients who helped test new psychiatric drugs or 'electro-convulsive therapy' that aimed to alleviate severe depression. Is it possible, enquired Dr Neville-Smith in a letter to the *BMJ*, that fully informed consent is never achievable because the person in mental ill-health has an unbalanced mind? Others were likewise questioning what happens in organ donation to those so bereaved after a fatality that they cannot think straight. In response, a member of the psychiatric department at Leicester Royal Infirmary claimed that:

SIR,- Dr Neville-Smith raises an important ethical issue when he questions the nature of informed consent. It is, however, impossible to offer a simple solution. The protection of the individual patient, the need for research to improve both fundamental knowledge and patient care, and the need to maintain a humane and scientific profession must all be secured by policies acceptable to doctors and open to public scrutiny.<sup>31</sup>

It was the emphasis in this letter of reply on matters of consent being 'acceptable to doctors' (first – paternalism) and open to 'public scrutiny' (second – accountability) in that running order of priority that would prove to be contentious by the end of the 1980s. Eventually, the *Isaacs Report* (2003) would set out how and why the various statutes had proven to be inadequate by the end of the 1990s, even without the various NHS scandals that were to be catalysts for HTA2004:

9.3 No claim by statute is available to the person from whom tissue is removed. Indeed, the implication of the Human Tissue Act 1961, the Human Organ Transplants Act 1989 and the Anatomy Act 1984, though it is not expressly stated, is that the tissue removed pursuant to these Acts is given free of all claims, that is an unconditional gift. The Human Fertilisation and Embryology Act 1990, is less straightforward. Donors of gametes or embryos may impose conditions on use and may vary or withdraw any consent given. By adopting a scheme of consents, however, the Act avoids vesting any property claim in the donor [*sic*].<sup>32</sup>

The ethical issue was that the piecemeal nature of legislation was matching the piecemeal climate of actual research on the body – disassembled into parts – opened up for transplant harvesting of organs – and disaggregated to facilitate tissue, cellular and DNA modification. As Ronald Munson in his thought-provoking study of organ transplantation, ethics and society observes: 'Here is the "body that will not die" or at least not until the medical sciences is "done with it"'.<sup>33</sup> Thus, the ethical question remains, why was (and is) the public not sharing in the profitable outcomes of this enterprise? For, Munson insists, to describe the reach of scientific research as a simple 'gift exchange' in a biomedical era is misleading, especially when 'transplantation . . . is a second-rate technology. . . . It's a crude, stop-gap measure to keep people from dying.'<sup>34</sup> It is a viewpoint shared with many others in the wider scientific community. Sir Robert Lechler, Chair of Immunology at King's College London, thus explained in an interview with the *Times* on 14 July 2018 that soon: 'organ regeneration could end "barbaric" transplants'.<sup>35</sup> His latest regenerative medical research aims to allow patients to 'regrow their own diseased tissue . . . through stem cell changes to their genetic machinery'. The leading journal *Nature* likewise featured the latest laboratory discovery that there is a 'latent capacity of some organs to grow back when they are damaged' without the sort of debilitating side-effects that can blight the lives of transplantation patients on permanent immune-suppressants drugs. Science now recognises that transplantation does extend life expectancy but it also has opportunity costs for patients too, and ones seldom elaborated honestly in public health campaigns. As Jacobs reflects in a similar refrain: 'what emerges from documentation practices [in patient case notes] is agency in abeyance, a form of submissive self'.<sup>36</sup> It was this lived experience that would culminate in HTA2004, but not before the question of brain research was resolved.



### Brain Banking

The final catalyst that would contribute to a very public set of debates about the need for a repeal of old legislation in its entirety was the publication of the *Isaacs Report* in 2003. Jeremy Metters, HM Inspectorate of Anatomy, conducted a public enquiry into the retention of brains at Manchester University for post-mortem investigation and further medical research. As he explained:

It is important to remember that this investigation followed the chance discovery by Mrs Elaine Isaacs in April 2000 that the brain of her late husband had been retained for research in February 1987.

Had Mrs Isaacs not come across the letter sent to Mr Isaacs' general practitioner by the joint research team, she would never have known that her husband's brain had been retained, and the widespread retention of brains, and other organs, from Coroners' post mortems might have remained undisclosed.

Most of the brains from Coroners' cases in the 1980s and 1990s were initially held for entirely proper diagnostic investigation into the cause of death. A very much smaller number were retained specifically for research or teaching. The feature that unifies both these categories is that very few relatives were aware of the practice and I found no evidence that any were asked for their consent for later research or teaching use.

In this way the requirements of the Human Tissue Act [1984] were consistently disregarded.<sup>37</sup>

Metters undertook an audit and discovered that '21,000 brains collected between 1970 and 1990 were still held' for medical research. It was unclear how and under what circumstances Coronial cases generated human material from hospital mortuaries, or asylums, in England and Wales. He concluded that: 'Among the limited number of consent forms that I have examined, few specifically mention organ retention.' He thus reflected that: 'It appears the assumption was made that a signed post mortem consent form also indicated agreement to organ and tissue retention. It will never be known how many relatives were aware that organs might be retained from hospital post mortems without their knowledge.'<sup>38</sup> There was hence a need for an explicit and transparent form of informed consent keeping relatives fully and transparently engaged. This required new legislation to restore public confidence in post-mortems. His view was that there were 'serious weaknesses in the Human Tissue Act (1984)'. Perhaps the most obvious human one was that the statute made little allowance for the fact that:

The sudden death of a relative is among the most stressful of life's experiences and the closer the relative the greater the distress. The same usually holds true for the relatives of those whose deaths are reported to the Coroner for other reasons.

Many who are suddenly bereaved are 'in shock' in the days that immediately follow. More ready access is needed to the advice, support and counselling that is available for the relatives of those who die in NHS hospitals. . . .

When for the Coroner's purposes a formal statement is needed, there should be no pressure on a relative for its urgent completion or duress over the contents. While 'in shock', erroneous information may too easily be included.

As many relatives do not, at first, take in details of what is explained to them a written summary should be provided.<sup>39</sup>

It was imperative that those bereaved had a process of informed consent explained to them, a notion that echoed what some correspondents had been saying in the letter page of the *BMJ* since 1984. In the case of Mr Isaacs whose brain had been retained, allegedly used for medical research, but in reality 'destroyed' (according to the official report) without the knowledge of his Orthodox Jewish family, an apology was sent by Professor Deaking, head of the brain research unit at Manchester University, on 28 July 2000, that read:

*I do fully understand and sympathise with the additional distress this discovery has caused you. I very much regret that current standards and safeguards about post-mortem tissue that would have prevented this occurrence today, were not in place 13 years ago. At that time there was little awareness that a relative might have strong views or legitimate rights concerning the removal of tissue and this was overshadowed by a strong desire to assist research. While not in any way condoning these attitudes, it is worth reflecting that this UK research led directly to understanding the causes of Alzheimer's disease and to entirely new treatments for this incurable condition [sic].*<sup>40</sup>

There were two key misleading elements in this well-intentioned statement. The first is that Jeremy Metters, HM Inspectorate of Anatomy, concluded that: 'My enquiries have subsequently confirmed that no research had been undertaken on Mr Isaacs' brain, which had probably been disposed of in 1993.'<sup>41</sup> So the apology and its justification based on a medical research defence – namely the contribution that brain retention in this case may have made to a future cure for Alzheimer's – was a false one.<sup>42</sup> It was in fact very rare for a medical researcher at the time to be able to explicitly identify from their flimsy paperwork what they were hoping to achieve with specific human material at the point of so-called 'donation' or subsequently because the culture of record-keeping was to keep it sparse. This therefore looked and read like an officious excuse for an apology to those who read it. There was then the question of the culture of medical research and a lack of knowledge about wider cultural and religious sensitivities at the time that formed the basis of the second statement of apology in the letter to the Isaacs family. Again, this was incorrect.

Mrs Isaacs had repeatedly told the police, coroner and attending doctor on the night of her husband's suicide that he was an Orthodox Jew and that she needed therefore to bury the body intact within twenty-four hours according to her family's religious traditions, but she was ignored. This failure of oversight is striking. Given the publication of Ruth Richardson's renowned book, *Death, Dissection and the Destitute*, in 1987, there was ample

information in the public domain about the cultural and religious meaning of death and dissection since the original AA1832. Richardson's study received a lot of publicity in the medical press, and it was well known in the media that criticisms were being made about the cultural conduct of the medical research community *per se*. Indeed, so respected was her work that the Chief Medical Officer, Sir Liam Donaldson at the time of the various public enquiries into the NHS organ retention scandals at Liverpool and Bristol, had asked Richardson to assist with the cultural dimensions of his findings. It would therefore have been more honest to say in the Isaacs letter of apology that the medical profession did not choose to inform itself, rather than trying to use a weak ethical defence that '*current standards and safeguards were not in place*' and there was '*little awareness*' of the impact on grieving relatives. Indeed, it would be the scale of retention both at Manchester ('5,000 organs and tissues held at 4 locations'<sup>43</sup>) and elsewhere (some 50,000 organs<sup>44</sup> rising to 105,000 in the subsequent Redfern report<sup>45</sup>) that prompted a public backlash. It was no longer tenable to say that the medical sciences were sincere, but sincerely wrong.<sup>46</sup>

Today there is now an international recognition that bioethics is a very significant but also a somewhat complex and confusing legal framework which individual clinicians apply in their cultural settings in the global community. One key criticism of bioethicists that endures is how 'in terms of the classic triad of thought, emotion and action' – they have 'focused almost exclusively on thought – ethical thinking *per se* – and given inadequate attention to emotion and action'.<sup>47</sup> Thus, 'what has been lost in the academic processes' of evaluating the evolution of international and national ethical frameworks are 'concrete human dimensions ... the connection between ethical discourse and the full dimensions' of clinical decision-makers in a biomedical research facility between actors, particularly as technology advanced after WWII. To advance clinical ethics thus requires more careful historical consideration of rhetoric (ethical codes internationally) and reality (muddled national legislation), and its ambiguities. Moreover, as George Belkin wrote, we need medico-legal perspectives that are:

less concerned with generating rules of conduct than with deepening and enriching the self-understanding and perspective brought to bear when people confront choices and each other. And a humanist ongoing engagement and routine reflection can make medicine more deeply ethical than can duels over methodologies or ethics *per se*. Bioethics has narrowed how reflection in medicine about medicine takes place and has inhibited rather than rescued a medical humanism by an overrated focus on restrictive reduction to 'the ethical'.<sup>48</sup>

This book sits at this intersection – between rules and practicalities – between laws and choices in research spaces – between human stories and medical ethics that really happened.

### Conclusion

A raft of legislation in Britain, stretching from the Murder Act in 1752 to the Human Tissue Act in 2004, had sought to regulate the use of human material from the dead and the living for teaching and research purposes. Largely, however, regulations were piecemeal, and Parliament never took a robust oversight of all the stipulations to check that they still made sense in a fast-changing biomedical world. Those working inside laboratories (pathologists and neurologists), dissection rooms (anatomists), medical schools (clinicians and doctors), as well as specialists attached to cancer study centres, all assumed that the particular law they were following was correct. Few stopped to think about, much less check on, the robustness of their medical ethics and governance criteria. Everyone assumed that methods and training were correct, standard practice within the medical science community. It was the cultural changes taking place in modern British society which would lead to their investigation properly by the Chief Medical Officer around the Millennium. Meantime, the network of actors involved – in which the Coronial Office would prove to be a linchpin – followed fundamentally flawed statutes. The legal framework turned out to be akin to standing on ethical quicksand. Thus, to engage with the sort of ‘medical humanism’ that Belkin called for recently, we end Part I of this book by navigating a selection of human stories in Chapter 3 that reflect the main research themes to come in Chapters 4–6 in Part II. In this way, instead of dissecting bodies and mislaying their material histories, we begin to reconstruct, trace and analyse what it meant to conduct medical research behind closed doors, to sign up to train in human anatomy and to experience medically what soon became known colloquially in popular culture as the *Ministry of Offal*.

### Notes

1. Randall Lesaffer, ‘Argument from Roman law in current international law: occupation and acquisitive prescription’, *European Journal of International Law*, 16 (2005), 1: 25–58.
2. Refer, Elizabeth T. Hurren, *Dissecting the Criminal Corpse: Staging Post-Execution Punishment in Early Modern England* (Basingstoke: Palgrave Macmillan, 2016).
3. See Elizabeth T. Hurren, *Protesting about Pauperism: Poverty, Politics and Poor Relief in Late-Victorian England, c. 1870–1900*, Royal Historical Society Series (Woodbridge, Suffolk: Boydell & Brewer 2015 paperback edition).

4. Peregrine Horden and Richard Smith (eds.), *The Locus of Care: Families, Communities, Institutions and the Provision of Welfare since Antiquity*, Routledge Studies in the Social History of Medicine (New York & London: Routledge, 1988).
5. See, Hurren, *Protesting about Pauperism*, provides key historical context for trends.
6. See Elizabeth T. Hurren, *Dying for Victorian Medicine: English Anatomy and Its Trade in the Dead Poor c. 1834–1929* (Basingstoke: Palgrave Macmillan, 2011), chapters 5 and 6.
7. Edward Higgs, *The Information State in England: The Central Collection of Information on Citizens since 1500* (Basingstoke: Palgrave Macmillan, 2003).
8. See, Elizabeth T. Hurren, 'Remaking the medico-legal scene: a social history of the late-Victorian coroner in Oxford', *Journal of the History of Medicine and Allied Sciences*, 65 (April 2010): 207–252.
9. A complete PDF copy of *British Parliamentary Papers, Coroners (Amendment) Act* (16 & 17 Geo. 5 c. 59: 1926), was consulted on 20/10/2016 and can be accessed online at: [http://www.legislation.gov.uk/ukpga/1926/59/pdfs/ukpga\\_19260059\\_en.pdf](http://www.legislation.gov.uk/ukpga/1926/59/pdfs/ukpga_19260059_en.pdf)
10. Refer, for instance, Elizabeth T. Hurren and S. A King, 'Begging for a burial: form, function and meaning of nineteenth century pauper funeral provision', *Social History*, 20 (2005), 3: 1–41.
11. Hurren, *Dying for Victorian Medicine*, pp. 308–309 on stillbirth official changes.
12. *Ibid.*, discusses this backdrop in chapters 4, 5 and 6; see, also, Elizabeth T. Hurren, 'The pauper dead-house: the expansion of Cambridge anatomical teaching school under the late-Victorian Poor Law, 1870–1914', *Medical History*, 48 (2004), 1: 19–30, which identifies research on children and stillbirths.
13. Refer, *US Library of Medicine*, Medline Information Resource, 'Pituitary disorders', accessed 20/10/2016 at: <https://medlineplus.gov/pituitarydisorders.html>
14. *Ibid.*
15. In those who needed urgent treatment, there were four main types of deficiency that they suffered from, including a lack of: 'growth hormone, puberty hormones (or gonadotrophins), thyroid stimulating hormone (TSH, which stimulates the thyroid gland to make Thyroxine), and Prolactin and Adrenocorticotrophic Hormone (ACTH, which stimulates the adrenal stress hormone, cortisol). The posterior pituitary makes the fluid balance hormone called anti-diuretic hormone (ADH)' – Refer, *The Pituitary Foundation*, for accurate medical information about the range of conditions and current treatments available at: [www.pituitary.org.uk/information/what-is-the-pituitary-gland/](http://www.pituitary.org.uk/information/what-is-the-pituitary-gland/)
16. Marie-Andree Jacob, *Contemporary Ethnography: Matching Organs to Donors, Legalising and Kinship in Transplants* (Philadelphia: University of Pennsylvania Press, 2012), p. 8.
17. B. W. Rycroft, 'The Corneal Grafting Act', *British Medical Journal*, 37 (1953): 349.
18. P. Sohl and H. A. Basford, 'Codes of medical ethics: traditional foundations and contemporary practice', *Journal of Social Science Medicine* 22 (1986), 11: 1175–1179.
19. Notably, Paul J. Weindling, *Nazi Medicine and the Nuremberg Trials: From Medical War Crimes to Informed Consent* (Basingstoke: Palgrave Macmillan, 2006); Weindling, *Victims and Survivors of Nazi Human Experiments: Science and Suffering in the Holocaust* (London: Bloomsbury, 2014); Weindling, *From Clinic to*

- Concentration Camp: Reassessing Nazi Medicine and Racial Research, 1933–1945*, The History of Medicine in Context (New York & London: Routledge, 2017); and importantly, Michael Marrus, *The Nuremberg War Crimes Trial of 1945–6: A Brief History with Documents* (Basingstoke: Palgrave Macmillan, 1997).
20. See, World Medical Association Declaration of Helsinki, 'Ethical principles for medical research involving human subjects', *Journal of the American Medical Association*, 20 (27 November 2013), 10: 2191–2194, DOI: 10.1001/jama.2013.281053, retrieved 21/10/2016.
  21. 'Organ donation opt-out system given go-ahead in Wales', BBC News, 2 July 2013, accessed 21/10/2016 at: <http://www.bbc.co.uk/news/uk-wales-politics-23143236>
  22. Mary Jane Kagarise and George F. Sheldon, 'Translational ethics: a perspective for the new millennium', *Archives of Surgery, Journal of the American Medical Association* (2000), 135: 39–45.
  23. Margaret Brazier, 'Organ retention and return: problems of consent – symposium on consent and confidentiality', *Journal of Medical Ethics*, 29 (2003): 30–33. Professor Margaret Brazier, Chair in Law at Manchester University, had been asked to address the proposals of the Independent Review Group in Scotland on the Retention of Organs at Post Mortem to speak of authorisation rather than consent, and its attendant ethical issues when she spoke out about the flaws in HTA1961.
  24. *Hansard*, HC, vol. 753, cols. 334W, 6 November 1967, 'Prime Minister's Question Time answer on proposal to amend Human Tissue Act 1961 in the forthcoming Queen's Bill', reply by Prime Minister, Right Hon. Edward Heath, Leader of the Conservative Party.
  25. *Ibid.*, 15 June 1971, vol. 819, cols. 229–30.
  26. Brazier, 'Organ retention and return', p. 31.
  27. *Ibid.*, p. 32.
  28. Jacob, *Contemporary Ethnography*, p. 8.
  29. A historical connection made, persuasively, in Darrell M. West, *Biotechnology across National Boundaries: The Science-Industrial Complex* (Basingstoke: Palgrave, 2007).
  30. Hurren, *Dying for Victorian Medicine*, explains this context in chapter 1, pp. 16–17.
  31. Sydney Brandon (Department of Psychiatry, Leicester Royal Infirmary), Letters to the Editor, *British Medical Journal*, 289 (1 September 1984): 558.
  32. See, [http://image.guardian.co.uk/sys-files/Society/documents/2003/05/12/isaacs\\_report.pdf](http://image.guardian.co.uk/sys-files/Society/documents/2003/05/12/isaacs_report.pdf), accessed 24/10/2016, *Isaacs Report* (2003), Section 9.3. We will be returning to this report below since it dealt with the question of brain retention primarily.
  33. Ronald Munson, *Raising the Dead: Organ Transplants, Ethics and Society* (Oxford: Oxford University Press, 2002), preface.
  34. *Ibid.*, p. 22
  35. Oliver Moody, 'Organ regeneration could end "barbaric" transplants', *Times*, 24 July 2018, News section, p. 4, and leading article, p. 9, on *Nature*-published discoveries.
  36. Jacobs, *Contemporary Ethnography*, p. 42.
  37. *Isaacs Report*, Recommendations section, p. 11. See Chapter 6 later in this book on how Mr Isaacs died on 26 February 1987 aged 54. His family were of Orthodox Jewish descent and their belief was that the body should be buried whole, within 48

hours of death according to Jewish law. However, because Mr Isaacs had been treated for mental ill-health and he committed suicide at home, his body entered the post-mortem process of the Manchester Coronial Office. His body was taken to Prestwich mortuary where his brain was removed during post-mortem and kept for further research purposes at Manchester University.

38. *Ibid.*, Recommendations section, p. 11.
39. *Isaacs Report*, Recommendations 14 and 15, p. 24.
40. *Ibid.*, pp. 49–50, quoted in italics as per the original report.
41. *Isaacs Report*, p. 50.
42. Brains were likewise taken for research at Cambridge Addenbrookes Hospital for research into Huntington's disease and sometimes a 'control' brain was needed on which no research was done. This will be again discussed in Chapter 6.
43. *Isaacs Report*, p. 52, stated: 'The inventory had identified over 5000 organs and tissues held at four locations. These were: (i) the University Medical School in Oxford Road; (ii) the Central Manchester Hospital site (including the Children's Hospital); (iii) the Salford (Hope) Hospital site; (iv) the South Manchester Hospital (Wythenshawe/Withington) sites. A full list of specimens is held at each site, with a copy held centrally. Among these specimens were 473 brains in brain collections that had been reported to the Chief Medical Officer's Census.'
44. See for instance, Professors Ian Kennedy and Liam Donaldson's census estimates as reported in '50,000 organs secretly stored in hospitals', *Guardian*, 11 January 2001.
45. See, Elizabeth T. Hurren, 'Patients' rights: from Alder Hey to the Nuremberg Code', *History and Policy Papers* (6 May 2002), accessed 3/11/2016 at: <http://health-equity.pitt.edu/4042/1/policy-paper-03.html>
46. A split infinitive; and yet, an apt expression of the situation at the time.
47. See, Stephen Scher and Kasia Kozłowska, *Rethinking Health Care Ethics* (Basingstoke: Palgrave Pivot, 2018), p. 4.
48. George S. Belkin, 'Moving beyond bioethics: history and the search for medical humanism', *Perspectives in Biology and Medicine*, 47 (2004), 3: 372–385, quote at p. 378.