

**Blood in the Archive:
Rethinking the Public Umbilical Cord Blood Bank**

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Abstract

The collection of umbilical cord blood (UCB), a source of clinically-useful stem cells, has become a highly strategised process known as ‘banking’, with 160 banks globally. State-funded public banks rely on unremunerated donations of UCB from women. STS scholarship has explored the broader ethical and economic tensions of such banks and the private enterprises offering banking for a family’s exclusive future use of their own donated tissue. Less focus has been given to public banks’ institutional practices and strategic concerns. I address this gap by adopting an archival lens popularised by Jacques Derrida (1996). How, I explore, might it help to think of these collections not as banks, but as archives?

Using a number of qualitative data collection approaches, I develop an archival anatomy to highlight different elements of these selective collections of biological matter. I explore the issues of archival order and the racialised dimension of tissue selection criteria that guide UCB collection. I also interrogate the exclusionary practices of these collections. Whose donations are excluded, and what does this mean for a system reliant on the appeal to communitarian donation? Attention is given to how use is made of the archive. How might archivists be making the collection more appealing to these users? This leads to an exploration of the risk of obsolescence in UCB collections which struggle to sustain relevance alongside changing clinical requirement.

The thesis demonstrates how an archival lens offers the heuristic richness that ‘bank’ thinking cannot provide to highlight important aspects of operating and planning the future of a collection of biological material. It thus provides a novel contribution to the STS literature on regenerative medicine and tissue banking and the growing interdisciplinary corpus on the usefulness of the archive in understanding the complex aggregations of matter and data facilitated by contemporary technologies.

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Declaration

In accordance with University regulations, I hereby declare that the contents of this thesis are based entirely on my own original research and analysis, and have not been presented or submitted for any other degree or qualification. Interview data appearing in chapter four of this work have been formative in one published article. Another paper not using interview data collected for this project, unrelated to the substantive themes of this work, but reflecting on the fieldwork visit mentioned in chapter three is currently in press at the time of submission.

- **Williams, R.** (2015) Cords of Collaboration: Interests and Ethnicity in the UK's Public Stem Cell Inventory. *New Genetics and Society*, 34(3), 319-337.
- Brown, N. & **Williams, R.** (in press) Cord Blood Banking: Bio-objects on the Borderlands Between Community and Immunity. *Life Sciences, Society and Policy*.

Chapter One: Introduction

1.1 Introduction

Imagine finding out that you are probably going to die. But you have a chance, and it is in a freezer in Nottingham. Inside this big silver cask (which is probably just shorter than you but three times as wide) are lots of little slides. On each slide are many thousands of haematopoietic stem cells (HSCs), taken from somebody's umbilical cord just after birth. Maybe they were frozen last month, or five years ago (this matters, and I will get to that later). But they were frozen there in anticipation that somebody – possibly you – would one day need them. This story is rare, but it happens. In 2013, 93 people in the UK were told they had a similar chance in a freezer somewhere (Anthony Nolan and National Health Service Blood and Transplant, 2014: 25). But what makes all this possible? How did your clinician know to look at that particular freezer? Who did s/he have to speak to? How did s/he meaningfully decide that it was *that slide* that was your chance? Why was it *those* HSCs in the freezer and not some others? What networks, based on which knowledge, gave you this chance?

HSCs, which are used to reconstitute the bodies of patients with various blood malignancies, were found in the blood of human umbilical cords in 1974. Ten years later in the United States, a five year-old boy was given HSCs to cure his blood disorder. These had been taken from the umbilical cord that had sustained his newborn sister through gestation, well before the new personage of the saviour sibling had taken cultural root (Hocking and Ryrstedt, 2009). Soon after this, scientists in New York set up the first collection of individual umbilical cord blood units. Such collections, of which there are now 160 (World Marrow Donor Association, 2013: 2) are generally referred to as umbilical cord blood banks. But what strikes me about these collections of matter is that for one person to have their life saved relies on much more on than the act of depositing a unit in a 'bank'. The careful management of physical matter, the constant alertness to changes in scientific and clinical preferences, and the ongoing negotiation of whether a unit remains 'useful'. These themes of anticipation, futurity, resilience, use and so forth are much more readily drawn from what I think of as an *archival* sensibility than any kind of 'bank' logic.

I will step back first, though, and give some context. Before these collections of UCB existed, the only source of this type of stem cell was human bone marrow located via one of the established adult donor registries¹ that hold information but no physical matter from potential donors. It is umbilical cord blood banks and, to an extent, their relationship to other sources such as adult donor registries that form the context of what follows. More and more, UCB is figuring publically as a viable “weapon” in the clinical “arsenal” of “fighting” cancer, familiar language for an illness now as mortifying socially as it can be physically (Sontag, 1978). UCB’s prominence is particularly apparent in the occasional news articles that address the plight of the individuals who require these kinds of treatment. For example, a story for the *BBC* details the case of a toddler who received a UCB transplant:

‘A 19-month-old boy from Coventry is recovering after receiving blood cells from America that could save his life. [He] has a rare type of blood cancer and was told by doctors this summer he had only six weeks to find a donor. This week suitable blood cells from the umbilical cord of a newborn baby in the US were donated... the Anthony Nolan Trust ... said people from non-white backgrounds had a poorer chance of finding a suitable donor. [The patient] is mixed race and the cells he received were an 80% match rather than the 100% ideal. His family hopes to meet the donor when her identity is revealed. In the meantime they are campaigning to get more non-white donors on the bone marrow register’. (BBC News, 2014a)

In this news article about a young, ‘mixed race’ patient, the journalist explains that non-white individuals have ‘a poorer chance’ of finding a match. I could have chosen any number of examples for this. In the last year there have been numerous human

¹ *Adult donor registry* is the term that I use throughout this thesis although across the scientific and sociological literature it is used interchangeably with *bone marrow registries* or *registers*.

interest stories about this very issue: A woman with a Jewish-Hungarian father and a Croatian mother describes in *The Independent* how, because of her mixed-ethnicity background ‘the outlook was less encouraging’ (Partos, 2014). A Beijing correspondent for the *BBC* writes about a young British boy of ‘Chinese heritage’ who could not locate a match in the UK and found his donor on a registry in Shanghai instead (Hatton, 2015). *The Telegraph* features a British Pakistani girl who could not find a match on the registry, and felt ‘disappointed and angry’ at other Pakistanis for not having more of a presence on the UK’s bone marrow registries (Hoyle, 2014). A story in *The Mirror* introduces us to a young Londoner whose attempt to find a match has been made ‘even more difficult because of his Indian background’ (Manger, 2015).

These stories of disappointment, obligation, requirement and desperation all circulate around some configuration of race or ethnicity. When I read these stories, I feel a fundamental dissatisfaction. This is not dissatisfaction with the perceived ‘inequality’, but at the black boxed nature of these claims. Why is there thought to be a relationship between ethnicity and the chance of finding a match? In what realm of probabilities does this claim emerge, and how is it quantified? Is data collection really so fine-tuned that claims like this can really speak to the reality of stem cell provision? Let me return one final time to a news story. This one is about a man from Manchester.

‘A man who was given 18 months to live after being diagnosed with leukaemia has said his life has been saved by stem cells taken from umbilical cords ...The treatment for patients with cancers such as leukaemia uses donated blood stem cells, usually from adult donors, to replace damaged ones.... No suitable matches were found ... through a search of his family and a database of other donors. The grandfather ... said he “had never heard of getting stem cells from umbilical cords”...’ (BBC News, 2014b)

This grandfather from Manchester had not known that stem cells can be taken out of umbilical cord. It seems that he only knows about it because he could not find suitable tissue in his family or ‘a database of other donors’. It was, therefore, lower

down on the list of his clinician's preferences, only checked because the preferred sources were not available in this instance. Of course, it once was the case that umbilical cord blood would never have been considered at all. These technologies, of course, have not always been around. How, as a treatment option, did it transition into being on his clinician's list of treatment options? Would it always have been there as an option for him? In ten years' time would this man's clinician even bother to look through the adult database or would the clinician search for cord blood first? This story also highlights the requirement of needing interconnected, searchable collections of these sorts of tissues. There is a sense, even simply in knowing somebody was searching through these databases and collections that – at a given time – one of them held suitable tissue. These are, it seems, *managed* spaces with practices akin to curated, retrievable collections in which matter and data are thoughtfully archived away for a future time.

News stories like the ones above tend to focus on the individual trials of patients. A Mancunian grandfather, a mixed-race toddler. These are, of course, important and influential narratives. They help not only to engage audiences but steer public understanding in how these kinds of illnesses (and their possible cures) work (Henderson and Kitzinger, 1999). But there is not much more in the way of patient stories in this thesis. In part, this is because I am interested in the availability of HSCs and patients actually have little to do with the search for tissue. They do not ask for a particular treatment, but “place their faith” in the practitioner to make informed choices on behalf of them. Nor is there any data from the actual or potential UCB donors as my interest is focused more on those *who collect*, rather than who they collect from. These decisions, made early on in the research, were informed by Healy's contention that we are best thinking of these sorts of systems as systems of procurement instead of systems of donation. He writes that human tissues are

‘...collected and distributed by complex organizations ... The coordinating organizations work to elicit donations from donors, to elaborate the meaning of the donation, and to specify the nature of the gift and the obligations that flow from it. This work involves both logistical and cultural effort. The result is a practical system of

procurement and distribution, but also a moral order of exchange.’

(2006: 17)

Healy’s work focuses on procurement of blood and organs, not blood stem cells. But I take important guidance from Healy. What I am looking at is a complex system of procurement that cannot be reduced down to many singular acts of donation. Each unit of cord blood, each saliva sample at an adult donor drive, can only be donated because a system makes it possible. Part of my general interest has been in trying simply to understand that system. How does it operate? What knowledge and motivations guide it? What practices sustain it?

In the UK, the two main British umbilical cord blood banks are run by independent organisations: the National Health Service Blood and Transplant (NHSBT) agency and a charitable trust called Anthony Nolan (AN). In 2010, a government minister announced the production of a unified national UCB banking strategy as part of a plan to produce recommendations for managing and developing the UK’s own supply of publically available blood stem cells (Hansard HC Deb., 2010). The UK’s Department of Health oversaw this forum, which was called the Stem Cell Strategic Forum (SCSF). It was made up of different parties including representatives of AN and NHSBT, along with senior practitioners working with stem cells and generally attached also to Universities and actively publishing academic work, and patient charity activists involved in this area of transplantation. This manifested in a report (UK Stem Cell Strategic Forum, 2010a, 2010b). But why would the collection of tissue into a freezer require so much planning?

In 2012, a few months before my project began, the SCSF report recommendations were taken up by the All-Party Parliamentary Group on Stem Cell Transplantation (APPG) which hosts SCSF members to discuss points of the collaborative governance arrangement as it develops. The APPG produced its own report (2012) that re-asserted the requirements and recommendations laid out initially by the SCSF. It reasserted there was a need for practitioners (in the clinic) and scientists (in the bank) to be in dialogue. Why would it be that a bank of UCB stem cells would need a “strategy”? What makes the scenario so challenging that it demands such regular reconsideration, and from so many parties?

This thesis addresses these themes, arguing primarily that the most comprehensive understanding of these public collections of UCB comes through trying to reconceive them not as banks, but as ‘archives’. This is done through laying out what I call an archival anatomy, which I then use to explore how these collections are understood, managed, and used. How, I explore, can archival thinking help us to understand the ways in which collections of cord blood are *ordered*? This draws in an exploration of race as a complex and contested ordering mechanism in contemporary collections of human tissue. The thesis also asks how these public collections of cord blood can be seen, like all archival collections, as *exclusionary*. Here, new issues about the validity of the extant public/private binary of banking are raised. The archival anatomy also gives rise to questions of *use*. How clinicians’ affective and rational repertoires of decision-making combine to make a collection more or less useful becomes central here, as well as how those working in such collections respond to shifts in these preferences. Finally, the thesis explores how the element of *risk*, central to the longevity and relevance of all archives, plays out in public collections of umbilical cord blood. What different risks confront those charged with maintaining and sustaining these gatherings of matter, and what is done to efface such issues?

Before this, however, the following chapter plots out the history that made the asking of all these questions possible. It provides an introduction to the varied understandings that scientists have had about how bodies come to be “compatible”, and how our molecular constitutions are framed within the language of ethnicity and race. I also plot out the emergence firstly of collected data about adult stem cell donors, and secondly of UCB matter, before contextualising the UK’s provision of these sources. I do this to introduce the suggestion that what is at work within the strategic management of such collections is an archival practice of sorts. Before all of this, though, it is important to note that the provenance of UCB lies, perhaps a little surprisingly, in the tumultuous beginnings of nuclear science. Bomb making seems far away from the stories mentioned above. However, this context helps to frame the technology I write about in the chapters that follow, as well as the careful, selective, archival practices that I discuss within them.

1.2 From Military Research to Treatment Paradigm

Writing about the convergence of military interests and scientific development, Naomi Oreskes warns that ‘any account of knowledge that does not include its cultural origins is at best incomplete, and at worse misleading in intellectually and politically significant ways’ (2014: 1). Laying out a definitive teleology of historical events is, perhaps, impossible. In attempts to do so, we must posit even more questions than we perhaps can answer. The stories I tap into now come both from the scientists themselves, and comprehensive accounts of the intellectual emergence of the theory and practice of haematopoietic stem cell transplantation that have been laid out by others (Kraft, 2009; Kutcher, 2003, 2009). It is necessary to explore, if only fairly briefly, some of the ‘cultural origins’ of the ‘account of knowledge’ (to borrow from Oreskes again). This is because to understand the contingencies and anticipations that I want to illuminate in the chapters that follow, the reader must recognise that things were never certain, never known.

To really emphasise the unsettled foundations of a science that is now one of the mainstays of the regenerative medicine repertoire, it is worth noting that early iterations of this kind of health intervention, particular bone marrow transplantation, a cancer treatment, ‘was not developed by clinicians for the treatment of cancer’ (Kraft, 2009: 173). Bone marrow transplantation, which preceded the banks of umbilical cord tissue that join it as a treatment option in contemporary cancer patient experiences, was developed purely to address underlying concerns for the welfare of military personnel working directly with nuclear material (Kutcher, 2003). It was also intended to remedy the increasingly frequent incidents of lethal radiation amongst clinicians given the increased use of x-rays (Kraft, 2009). Indeed, in their history of the radiography professional, Thomas and Banerjee suggest that concerns about dose reduction in diagnostic radiology emerged because ‘many of the early generation of X-ray workers’ (2013: 14) actually died from using the equipment. These were some of the many ‘*radiation martyrs*’, as the authors call them, of early radiology.

More broadly, as nuclear fear began to emerge in the wake of the Japanese atomic bomb attacks (Weart, 2009) a need for effective treatment for radiation became even

more pressing. As Kutcher notes, ‘In the period immediately following ... Hiroshima and Nagasaki, a new type of illness was identified’ (2003: 109). Depicted in contemporaneous journalism as the ‘atomic plague’ (Lindee, 1994: 11), such events highlighted the risk to civilians in addition to the existing concern for military and medical personnel. Based upon such accounts, it makes sense that E. Donnall Thomas, one of the leading early bone marrow transplantation researchers, felt it was out of concern ‘for the atomic disaster of tomorrow’ that medical interventions for irradiation should be developed without delay. The following came from one of the early papers he authored with colleagues. Its importance is perhaps evidenced by his own re-iteration of the same tract in his 1990 Nobel Prize lecture where he framed the history for which he had won the award.

‘In an atomic age, with reactor accidents not to mention stupidities with bombs, somebody is going to get more radiation than is good for him. If infusion of marrow can induce recovery in a mouse or monkey after lethal radiation, one had best be prepared with this form of treatment in man. The leukemic patient who needs radiation and bone marrow ... From helping them one will be preparing for the atomic disaster of tomorrow and it is high time one did.’ (Thomas *et al.*, 1957: 496)

Perhaps unsurprisingly, this ‘military face of leukaemia therapy was made to vanish from the history of medicine’ (Kutcher, 2003: 117). It is only in critical histories of the technologies written later and in some very brief reflective moments later on by those involved in the technology at the time (Thomas, 1994) that we see such stories told. Indeed, it is unlikely that most people receiving this kind of treatment (and probably plenty of the people facilitating it) are even aware that most of the early research on this kind of treatment, almost exclusively happening to mice and dog models, was catalysed and funded by state military institutions such as the U.S. Atomic Energy Commission and the U.K. Atomic Energy Research Establishment. And just as it is difficult to give the teleology of a technology, it would be hard to know what kind of impact, if any, this knowledge of the past might have on a stem cell recipient today.

As I have already noted, bar a few historical accounts of the emergence of stem cell technology, there is not much to draw from in trying to give some historical context to the chapters that follow. As such, I want to consider a few of the original studies by what are now considered to be some of the most significant groups according to these accounts. In particular, the group that was led by E. Donnall Thomas who features prominently in the academic accounts mentioned above. But in telling histories we are at risks of obscuring or reducing the multiple processes that bring the present into being. Readers might notice the androcentrism of the chapter that follows. Indeed, it was a highly masculine environment where research teams comprised only men. In January 2015, when E. Donnall Thomas's widow Dorothy "Dottie" Thomas passed away, the New York Times obituary noted a comment once made by her husband:

‘In the laboratory days, my sometime friends pointed out that Dottie, who had the library experience, would go to the library and look up all the background information for a study that we were going to do, and then she would go into the laboratory and do the work and get the data, and then with her writing skills, she'd write the paper and complete the bibliography. And all I would do is sign the letter to the editor.’ (Roberts, 2015)

Sure enough, Dottie Thomas is not on the list of authors of these papers, and it is arguably only because of the professional success of her husband that we can glean this knowledge of her story. Thus, we must proceed with caution that in the context I now explicate there are unavoidable omissions, not least about the roles of the many women who doubtless brought this science into being without any of the scientific credit granted to their male counterparts.

In the 1950s, the uncredited Dottie, her husband, and his team attempted to demonstrate that bone marrow contained cellular entities that might act as the seed for further cell production. Kraft argues that this research period constituted an attempt to reinforce the existing ‘cellular’ hypothesis that one cell could seed the repopulation of the body with its various kinds of cells. This theory was gaining traction against the ‘humoral’ hypothesis that a hormone might promote cell

production. The cellular hypothesis would – as Warwick Anderson and Ian MacKay (2014) have since pointed out about the duelling theories – only reinforce the case for the construction of the body as a defensive space that could fold in on itself and ultimately breakdown from within.

Thomas *et al.* (1957) reported results of allogeneic marrow grafts in a series of six human patients with different forms of immunitary illness. The marrow that patients received had been taken from living and cadaveric donors, aborted foetal tissue and, in one case, a human rib removed during an operation to open up their chest. There is perhaps some biblical irony that it was the only woman in this series of six patients that received the rib marrow. Several patients died soon after treatment, whilst others became ‘ambulatory’. Beyond this, the success of the treatment was not detailed though it has since been noted in a piece to commemorate the 50th anniversary of the paper that all the patient treatments were unsuccessful (Forbes, 2007).

Human patients were used for these ‘experiments’ when opportunities to do so presented themselves. However, as Thomas would point out in his Nobel Prize lecture (1994), researchers could be more systematic in their efforts by using animal models. Perhaps unsurprisingly, his account does not reflect on some of the ethical tensions engendered in this reliance on animals, or even how the research in this period was vital in standardising animal models for the biomedical research that would follow (see Rader, 2004). The potential ethical tensions that might beset such studies today notwithstanding, the most revealing early research on HSCs came from research on dogs and mice. Thomas and his colleagues were making direct causal links between clinical success and the donor and recipient being genetically related litter-mates (Ferrebee *et al.*, 1958; Thomas *et al.*, 1959).

Their studies also made reference to work early in the decade by Barnes and colleagues, a team based between Paris and London. In this study, the authors had induced leukaemia in mice from one strain through whole body irradiation. The researchers then injected the irradiated mice with marrow from other, healthy mice. Some would receive this marrow from another mouse from within their strain, and others would receive marrow from unrelated strains. Grafts from these latter unrelated strains were less successful in the mice. The authors noted that, as of 1956,

the failure could not be explained. ‘The detailed pathological processes,’ they wrote, ‘are not yet understood’ (Barnes *et al.*, 1956: 627). But they were more optimistic about the grafts that *were* successful. Mainly these successes occurred when the source of tissue came from a healthy mouse of the same ‘strain’, i.e. genetically related animals.

Thomas would later point out the importance of this link in his Nobel Prize recipient’s lecture. He would note that allogeneic transplantation (that is, tissue taken one dog and grafted into another) mainly resulted in either immediate failure or a successful engraftment proceeded by a deadly wave of illness. This was what clinicians now understand to be graft-versus-host disease (GVHD). GVHD was conceived of as the ‘secondary syndrome’ and began to be understood, as it still is now, as a situation where the cells seeded by the transplanted marrow attack the recipient’s body (Kutcher, 2003). But Thomas *did* find some encouragement in ‘the fact that an occasional dog, usually with a littermate donor, went through the grafting procedure successfully’ (Thomas, 1994: 341). Results presented in the 1959 study also gave some suggestion that there was the capacity for unrelated canine marrow transplants too. The 1959 paper concluded that ‘marrow transplants between unrelated animals appeared more difficult but not impossible’ (Thomas *et al.*, 1959: 734). With encouragement from successful *related* engraftments in a few dogs and a sense of the possibility of *unrelated* engraftment, researchers in the field were moving towards an understanding simultaneously emerging more widely in the nascent profession of immunology that it was possible for two beings to have some gradient of ‘compatibility’.

1.3 Molecular Individuality and Race

As Warwick Anderson and Ian MacKay note, 1950s immunology saw the suggestion that a human might have a particular expression of antigens across all their cells that could be either more or less compatible with another person’s. But short of the breakthrough success of extended patient survival post-graft, it would not be until the 1970s that a link would emerge between these ‘transplant antigens’, and immunological responses between donors and recipients. Importantly, this meant that a single human could then have one expression or ‘type’ common across their cells.

This, as Anderson and MacKay put it, compelled ‘a deeper understanding of the molecular meaning of individuality’ (2014: 117) which speaks to the dominant logic of tissue transplantation as it emerged in the 20th century, and as it develops today.

This logic operates on an immunitary distinction between the *allogeneic* and the *autologous* derived from the Greek *autós* (self) and *állos* (other). An autologous transplant (or ‘autograft’) is therefore one in which the patient is the recipient of their own tissue, taken from and then re-placed into, the self. An allogeneic transplant (or ‘allograft’) describes the opposite, any scenario in which a patient receives tissue from somebody else, an ‘other’ – be they a stranger, a friend, or a relative. Transplantation technology is thus held together by a fundamental understanding of self/other distinction and that some bodies are, corporeally, more or less compatible than others. In the dominant model of immunological understanding, transplant compatibility between a donor and a recipient is determined by their Human Leukocyte Antigen (HLA) type. Using molecular analysis, tissues can be ‘typed’ for their HLA composition. According to the current consensus, the formation of ‘a unique protein sequence’ (Hollenbach *et al.*, 2011: 336) on the surface of individual cells is guided by a particular set of genes. These genes can be analysed to determine (referring back to Anderson and MacKay’s compelling term) a person’s molecular individuality.

Guided by an understanding that it is a small section of genes that determine a person’s cell surfaces, this technology is used to establish a tissue type. In a bone marrow transplant, up to five genes are looked at. These are the genes currently called *HLA-A*, *HLA-B*, *HLA-C*, *HLA-DRB1* and *HLA-DQ* (Howard *et al.*, 2015; Shaw *et al.*, 2009). As per the current consensus in the field, all individuals ‘inherit both a maternal and a paternal HLA allele, co-dominantly expressed in the cell’ (Erlich, 2012: 2). Accordingly, two versions of each of these five genes must be looked at. A tissue type must therefore offer an analysis of 10 genes (the maternal and paternal versions of the HLA antigens deemed important to compatibility). Both recipient and donor are typed in this way, and their compatibility can be measured by how closely matched these genes are. Two people could conceivably be compatible at each antigen, and thus be a 10 out of 10 match. This is, of course, just an account of the current model of understanding. This account has changed as more research

has highlighted the relevance of hitherto unconsidered factors. As a recent consensus status notes, ‘typing resolution terms have the potential to change over time as new alleles are identified’ (Hollenbach *et al.*, 2011: 339). As such, one of the questions that must be asked is how the model and the wider field contend with these changes as they happen.

The 1950s- and 1960s-era research on HLA typology took place in a highly competitive environment. In his history of the profession of immunology, Leslie Brent notes that HLA research was being undertaken by ‘powerful personalities’ in a professional world with a ‘strong competitive edge’ (Brent, 1996: 141). In the 1960s, the leaders in the field were searching for assent to their own systems that would adequately describe these antigens and their molecular variability. To do so, they ‘arranged annual international histocompatibility workshops to bring some order to the research enterprise and to standardize classification’ (Anderson and MacKay, 2014: 128).

The bringing of order, then, was central to the historical emergence of the immunological individual. The individuated body’s identity in immunological terms, was (and is) ‘still in formation, still learning, shaped by its continuing history’ (Anderson and MacKay, 2014: 132). It was, the authors note, out of such meetings that a consensus developed by the end of the sixties that there was one major histocompatibility complex in the human body, the overarching HLA framework. Discussions over standardisation and the controversies that surround them are germane to this field. As STS scholars have noted, the clinical application of nascent technologies requires the setting of standards, workflows and nomenclatures (Berg and Timmermans, 2000). To refer back to Anderson and MacKay, the compunction to ‘bring some order’ is inscribed in the field of immunology. As such, it is important to ask how the endeavour for standardisation and order informs the practices of contemporary stem cell transplantation.

As Thomas would reflect in his Nobel Prize lecture, after a number of allograft (self-to-other) failures in human patients, researchers abandoned further study of the area. It was work beyond the field of marrow cell transplantation, namely by immunologists exploring the HLA framework, that would bridge that gap between

knowing that tissue transplantation *could* be done, and learning more about *how* it was done:

‘As we developed our knowledge of DLA [Dog Leukocyte Antigen] matching, we followed closely the work of Dausset (Nobel Laureate, 1980), van Rood, Payne, Bodmer and Amos in the human, the HL-A system. By 1967, we thought that the time was right to return to allogeneic marrow grafting in humans.’ (1994: 341)

These antigen discoveries of the fifties joined the ABO antigen group as another means of locating and articulating molecular differences between bodies. The ABO group meant that people (anybody donating or receiving blood) could be divided up. For example, I can say I am “O rhesus positive” which distinguishes me and fellow group members from anybody who is *not*. So too did the ABO conception allow people to be divided up, as Lawrence Hill (2014) has noted, into *racial* groups even though two people from anywhere, of any skin tone, who have the same blood type can share blood in a transfusion safely. Blood, as Hill adeptly demonstrates, has a racialised history that precedes all the advances of the 18th, 19th and 20th century in the laboratory.

Race is tenacious and so, perhaps unsurprisingly, it emerged as a meaningful category around which a lot of the immunology profession’s early work would coalesce, particularly in their work with geneticists. For example, Dausset (whom Thomas cites above as an important influence in his own understanding of bodily compatibility) became ‘obsessed with mapping patterns of HLA expression around the world’. He was joined by geneticist Luca Cavalli-Sforza known (in)famously for the ill-fated Human Genome Diversity Project (Reardon, 2005) where indigenous activists’ accusations of ‘biocolonialism’ stymied any further research in that vein. Dausset and Cavalli-Sforza attempted ‘to trace the global distribution of human polymorphism, or genome diversity’ (Anderson and MacKay, 2014: 129). Walter Bodmer, whom Thomas credits too, also engaged in research about human polymorphism with Cavalli-Sforza.

This involvement of population geneticists and immunologists had repercussions that emerge in a racialised way. I have already noted that, as the dominant immunological model would have it, half of any cell's surface in a given human body is 'maternal'. The other half, by this logic, is 'paternal'. The gendered dynamics of this language aside, it is understood that the surfaces of cells are dependent on one's parentage (Erlich, 2012). Population geneticists such as Bodmer, it could be argued, extrapolate out from this basic tenet. They suggest that different 'populations' have different 'frequencies' of HLA types. In the literature, notions of populations often transmute into racialised language. Race, the tenacious category, thus re-emerges in this conception of bodily difference as it did in the organisation of tissue matter in light of the discovery of the ABO antigen system (Hill, 2014). 'White', for example, could have several near-synonyms. If you are white in one instance, you could be 'Caucasian', 'European', or 'Caucasoid'. Though each permutation might have different meanings, they are used in the literature interchangeably, something that Catherine Bliss (2011) calls a conceptual 'slippage' in her systematic literature review of the use of racialised language in genomic research.

In 1971, Bodmer co-authored a book with Luca Cavalli-Sforza, the Italian geneticist who had worked with Dausset. *The Genetics of Human Populations* (1971) explored the methodological and theoretical underpinnings of global studies of genetic difference, including HLA-type differences, around the world. The work remains a reference point for studies of the HLA frequencies in different marrow donor groups around the world (for example, see Mori *et al.*, 1997; Schipper *et al.*, 1997). In 1994, Cavalli-Sforza and colleagues published *The History and Geography of Human Genes*. This is now a much celebrated milestone title in human genetics, its most recent citation being in a paper on 'racial and ethnic differences' in drug disposition and response by Ramamoorthy *et al.* (2015) demonstrating that the echoes of its publication over forty years ago can still be heard.

In the field, the pervasiveness of the immunological thinking set out in these key texts became manifestly apparent during a conversation with a scientist. Just after they had signed their informed consent form, and I had turned on the voice recorder, they queried my interest in the research topic. I explained that I had been very interested in the work of population geneticists, and the controversy surrounding

Luca Cavalli-Sforza. Hearing this, the interviewee stood up from their chair to consider their book shelf, full of large folders and a handful of textbooks. They pulled out a copy of *The History and Geography of Human Genes* as if to evidence our shared interest. They explained:

I've got his book. It just happens to be one of my interests as well.

The front cover of this book displays a world map colour-coded to depict what the authors believe to be four major 'ethnic groups'. They are keen to avoid the term race, laying out in the book how the term has suffered 'scientific failure' at the hands of 'modern taxonomists' whose seemingly classification-happy work had produced '3 to 60 or more races'. Cavalli-Sforza *et al.* explain that 'this latitude depends on the personal preference of taxonomists, who may choose to be 'lumpers' or 'splitters' (1994: 19). Cavalli-Sforza and his colleagues thus prefer the term 'ethnic group' by which they refer to places on the globe where they had data to evidence that people living there were more likely to present particular antigens on their cell surfaces (that is, HLA tissue types). Of course, this could be read as *their* personal preference for lumping and splitting. In Carter and Dyson's discussion of the apparently benign language of ethnicity, they argue that the term is 'a clever contrivance to allow researchers to talk about the fixity of social character without using disreputable notions of race' (2011: 966). Similarly, we might argue that the term 'ethnic group' seems to allow the authors of *The History and Geography of Human Genes* to talk about race without actually having to say the word.

Colour means something when we talk about race. Since the start of the 20th century we have witnessed the theoretical proposition of a 'color line' (Du Bois, 1903) and a 'color complex' (Russell-Cole *et al.*, 2013). Colour has a lot of weight given its political centrality to the project of race equality. Therefore it seems at best problematic that the front page of a book that at once extolls the 'scientific failure of race' whilst arguing for the ontological facticity of ethnic grouping, should so prominently feature a colour coded world map. Each colour represents an ethnic group. *Yellow* for 'Africans', *red* for 'Australians', *blue* for 'Mongoloids' and *green* for 'Caucasoids.'

Jonathan Marks argues that Cavalli-Sforza exemplifies the unreflexive use of race (2010: 266). The lack of reflexive engagement with the terminology used in studies such as these could, it has been argued, mean that scientists are potentially unproductively delimiting public understandings about what genetic differences between individuals actually mean (Lee, 2009). A sustained awareness of the use of these terms is vital because uncritical employment of them might ‘serve to produce and reproduce wider forms of essentialism, stereotyping and racism’ (Gunaratnam, 2003: 19). It would indeed be helpful for scientists or, as Anderson calls them, ‘nature’s interlocutors’ (2006: 253), to explain their adoption of specific taxonomies. This is because, as Bliss points out, one might be reifying race as a genetic fixity whenever one uses it to produce and disseminate genomic research. Such categories, which are ‘imported from the social sphere must be carefully explained and defined’ (2011: 1026).

It is in this critical context that Jonathan Marks (2010) draws comparisons of Cavalli-Sforza and colleagues’ contention with the work of Carl Linnaeus, ‘the grandfather of modern taxonomy’ (Bowker, 2005: 129). In particular, his effort to taxonomise the world’s population into four races (white Europeans, red Americans, brown Asians and black Africans) as the below table, reproduced from Sundquist (2008), plots out.

Table 1: The world’s races according to Carl Linnaeus’ “Systema Naturae”

Europeus	Skin (white); build (muscular); hair (long, flowing), eyes (blue); disposition (gentle, and inventive)
Americanus	Skin (reddish); build (erect); hair (black, straight, thick); distinct facial features (wide nostrils); disposition (stubborn and angered easily)
Asiaticus	Skin (sallow; yellow); hair (black); eyes (dark); disposition (avaricious and easily distracted)
Africanus	Skin (black); hair (black; frizzled); skin texture (silky); distinct facial features (nose flat, lips tumid); disposition (relaxed and negligent)

In this thesis, I do not attempt to evaluate the facticity of the race-based claims made in the field. Putting this simply, I do not want to make any attempt to question race's (in)existence. Brett St. Louis writes that sociological critiques of race category usage 'have arrived at the following conclusions: race does/does not exist and we should/should not use the concept' (2005: 30). We might therefore take on board Rogers Brubaker's understanding of races as 'practical categories, situated actions ... organizational routines, institutional forms, political projects, and contingent events' (2004: 11). This is borne of an understanding of racialisation as, primarily, a political practice. He argues that we must take 'as a basic analytic category not the "group" as an entity but groupness as a contextually fluctuating conceptual variable' (*ibid.*). Brubaker's argument engages with overt political groupings based around ethnicities, but its logic can be extrapolated into the arena of public stem cell banking, wherein processes of 'groupness' can be located in the mobilisation of organisations. Perhaps most importantly, Brubaker argues that to understand race 'does not require us to posit the existence of race'. Rather, to borrow from the same writer again, I am interested in considering the means and processes through which 'people – and organizations – *do things* with categories' (*ibid.*: 13). Thinking back to the story of the mixed raced toddler at the beginning of this chapter, it is crucial that we ask what work race is being put to in this context. How do these categories emerge, and to what end?

1.4 Saving It for Later

Thus far, we have explored the emergence of HSC technology in the form of bone marrow transplantation. Its early iterations were a response to concerns for military personnel, then clinicians, and finally the public. But HSC technology is now, as Kraft notes, a firmly clinical intervention with cancer treatment at its centre. This transition, as we have seen, has been informed by the development of a framework of understanding in which different bodies can be seen as more (or less) compatible. This framework is articulated through the language of racial difference, and offers a context for understanding how contemporary HSC technology is enrolled. However, Thomas and colleagues' animal models, yet another tale of 'men and their organisms' (Rader, 1999: 319), are an interesting point of discussion. Here was the first suggestion that it might be possible (and indeed prudent, a rhetoric we see re-

emerge in the literature of many private tissue banks today (Fannin, 2013)) to store tissue into repositories in anticipation of some future *requirement*. As we know, such ideas have (in a sense) been realised though probably not in any way that would have been recognisable to Thomas and his colleagues.

Back with Thomas' team of researchers, another paper in 1960 again raised the feasibility of storing tissue. Mannick and colleagues' study on autologous marrow grafts in dogs – went so far as to suggest that it would be useful to consider 'the establishment of autologous marrow banks for personnel potentially exposed to radiation and for patients about to receive consequential radiation or chemotherapy' (Mannick *et al.*, 1960: 264). The fact that the authors described it as a 'bank' echoes a trend of describing collections of human tissue with this word. As Kara Swanson (2014) notes, in the United States sperm was being systematically "banked" by 1953, human blood from 1937 and, before all of this, breast milk in 1910. I will take up my issue with the term bank in chapter two, suffice for now to repeat Swanson's position that using the bank metaphor this way fundamentally shapes the way we 'think about body products' (2014: 4). This is the point of a metaphor – to help us understand an instance or an entity in a particular way. This is something to which I will shortly return.

For now, it is important to note that Mannick *et al.*'s suggestion was one of a 'bank' of tissue for people working with hazardous radiation material, and for patients about to be irradiated in curative procedures. These would be autologous banks because the tissue would be saved with the purposes of being injected *back into* the self in case that self should become irradiated. This could be a kind of prudential storage of matter for those people most likely to need it. As we will see, this imagined scenario would not play out with bone marrow, but some forty years later with a different source of HSCs: umbilical cord blood. At the time, however, the researchers were still pondering a scenario in which repositories of adult-derived tissue could become a reality. This historical context makes plain that requirement was the guiding force behind these early (imagined) banks. Need was anticipated, and the banks were posited in response. So to what extent are requirements and anticipation still at the core of contemporary practices?

The autologous marrow bank that Mannick and his colleagues described was perhaps prohibited by the slow development of the science that would determine it to be a worthwhile investment. Perhaps the banks were never developed because of the likely high cost of the endeavour. Based on the original motivations for the initial studies, it might even have been an assuaging fear of atomic power. Perhaps it was because, for the military personnel, unless leukaemia had already been clinically indicated, an invasive procedure requiring surgical extraction would seem unnecessary. As it turns out, post-indication of leukaemia, harvesting stem cells would probably not have been much use anyway, given that leukaemic cells might have resided in whatever was sequestered (Kurtzberg *et al.*, 2005).

The explanations are unavailable to us now, but perhaps, as Kraft argues about the general dispersal of interest in the field after its active beginnings, ‘the moment had passed, the cohort had dispersed, and new research agendas emerged’ (2009: 175). By the 1970s, autologous banks had lost all priority and the first transplants from allogeneic, sibling donors were taking place (Bortin and Rimm, 1978; Speck *et al.*, 1973). Even more momentously, in 1973 a transplant of allogeneic HSCs from a completely unrelated donor into a three year-old boy, Simon Bostic, was successful (Foroozfar *et al.*, 1977). Bostic would be the first recipient of allogeneic HSCs derived from an individual not from within their own family (Hughes-Jones *et al.*, 1991), a procedure now simply called an “unrelated transplant”.

It was because of this newsworthy success that the mother of another young boy requiring similar treatment sought out the same intervention received by Bostic. Shirley Nolan would travel from Australia to London, where Bostic’s treatment took place, to see if it was possible for her son, Anthony, to receive it. In 1974, on discovery that she and her family were not sufficiently compatible as tissue donors and she would have to find an unrelated donor she founded the Anthony Nolan Trust. As the organisation’s 40th Anniversary retrospective (2014) tells it, the Nolan family faced such a challenge in trying to find a match that they began compiling a list of potential donors and their tissue types. In other words, a bone marrow registry.

Creating a solution for the requirement for allogeneic tissue was pressing by the 1970s given that it was now required for a proven medical intervention that had the

capacity to save lives. The notion of requirement was central. Interestingly, the pressure was compounded by concerns that family sizes (and thus, related donor options) were decreasing (Pavlů *et al.*, 2011). Her son Anthony died, having never found a compatible donor. Despite this or, perhaps, because of it, Nolan remained active at the Trust. As one of her obituaries would note, after Anthony Nolan's death, Shirley Nolan 'resolved to continue campaigning', eventually setting up the charity in its official quarters in London. Shirley Nolan died in 2002. John Goldman, the London-based clinician who would work with her to tissue type volunteers willing to donate to Anthony, reflected on Shirley Nolan's legacy in her obituary in the international journal *Bone Marrow Transplantation*.

'Most haematologists at the time were not immediately enamoured of the idea of HLA-typing large numbers of volunteers from the general public in the hope of finding just one suitable donor, but Shirley's enthusiasm and commitment were persuasive. The project was publicised by every available route and more than 300000 potential donors were tissue-typed in the next few years.' (Goldman, 2002: 627)

The Anthony Nolan Trust's list of tissue-typed volunteers is now used as the first example of a bone marrow registry (Pavlů *et al.*, 2011). Other developed countries would follow suit with bone marrow registries being established in Australia, North America, and across Europe. Such registries are databases of volunteers (usually referred to as donors, although most will never actually donate), each having given a sample of blood or saliva that has been tissue typed. The database holds the donor's personal information and their tissue type, but none of their physical matter.

As clinician Effie Petersdorf noted in 2010, many of these registries would eventually unite under the efforts of Thomas (the Nobel Prize-winning clinician who had worked on the dog models), Goldman (who had worked with Shirley Nolan to develop the first register) and others to establish the 'Cooperative Marrow Donor Program'. This group aimed to produce guidelines for the nascent practice of tissue exchanges between donors and recipients living in different countries. It was this initial group, Petersdorf notes, which gave impetus for the later establishment of the

World Marrow Donor Association (WMDA). In 1995, the WMDA was founded to both promote and formalise the international exchange of donor HSCs:

‘It is in this spirit that the mission of the WMDA - to work towards making high quality and secure hematopoietic stem cell products available for all patients worldwide while maintaining the health and welfare of the stem cell donors – has led to a global effort.’
(Petersdorf, 2010: 807)

Bone marrow registries are now also called ‘adult donor registries’, partly because since the establishment of the first registries, bone marrow is no longer the primary means of sourcing HSCs from the adult body. Adult stem cells are now much more frequently sourced from “peripheral blood”. That is, the blood which flows around the body. The donor is given a regimen of drugs that augments the number of HSCs entering into the blood, and then is connected to an extracorporeal machine that separates the HSCs from the blood before returning it to the donor’s body. The donor can expect to return to the hospital over the course of several days to complete the process. In 2009, out of the 812 stem cell donations sourced in the UK, only 13% were directly drawn from bone marrow, whilst 74% came from peripheral blood (UK Stem Cell Strategic Forum, 2010b: 15). Another reason why the nomenclature has changed to adult donation has been the emergence of a non-adult source: the umbilical cord. As of 2013, the WMDA connected 71 adult donor registries and 160 collections of umbilical cord blood (World Marrow Donor Association, 2013: 2).

1.5 Umbilical Cord Blood as an Alternative HSC Source

It was out of this historical context that umbilical cord was first found to be a source of HSCs (Knudtson, 1974). As I mentioned briefly at the start of the chapter, it was in 1988 that cord blood was used to treat a blood malignancy, Fanconi’s Anaemia. The cells, taken from the umbilical cord of the young patient’s sister, grafted successfully and the treatment details were published the next year by Eliane Gluckman and colleagues (1989). It was, noted a leading cord blood clinician in the US in the mid-nineties, because of these first successes with transplantation of UCB sourced from sibling donors that the first initial programs for the collection of

unrelated UCB began (Wagner, 1995). But what need was there if a source already existed? Around this period, authors with a professional interest in cord blood were amassing lists of issues with the state of bone marrow provision as it stood at the end of the 20th century (see, for example, Rubinstein *et al.*, 1993). For instance, as Wagner and his colleagues asserted:

‘...there are several important obstacles that limit the successful use of unrelated donor marrow; these include, (1) the long length of the donor search process which is currently a median of 3.5 months (range 1 month to 6 years,) (2) limited numbers of donors in certain racial and ethnic subpopulations, (3) donor unavailability at the time of request, and (4) an increased risk of graft rejection, severe graft-versus-host disease (GVHD) and opportunistic infection after the transplant procedure. Various strategies for ameliorating these problems are currently being investigated.’ (Wagner *et al.*, 1996: 795)

The lengthy wait for an adult donor and the risk of unavailability or attrition of donors in the meanwhile, the persistence of GVHD, and an apparent dearth of particular ‘racial and ethnic subpopulations’. These coalesce in these mid-nineties accounts as sufficient motivation to look further afield. One of the strategies of amelioration was thought to be umbilical cord blood. As members of the team behind the first UCB transplant explained, UCB blood ‘has the potential to overcome some of the limitations of the current system of registries’ (Socié *et al.*, 1994: 340). The same argument was taken up by the team involved in setting up the first umbilical cord blood collection, based in New York. They wrote that “‘banks” of cryopreserved placental bloods would not depend, for example, on the recruitment and continued collaboration of large numbers of volunteer potential donors and on compensating for the unavoidable attrition caused by retired volunteers’ (Rubinstein *et al.*, 1993: 1679).

In such accounts, there is an implication that there are a number of advantages in utilising umbilical cord blood extraction in lieu of other methods of isolating HSCs. Extraction does not, it is argued, necessitate obvious physical pain or discomfort (see

Brown, 2013 for a sociological examination of the claim of safety in CB banking), whilst the extraction of bone marrow-sourced stem cells and peripheral blood donation is invasive and requires repeated hospital visits on the part of the donor. One of the most attractive qualities of UCB is that the tissue is *already there in the repository* and immediately available for the ordering clinician. Adult donor registries require donor correspondence information to be continually updated, and rely on the potential donor remaining willing to donate and physically available to do so.

These images were taken during a visit to a public UCB bank in Madrid that I contextualise in chapter three. These visual data are used to illustrate how umbilical cord blood units can be immediately removed from the freezer, placed in a travel freezer and swiftly couriered worldwide. The travel canister in these images had just returned to the Madrid bank from a clinic in New Zealand. The visit to this cord blood bank, and more detail about the heavily-stickered travel canister is recounted elsewhere (Brown and Williams, 2015).

Figure 1: An open cryogenic freezer in Madrid



Figure 2: (below) An umbilical cord blood unit being draw out of the cryogenic freezer in Madrid



Figure 3: (below) Travel canisters in Madrid for sending units out to hospitals



Along with this, UCB-derived stem cells offer a solution to what is considered to be one of the most significant issues regarding the current configuration of adult donor registries. Established registries, for example in Australia (Samuel *et al.*, 2007) the United States (Johansen *et al.*, 2008) and the United Kingdom (Brown *et al.*, 2000), are mainly populated with data from donors who identify as white. Because of the understanding of a link between ethnicity and HLA typing that I touched upon earlier in the chapter, this is construed as an over-representation of white donors and a dearth of minority donors which, it has been noted, has evident consequences for minority ethnicity would-be tissue recipients for whom a match cannot be found. I have given further critical exploration of this point elsewhere (Williams, 2015) but other questions concern me here. The notion of over-representation implies a normative point of representativeness from which banks and registers can deviate. Why is representativeness thought to be a good thing in the first place? Furthermore, how is representativeness measured in contexts such as this? When we see racialised language appear, it is important to explore, in Rogers Brubaker's (2002, 2004) terms, what interests these invocations of groupness serve.

We have seen, then, that UCB collection practices emerge out of a particular history. The situation we have now, of 160 allogeneic umbilical cord blood banks (World Marrow Donor Association, 2013), was not quite what Mannick and colleagues had earlier imagined with their autologous bank for military personnel and cancer patients. This thesis is interested specifically in the contemporary UK context of UCB collection, which exists today far removed from its militaristic roots. In the next, final section of this chapter, I plot out this context in a little more detail to contextualise the preceding chapters.

1.6 Umbilical Cord Blood in a UK Context

Not too far behind the first collections of UCB in the early nineties, by 1995 the UK's National Blood Service had established its own umbilical cord blood repository which they called a umbilical cord blood "bank" (National Blood Service, 1997: 12). In 2010 the Anthony Nolan Trust, rebranded simply as *Anthony Nolan*, established a

UCB repository in the UK again named a “bank”, a linguistic trend that is now pervasive internationally. Historically, these two organisations (the former, now called the NHS Blood and Transplant authority, or NHSBT) have operated separately, managing their own individual adult donor registries and umbilical cord blood collections. However, in 2010 the UK’s Parliamentary Under-Secretary of State for Health, Anne Milton announced the production of a unified national UCB banking strategy:

‘A properly developed infrastructure for the collection and storage of cord blood will do much to alleviate the severe shortage of life-saving stem cells needed for transplantation and to facilitate research ... it would be neglectful for the UK not to embrace to the full this exciting option.’ (Hansard HC Deb., 2010)

The UK’s Department of Health, oversaw this forum, which was called the Stem Cell Strategic Forum (SCSF) made up of different parties including representatives of Anthony Nolan and NHSBT, along with practitioners working with stem cells and patient activists involved in the area of transplant. The Department of Health requested information on the current state of publically available blood stem cells in the UK and recommendations for its development which appeared in a report (UK Stem Cell Strategic Forum, 2010a, 2010b). It was in this initial forum that the seeds of the current collaborative arrangement were sown. In 2011, it was announced that £4m was to be given to AN and NSHBT to realise the various recommendations of the SCSF, which included the alignment of data from both institutions’ blood stem cell inventories, including their individual adult donor registries and UCB banks (NHS Blood and Transplant, 2011). The SCSF report recommendations are now a point of interest for the All-Party Parliamentary Group on Stem Cell Transplantation (APPG) which hosts SCSF members to discuss points of the collaborative governance arrangement as it develops. The APPG produced its own report (2012) that re-asserted the requirements and recommendations laid out initially by the SCSF:

‘Stem cell transplantation already transforms many lives, curing otherwise untreatable blood diseases. Yet finding a match is a

painstaking process and – tragically – matches are not available for all patients ... we must not forget the lives that can be transformed by getting this right ... It is an investment for today’s patients as well as those in the future.’ (All Party Parliamentary Group on Stem Cell Transplantation, 2012: 3)

However, based upon the reflections from earlier in this chapter (particularly those of Anderson and MacKay (2014) who draw attention to the contingency of consensus in this field), a static list of recommendations prompts important questions. What use might the field have in a singular list of recommendations produced in 2010 when scientific consensus and medical practice has inevitably moved forward? Whilst these questions are amongst those that I explore more broadly in the following chapters, it is important at this stage to situate this study as one regarding the strategic management of the UK’s two public collections of UCB. Readers will note that I treat these two collections as if they are managed as one united inventory. This decision has been made mainly because their collection practices (explored later in the thesis) and much of their funding has been aligned since 2013 (Anthony Nolan and National Health Service Blood and Transplant, 2014) when this project began. Importantly, I have not undertaken a comparative study between the two separate collections here, which would have required a different approach. Rather, it is a study of how these two collections, working together, are managed strategically.

Before I move on to explain how I collected data for this thesis, it would be useful to foreground how I have approached the project theoretically. Broadly speaking, as I lay out in the next chapter, the theoretical approach I undertake here is one that implicitly takes a critical stance at the notion of the umbilical cord blood collection as a “bank”, whilst more explicitly advocating an understanding of the UCB collections as managed through a more selective, ordered, considered approach that can be described as an archival sensibility.

Chapter Two: From Bank to Archive

2.1 Introduction

Out of the context provided in the first chapter, this second chapter offers a critical overview of the existing conceptualisation of umbilical cord blood collections as “banks”, dividing into public and private models of practice. Here, I introduce the readers to a number of STS scholars who have already been working in the area of UCB collection through the language of banking. Although this thesis is indebted to their scholarship, the first part of this chapter is interested in highlighting the shortcomings of ‘bank’ thinking as a means of understanding the past, present and futures of UCB collections.

With this critical engagement as its foreground, the rest of the chapter sets the scene for a different way of understanding how these collections might be conceived. The understanding, which I adopt through the rest of the thesis, is based on the notion of the archive, a once easily-defined word that has transitioned more recently into a theoretical tool of protean capabilities. The chapter explains what I mean by the “archive”, offering examples of its previous use and critical exploration of the thoughts of scholars that span a diversity of disciplines. The chapter ends by plotting out how each of the remaining chapters of the thesis unfolds.

2.2 The Bank Logic

Much of the literature that already exists in the area of umbilical cord blood banking is concerned with the binary of public and private models of banking. For those who elect to bank privately, a growing number of enterprises offer the collection, banking and exclusive use of units. Customers pay from £1500 to £3000. Perhaps unsurprisingly, critical attention has been drawn to the private UCB banking enterprise, not least the use of a health insurance rhetoric (Appleby-Arnold, 2012) which is perhaps not dissimilar from the radiation-personnel autologous banks that Mannick and colleagues were imagining in 1960. What distinguishes the imagined autologous marrow banks of 1960s and the existing service of private umbilical cord blood banks is that Mannick’s banks had a specific use – personnel more likely to

need it, and chemotherapy patients anticipatorily banking their tissue for use on the ‘other side’ of their treatment. In contrast, as Brown (2005) puts it, private UCB banks engender a ‘regime of hope’ because the enterprise *produces* its market by bringing attention to highly contingent, potential future outcomes so far not evidenced in either the clinic or the laboratory.

More recently, this binary of public and private has been complicated. In practice, so-called ‘hybrid’ models (in which a private donation can also be made available on a public registry) have emerged. Public models, which follow the same logic of unremunerated donation and international accessibility as adult donor registries, are the main point of focus of this thesis. It has been suggested that public banks might offer a window of opportunity to ‘recreate the commons’ (Dickenson, 2007: 102) shifting attention away from for-profit private banking models, whilst umbilical cord blood technology has been seen to renegotiate the limits of the female body’s reproductivity (Waldby and Cooper, 2010) and engage these bodies in tissue economies that imbricate women’s bodily capacities for reproduction within broader institutional and national interests. In opposition to private banks, public banking has also been conceptualised as a ‘regime of truth’ (Martin *et al.*, 2008), as such models do not capitalise on future-based contingent claims, but instead highlight currently used therapeutic options. Out of this context it is important to ask what ‘public’ might mean in practice.

Significant flaws in private UCB collection procedures and possibilities belie the promissory marketing claims used by the sector. The promise, for instance, that a child might utilise the stem cells that were banked when they were born should they later present leukaemia, ignores the possibility that leukaemic cells might reside within the initially banked stem cell unit (Kurtzberg *et al.*, 2005). There are further concerns about the viability of privately banked units. Whilst publically banked units are tested to see whether there are sufficient stem cells within the retrieved tissue, privately banked cord blood is not generally subjected to the same testing. This results in all samples being stored, including those with insufficient stem cells to ever be used in the clinic (Sun *et al.*, 2010). This has been a point of critique for private banks given that parents pay for a service that is, perhaps even at the point of

collection, redundant and never going to amount to a viable treatment option (Brown and Kraft, 2006).

But although there might be less of a negative moral inflection, similar issues around redundancy have become apparent in public banking. Tissues collected in the early period of banking were saved because they met different (and generally less stringent) criteria, a point I pick up in some depth in the chapters that follow. In STS, the transience of standards and criteria (Berg and Timmermans, 2000) and the more and less pliable classificatory frameworks enrolled in standard-setting (Bowker and Star, 1999; Mackenzie *et al.*, 2013) are central themes. The emergence of private banking, and its moral economy wherein the promise of technology is harnessed for capital accumulation, has perhaps taken attention away from how these standards play out in the public banking context, an issue I address in the chapters ahead.

2.3 Leaving the Bank Behind

I have already drawn attention to the use of the term ‘bank’ in describing a collection of umbilical cord blood units. Before Thomas and his colleagues proposed tentatively ‘the establishment of autologous marrow banks’ (Mannick *et al.*, 1960: 264) there was an established pattern of describing human tissue collections as banks (Swanson, 2014). Since then, “bank” appears to have become the accepted moniker but not without prompting lively debate. The use of the term has been particularly prominent in the collection of biological materials for research. The term biobanking, often enrolled to describe such practices, is used to ‘emphasize the ability to use biological materials for extraction of DNA and link it to other data about the person from whom the sample was taken’ (Ratto and Beaulieu, 2007: 177). For example *UK Biobank* is a government-funded institution which studies the relationship between genetics, environment, and disease development (see Busby and Martin, 2006). But as Alan Petersen notes, the invocation of the term bank does more than this. It draws particular attention to the notion that the information collected ‘will prove to be an ‘investment’ or ‘asset’, benefiting individual ‘investors’ and the community as a whole’ (2005: 279). It is perhaps telling that, as Petersen goes on to note, the *UK Biobank* was initially called the *UK Population Biomedical Collection* and, as such, a conscious decision was made to rename it. Beyond the UCB bank, then, there has

been discussion about what the term “bank” *does*. But what might it do in the UCB context?

A particularly vocal strand of discussion on this point emerged amongst bioethicists in response to an article authored by Hofmann, Solbakk and Holm (2006) where the authors argue that we need a more coherent understanding of ‘the prominent role that analogies play’ (2006: 49) in reference to UCB. The authors unpack what terms such as “waste” do in this context. This word has also received attention in the STS literature as a discursive means of positioning the non-donor as actively wasteful to the extent that to call UCB “waste” might be seen in itself as a moral injunction (Brown, 2013; Waldby and Cooper, 2010). Hofmann, Solbakk and Holm, however, spend less time thinking through the notion of “bank” itself. Thanks to an active forum feature in the *American Journal of Bioethics*, responses to the article were numerous and quickly took to unpacking what the analogy might be doing.

Holland (2006), for example, notes that the term “banking” is suggestive of a ‘save for a rainy day’ ethos whilst López’s response cites a French *Committee Consultatif National d’Ethique* (CCNE) report on the notion of the ‘biobank’ as an overemphasis of ‘the market and proprietary dimensions of the deposited biological material’ which the CCNE argued could be counterbalanced by the term ‘biolibrary’ (López, 2006: 62). Another report that I would add to López’s interjection, with similar conclusions to the CCNE, came from *Organisation of European Cancer Institutes*, which proposed in the original Italian report to use the term ‘bio-teca’, a biological repository, which was felt to be more appropriate. The terminology of bank ‘recalls a lucrative scope,’ the report contends, whilst ‘the word ‘teca’ gives an idea of sacredness’ (Organisation of European Cancer Institutes, 2010: 1).

Perhaps the most important response to Hofmann, Solbakk and Holm came from bioethicists in Australia. Their main point is not only salient, but helps to frame the approach I have taken with this thesis. They write that Hoffman, Solbakk and Holm’s piece neglected consideration of the *types of storage* that exist in reference to UCB banks. They argue that the traction and validity of metaphors in the umbilical cord blood context can be determined by the ethos behind the collection. From their position, different language befits a public collection wherein tissue is accessible by

anybody who should need it, than suits the act of retention for personal use through the use of a private storage provider.

‘...storage of UCB within a public institution should be referred to as just that—storage—and not by the term banking, which should be used only in relation to private UCB storage as it implies an investment—the retention of tissue for one’s own benefit at some point in the future ... The adoption of this language will allow researchers and readers alike to make a clear distinction as to the nature of UCB storage under discussion ... Public and private banks are different in almost every respect and must therefore be examined using different language and different philosophical concepts.’
(Samuel *et al.*, 2006: 58-59)

Private banks and public banks are predicated on very different, though sometimes hybrid, logics that I have mapped out elsewhere (Brown and Williams, 2015) and as such I am inclined to agree with Samuel, Anken and Kerridge’s response. The language of ‘banks’ does not fit well with the public model. However I would argue that critiques like those I have set out above all coagulate around the *problematic inflections* of a term like bank. The bank suggests investment, perhaps even atomistic self-interest and asset management. In these arguments, ‘bank’ emphasises a particular ethos behind collection. To the extent that these critiques engage with the problematic omissions created by what the term ‘bank’ *fails to capture*, the concern is about the ethos behind collection. According to this particular bioethical discourse, ‘bank’ conceals the gift relationship (Samuel *et al.*, 2006), and does not confer the sacredness that befits human tissue (Organisation of European Cancer Institutes, 2010). There is scope, therefore, to develop the foundations of this critique of bank language on the grounds that it is not just the abstract motivations of donors that is lost in this terminology. We have to ask, what practices, purposes and meanings might be concealed by what is framed by bioethicists as potentially limiting language? What language might help us to better unpack these elements?

To capture the future-orientated practices of collection establishment and the variegated, dynamic practices of collection management, I offer a different

suggestion. That we can think of these collections as archives. *Archive*, as I will explore shortly, is a complex notion that (thanks to the work of a great many writers whom I will introduce) has emerged over the last two decades as a viable paradigmatic entity, a lens through which collections and their practices can be considered more comprehensively. It is out of the context that I have laid down in this chapter that I argue that the complexity enfolded into the practice of UCB banking today needs to be thought of as more than a collection of matter or data. These collections are inflected with a profession's view of what constitutes requirement, representativeness and usefulness. They are not stagnant gatherings, but inherently temporal. They are informed by past technological innovation, present scientific consensus, and the manifold unknown demands of a future always on the precipice of becoming.

2.4 The Archival Lens

Umbilical cord blood collections, then, are almost always referred to as 'banks'. In the last section, I laid out the arguments of bioethicists who highlight the various issues of such language, asking what practices and purposes might be obscured by such a notion. I also suggested that the heuristic paradigm of the 'archive' could be a useful way of understanding the publically-available collection of umbilical cord blood. In the rest of this chapter, I want to lay out what I mean by the archive-as-paradigm approach.

For many historians, writes Laura Ann Stoler, the archive is simply a collection of documents and the institution that keeps them. In the cultural theory domain, however, it becomes 'a metaphoric invocation for any corpus of selective collections' (2009: 45). In the chapters that follow, I use the archive as a kind of paradigmatic lens to bring to light features of the public UCB bank, a selective collection of biological matter. As Mike Featherstone argues, the "archive" can be thought of 'as a paradigmatic entity as well as a concrete institution' (2006: 596). In what follows, I plot out how the paradigmatic "archive" came to be understood as such through the work of Jacques Derrida, Michel Foucault, and a number of writers (professional archivists, anthropologists, historians, social and cultural theorists, and STS scholars) who have been influenced by these philosophers, particularly Derrida.

By doing this, I offer a kind of archival ‘anatomy’ upon which the rest of this thesis builds, highlighting avenues of exploration that I take up in the rest of the thesis. The chapter finishes with the exploratory starting points of the four empirical chapters that follow.

I wrote a lot of this section of my thesis in a library just outside Stoke-on-Trent. To the left of the desk I am sat at today are shelves full of manila files, themselves full of manila envelopes, again full of something. I do not know what is in them because the files are numbered, and the numbers mean nothing to me without a reference guide. A lot of people will think of this scene when they think of an archive. They might even find the imagined scene a little uninspiring. That is, before becoming aware of the integral role played by filing stationery in the transformation of modern recording keeping and office management (see Yates, 1993). But, the revolutionary manila file notwithstanding, Verne Harris argues that the theoretical literature produced by professional archivists is ‘one of the dullest bodies of written work imaginable’ (2005: 141). However the 1990s, he contends, saw a shift, with the ‘the emergence of a new generation of archivists ... willing to allow imagination space’ (*ibid.*) with several practising archivists publishing work with significant postmodern influence including Brien Brothman and Terry Cook. Their work, along with other contemporaries, features in this chapter and those that follow. Broadly, though, this chapter asks the reader to do what Harris advocates, and allow some imagination space.

What, then, do I mean when I use the word *archive*? As I have said, Stoler notes that the archive for historians and the archive for cultural theorists are very different objects of analysis. The archive of cultural theory ‘is figurative, and leads elsewhere’ (2002: 94). The point here is that taken out of its traditional domain, the archive is heuristic, prompting questions about the various selective collections we might be interested in. A similar point is made by Thomas Osborne who asserts that the archive is useful because of its elasticity, that ‘it enables us to oscillate between literalism and idealism’ (1999: 51). STS scholar Geoffrey Bowker similarly describes this as *folding* the archive ‘into our set of actions in the present and in the built and shaped environment’ (2005: 21).

One can speak of archives as *physical spaces*, but they do not have to be visible, or even touchable. The archive can refer to ‘an ideal, or generalized, place’ (*ibid.*: 52). We might argue that the archive is therefore an ideal type of sorts, its heuristic qualities formed by the ‘synthesis of a great many diffuse, discrete, more or less present and occasionally absent concrete individual phenomena, which are arranged according to those one-sidedly emphasized viewpoints into a unified analytic construct’ (Weber, 1949: 90). The archival paradigm is thus a starting point through which a given area of research can come to be known in a particular way, by allowing certain questions to be asked. The archive itself is a kind of theoretical framework.

Before moving towards this, though, a quick note on language is in order. In this chapter, there are many references to “the archive” and “the archival”, but throughout the chapters after it I have generally avoided doing this. In part, this is because I will be talking about particular collections of matter (umbilical cord blood collections) in a particular context (that is, the UK). As will become clear, though, I do suggest in a modest way that certain features I have located in my study context may have some (or a lot of) semblance to other similar collections around the world. In this current chapter, though, I – and the authors I have quoted here – employ “the archive” to propose features that are perhaps common across the diversity of archives that have been, are being, and may one day be, constructed. This lexical diversion hopefully gives the reader some sense of the direction of both this chapter and the thesis as a whole.

2.5 How the Archive Has Been Used

To understand the archive as a heuristic tool, I now turn to look at how others have used it. The elevation of the archive to a ‘new theoretical status, with enough cachet to warrant distinct billing, worthy of scrutiny on its own’ (Stoler, 2002: 92) tends to be pinpointed in the work of Foucault and Derrida whose writings have helped to form the landscape on which people are now thinking with the archive. In *The Archaeology of Knowledge*, Foucault employs a notion of the archive in which it is not an institution and cannot be ‘seen’. Instead, he uses it to describe all of those discursive practices through which statements are established as events and objects

(an act, a personage and so forth). Foucault develops this definition in reference to the idea that all discourse is based on the 'already-said' (1972: 27). His claim is that an object can only exist in reference to an externality of complex relations that allow it to appear with, be compared to, and situated against, other objects, and 'be placed in a field of exteriority' (1972: 50). He prefaces his point, noting that any book is,

'...beyond the title, the first lines, and the last full stop, beyond its internal configuration and its autonomous form ... caught up in a system of references to other books, other texts, other sentences: it is a node within a network.' (*ibid.*)

It is thus in reference to the 'archive' – not simply a canon of literature, but of texts (in its literary theory valence, i.e. any object that might be 'read'), and of sentences (language, syntax, grammar) – which encircles us and brings meaning to every enunciation that things are made meaningful. Foucault's archive makes a case for thinking as much of context as text, of the 'system of references' in which an utterance occurs. This point, that the infrastructure brings meaning to its content, is broadly one that I take forward in the discussion that follows. But whilst Foucault's work is often mentioned in reference to the archive, it is Jacques Derrida who has been more widely credited with, to borrow from Osborne, elasticising the archive.

Derrida is considered 'a key mover in what has been recognised by many as an archival turn in intellectual work' (Harris, 2005: 131). This is due in large part to his lecture-turned-monograph, *Archive Fever*. The book has been formative to many explorations of the archive in different settings, from biodiversity databases (Waterton *et al.*, 2013) to YouTube and Facebook (Beer, 2013). It is also quite foundational to the chapters that follow. Most of it, however, is not really about archives. Mainly, *Archive Fever* explores Jewish scholar Yerushalmi's (1991) analysis of Freud's *Moses and Monotheism* (1939). During the book, Derrida argues that Freud's work is a platform on which we can begin to think of the mind's requirement to archive. There are also a number of moments where we see Freud and the archive overlap in Derrida's discussion. However, as Carolyn Steedman notes, the bulk of the book feels 'curiously dislocated' (1998: 66) from the Greek etymology of the word 'archive' that Derrida offers at the beginning of the

manuscript. He notes that the originary Greek term *arkheion* specifically denotes the domicile of the *archons* – the individuals in command, guarding the archive. The archive was initially found in the environment of those with a publically recognised authority and it was here that documents pertaining to, or perhaps of interest to, the polity were housed. As custodians of documentation, these first archivists ensured that documents were secured.

Derrida having made these important steps, one of the most effective uses of the term “archive” beyond its traditional mainstay can be found in recent analyses of contemporary cultural consumption. This is particularly apparent in the theoretical ground work of Mike Featherstone who argues that culture can increasingly *only* be understood in terms of the archive (Featherstone, 2000, 2006) and Dave Beer, whose work (2013) puts Featherstone’s conceptual configuration into practice. It is worth briefly considering this scholarship because it elucidates how the archival paradigm can illuminate important facets of the researched subject, particularly around the themes of issues of political participation, organisational infrastructure, and selectivity that make frequent appearances in the following chapters.

Featherstone builds on the work on Georg Simmel and Walter Benjamin to consider how theorists have looked at organisation and ordering in the wake of commodity capitalism’s ‘overload of cultural production’ (2000: 163). Beer takes up Featherstone’s suggestion that the paradigmatic archive would throw up ‘new agendas for sociology’ (Featherstone, 2000: 173) arguing in his monograph *Popular Culture and New Media* that ‘the history of cultural production and consumption can be seen as a history of archiving’ (Beer, 2013: 49). In particular, he argues that using the concept of archiving elucidates contemporary processes of organisation, structuring and ordering of (particularly) digital data. There is a value of thinking about selective accumulations of data, as Beer puts it, ‘in terms of archives and archiving’ because ‘it forces us to consider how they are organised, structured and ordered’ (2013: 49).

In the archives Beer discusses, the amassing of digital content compels individual gatekeepers to archive data in personal archives. Importantly, Beer’s contemporary archives hold content produced by the people using it. Thus, they are ‘based upon

some form of participation' (2013: 51). His concern is with how we understand this participatory landscape. Archives of this kind may be 'infrastructures of participation', but they must also be understood as 'infrastructures of participative organisation' (*ibid.*: 53). He explores this in reference to the act of "tagging" digital data, which highlights the role of users in the organisation, as well as consumption of, content. 'It is not just the content that is open' notes Beer, 'but often also the classificatory system underpinning it' (*ibid.*: 54). Beer's point, however, is that the new archives, like the older archives, 'are deeply political spaces that cannot be simplified with terms like decentralised, democratised or participatory' (*ibid.*: 55). The normality of these archives in our lives means that political issues can be obscured and we may assume that they are empowering spaces. Beer cautions against this, noting that whilst they 'might be less visible ... it does not mean that these hierarchies and structural systems of power do not reside within them'.

For Beer, then, we can see how assuming the archival lens opens up particular aggregations of data to questions of politics and propriety. Take, for example, Arjun Appadurai's point that we are witnessing the archive becoming 'gradually freed of the orbit of the state and its official networks' (2003: 17). An important point raised by Beer is that these personal archives – such as Facebook – are often corporately owned. He is wary of rose-tinted visions of democratised space, echoing the concern evident in Featherstone's aporetic question, 'who will archive cultures in the future – the state, or the corporations, or the public?' (2000: 167). As a heuristic, the archive lends itself to asking questions about inclusion and exclusion. In a given collection, who has access to *use* the archive? Who is included or represented *in* it?

Another side of this point is illustrated by Featherstone's argument that technological innovation allows massive data to be produced and consumed 'at a rate that defies organization' (2006: 595). A seemingly trivial example of popular culture consumption in late 2014 brings Featherstone's 2006 suggestion into relief. User-content video archive YouTube's individual video view counter had been coded such that the largest view count that could be recorded was 2,147,483,647. As the popularity of South-Korean musician Psy's record *Gangnam Style* pushed the video ever-further over the brink of two billion views, YouTube's programmers then had to

recode the website's view counter in anticipation of viewing numbers that the current organisational arrangement would not have allowed (Griggs, 2014).

This has very obvious implications for particular interests given the commercial gains of measurably high video views and as such, the 'new number should give viral video artists something to shoot for' (Selcke, 2014). But more generally, this demonstrates that the archive's infrastructure is at constant risk, to use Featherstone's parlance, of being defied. Featherstone argues that the drive to archive 'runs up against the speed and flexibility of the technologies which undermine stable classification and indexing' (2006: 595). In this sense, the use of the archive as a means of understanding cultural consumption brings attention to the technologies on which the archive's metrics, measurements and, ultimately, its order rests. Accordingly, this prompts us to ask how, when, and why those technologies may (or may not) fail and may (or may not) change?

For Featherstone, there is another important element in the archive. That is, the amassing material of contemporary cultural practices presents us with a peculiar archival problem of 'not what to put into the archive, but what one dare leave out' (2000: 170). This question is an important one, because it highlights the 'problem of selectivity' (*ibid.*: 162) in the construction of archives where more and more of everything can *potentially be archived*. Featherstone's piece considers the work of the Internet Archive which was, at the time, a new organisation confronting the 'daunting task' of archiving the internet, 'collecting public materials on the internet in order to construct a public library' (*ibid.*: 178). Recent events speak to the political salience of these kinds of archives' practices of selectivity, such as the MH17 passenger flight shot down in July 2014 near Donetsk Oblast in Ukraine, during the ongoing Russia-Ukraine conflict. Somebody (importantly, an unknown person with unknown motives) captured a Ukrainian separatist fighter's social media post soon before it was deleted and entered it, via the 'Wayback Machine' interface, into the *Internet Archive*. In the post, the author claimed that they had been party to shooting down the plane. As a digital archivist at the US Library Congress would later point out:

‘An important dimension of the smaller web archiving story is that the blog post didn’t make it into the Wayback Machine by the serendipity of Internet Archive’s web-wide crawlers; an unknown but apparently well-informed individual identified it as important and explicitly designated it for archiving.’ (Taylor, 2014)

The issue of selectivity once the archive becomes an actuality, rather than a plan, is clearly apparent. Who, then, chooses what to save (and, what not to save), by what criteria, and to what ends?

2.6 Towards an Archival Anatomy

Representation, inclusion and exclusion become central features of analysis when the archive is used to explore cultural consumption. There are also important issues surrounding how selective collections are ordered – what their infrastructures look like, how they might be at risk of failure, or subject to change – that come to light. In addition, we are also prompted to think about the selectivity of the archive. What is permitted entrance? Of equal importance, *why* are certain things placed in the archive? These are issues that I want take up now more broadly. In what follows, I offer the archival anatomy that informs how I analyse the UK’s publically available collection of umbilical cord blood. In highlighting these different avenues of exploration I draw on a diverse selection of scholars who span the disciplines of cultural and social theory, anthropology, history, archival practice, science and technology studies (STS) and philosophy. The intention of doing so is to offer an intellectual context to the explorative starting points for the four empirical chapters that lie ahead.

It is important to explore how archival material finds its way into the archive. Is it via the collusion of the viewer’s encoded eye and the reflexive knowledge that produces and surrounds that individual (Foucault, 1966: xxii)? Perhaps it is when the matter is viewed through a particular lens of cultural intelligibility which reifies particular assets of that matter with particular worth, power or sentiment (Butler, 1990). These are means of understanding the ‘multiple grammars of worth’ (Lamont, 2012: 9) brought to bear on the matter we interact with and witness. The vital point here,

regardless of the terminology we use to understand it, is that we recognise the importance of the archivist in locating worth in, and bringing meaning to, the matter they choose to place in the archive. For an archive to exist, one must select things to put into it.

As Featherstone notes, ‘the archivist’s gaze depends on an aesthetics of perception, a discriminating gaze.’ It is through this gaze, he goes on to argue, that events are isolated ‘out of the mass of detail and accorded significance’ (2006: 594). Here, Featherstone is building on Osborne’s argument that the archive can be understood as a ‘centre of interpretation’ (1999: 52) wherein there is a ‘whole process of scrutiny, interpretation and, one is tempted to say ... divination’ (*ibid.*: 58). The user must accord meaning to what is already in the archive, but the archivist must choose what goes into the archive first. Those managing the archive must therefore develop what Osborne calls ‘an aesthetic of perception’ that can isolate ‘significance out of a mass of detail’ (*ibid.*).

As such, we begin to see that the ‘archive is never raw’ (Lynch, 1999: 69). It is selectively put together, its omissions and inclusions determining the pathway walked by future users. As Terry Cook reminds us, the users of archives are only able to access what is there, in the archive. They have no knowledge of ‘what archivists saw *before* the appraisal decisions were made to give researchers what they get’ (2001: 35). This is an important point that takes centrality in Lynch’s argument. He notes that the archive must not be understood as a space of rawness, or the home of the primary datum:

‘...the prior consignment of documents to the archive limits what visitors can find in it, and in cases in which the archive is tightly constructed to enhance the reputation of an author or to cast an event in a way that supports a partisan cause, the archive can be said to embody an intentional design.’ (1999: 79)

This point is echoed in Achille Mbembe’s consideration of the archive, where he argues that archives are ‘primarily the product of a judgement ... which involves placing certain documents in an archive at the same time as others are discarded’

(2002: 20). The archivist must select, must discriminate. Mbembe argues that, because matter in the archive must pass this test of selection, being in the archive is itself a *status*, a point that Derrida made similarly. Things in the ‘uncommon place’ of the archive are there ‘by virtue of a privileged *topology*’ (Derrida, 1996: 3, original italics). As Mbembe notes, in ‘any given cultural system, only some documents fulfil the criteria of “archivability”’ (2002: 19). If we take this point one step further, some documents necessarily must *not* fulfil those criteria. The selectivity of archiving, its intentional design, as Lynch called it, is taken up by Boris Groys. To decide that something should *not* be relevant, to *not* give it the privileged status of archivable, is to say that it ‘is unimportant, irrelevant and, so, should be left out’ (2003: 179). But what constitutes relevance? What grammars of worth, or lens of valuation, operates within the archive? What metrics or orders inform such decisions?

We can also ask whether relevance is a stable quality. Does something always remain relevant? Obviously, relevance pertains to the context. A wooden spoon is relevant to baking, but would be of little relevance in this conceptual discussion (excepting my use of it here as an example). But context has a temporal dimension too. What is relevant today may not have relevance tomorrow. Therefore, no content has guaranteed permanence because archival status is contingent on the changing values to which the archive responds. Accordingly, archival matter ‘travels backwards and forwards ... between rubbish, junk and sacred’ (Featherstone, 2000: 593). It might be considered of worth at one point. It might transition into worthlessness at another. As Groys explains, importance is ‘usually defined as all that which is important for life, for history, for human beings. And things of such importance must necessarily be incorporated into the archive’ (2003: 179). Brouwer and Mulder argue that value is determined in how information can be *used*, or ‘its operability’ (2003: 5).

Not everything in the archive is being used in the present moment. Rather, most archival content waits for its time to be used at some point to come. As Elisabeth Kaplan puts it, those in charge of an archive ‘do what they do so that others ... now or in the distant future, can do what they do’ (2002: 217). Similarly, Appadurai argues that an archive’s design and intention are based upon ‘the uses we make of the

archive, not from the archive itself' (2003: 14). The future is therefore an important element in how the archive is managed and even why it exists. Because of this centrality on *potential* use, the archive stands as 'an irreducible experience of the future' (Derrida, 1996: 68). It *awaits* the use of its material, and is designed to maximise the likelihood of this use, be it imminent or latent. As Hilary Jenkinson (the archivist widely credited with professionalising archival practice in England) explained in 1938, archiving is a career of service, 'to make other people's work possible, unknown people for the most part and working very possibly on lines equally unknown to [the archivist], some of them in the quite distant future and upon lines as yet unpredictable' (cited in Evans, 1975: 153). Future, as Jenkinson made clear in the thirties, is a key facet of this discussion. How is the future anticipated, though? How is the archive managed in accordance with this anticipation?

An added vector that we should keep in mind when talking about archives is that they can be a referent in how we think about ourselves and the world around us. Many archives form an important element of identity construction, be it of ourselves, the 'other', or perhaps the nation state. As Brien Brothman puts it, through archiving, people have 'the power to generate and share meaning and to establish, amongst themselves, the identities of all things within the world' (1999: 65). Derrida similarly notes that '[t]here is no political power without control of the archive, if not of memory' (1996: 4). He argues that the level of a polity's democratization can be measured by 'the participating in and the access to the archive, its constitution, and its interpretation'. If groups are excluded from participating in what constitutes the archive – if they are not, as Joyce above suggests, 'represented', the archive is not as democratic as it can be. This is because, as Steedman puts it, in the archive, 'a whole world, a social order, may be imagined by the recurrence of a name in a register, through a scrap of paper, or some other little piece of flotsam' (1998: 76). What we see in the whole is not the whole of reality, but an aggregation of '*disaggregated* classifications that can at will be reassembled to take the form of facts about the world' (Bowker, 2005: 17).

If we are to believe Schwartz and Cook, that archives form 'the basis for and validation of the stories we tell ourselves, the story-telling narratives that give cohesion and meaning to individuals, groups, and societies' (2002: 13) then the

archive is necessarily a political space. This argument is similarly present in Stoler's book *Along the Archival Grain* (2009), building upon ideas initially presented in an earlier paper (2002), where she contends that archives were directly involved in the 'emotional economy' of colonialism, and a referent for the construction of identities of the imperial self and the colonised (and racialized) other:

'Managed hearts were critical to colonialism's political grammar. Imperial projects called upon specific sentiments, and assessed racial membership, in part by locating appropriate carriers and recipients of those feelings... Colonial statecraft required the calibration of sympathies and attachments, managing different degrees of subjugation both among its agents and those colonized ... Archival documents participate in this emotional economy.' (2009: 40-41)

Featherstone seems to agree, highlighting the multiplicity of historical purposes for archives. Archives, he argues, engender a 'whole epistemological complex' of information-gathering by a central administration to manage its imperial interests (2006: 591). Some archives had the capacity to assist in regulating domestic as well as colonial populations. As well as having a role in the global interests of Empire building, archives could also be seen as 'a crucial site for national memory', the safe place for storing the pivotal artefacts and writings used in the generation of social solidarity. In this way, argues Featherstone, archives could also be instruments with which national identity could be cultivated by housing the referents with which the imagined community could manifest itself (*ibid.*: 592).

Building more explicitly on Benedict Anderson's notion of imagined community (1983), Brown and Davis-Brown argue that modern, national archives can be understood as depositories of state history that, along with libraries and museums, 'help to preserve a collective national memory and thence to constitute a collective national identity' (1998: 19). They argue that along with national curricula, publically displayed monuments, national ceremonies and even Olympic teams, archives are enrolled in the construction of 'narratives of nationality'. We can push this a little further into the present from the modern archive of Brown and Davis-Brown. Contemporary instances of collecting data and matter – which the later

chapters of this thesis explore ‘can be seen as a relatively straightforward progression from an imperial impulse to a desire to archive knowledge in the service of the state and Empire’ (Waterton, 2002: 178) in the sense that they engender a desire to produce useable aggregations of information for some kind of public or state service.

As such, Osborne’s description of the archive as ever ‘oriented towards a space of public contestation, towards a never-ceasing politics’ (1999: 56) is surely true. Public archives have always bred a concern over the stories told, and the futures thereby made possible by the quiet, yet heavily mediated decision made about archival content. Why might some people be able to provide matter to the space, whilst others are denied? The beginning of the answer to this question, which is explored in more depth in later chapters, lies in Featherstone’s point that ‘the archive should be as exhaustive as possible’ (2006: 593). Archivists should consign to archives a diversity of matter, as if to make it ready for the unknown future. The archival process demands a level of selectivity as we have seen, but ‘the mandate for completeness’ obliges the archive to be composed under a rubric of ‘formal dissimilarity’ (Groys, 2003: 182).

Mbembe makes a similar argument, that through archives – an assembly of pieces that formulate a story – are no more than ‘a montage of fragments [that] creates an illusion of totality and continuity’ (Mbembe, 2002: 21). This is perhaps what Derrida argues, in his suggestion that those working in the archive aim ‘to coordinate a single corpus, in a system or a synchrony in which all the elements articulate the unity of an ideal configuration’ (1996: 3). The point he works towards here is that this ideal configuration comes at a cost. The gathering together of ‘the figure of a totalizing assemblage ... is never without violence’ (*ibid.*). This is the violence of *exclusion*. Therefore the archive, because it is a composite of *selected things*, is necessarily exclusionary. The US National Archive demonstrates this. They state, for example, that ‘[o]f all documents and materials created in the course of business conducted by the United States Federal government, only 1%-3% are so important for legal or historical reasons that they are kept by us forever’ (National Archives, 2015). Meanwhile, as Groys writes, ‘unimportant, irrelevant, worthless things remain in the profane realm, beyond the archive’ (2003: 179). The many irrelevant

correspondences are lost from the totality of the archive, excluded through the implicit political violence of selection.

By way of Derrida, Bowker argues that this is what constitutes the archive as a *jussive* space that permits certain things to be remembered and commits certain other things to the oblivion of forgetting. This, as Bowker puts it, is the ‘exclusionary principle’ of the archive (2005: 12). Given the importance of the archive in the construction of identities, it is perhaps unsurprising that we see archives designed to address this exclusion of material from other archives (see, for example, Nestle, 1998). Archives are inherently exclusionary spaces, but they can be harnessed to *address* that exclusion. The focus of an archive can be adapted to ensure a re-weighting of its contents, but it can never include everything. What, then, is excluded? What are the implications of this? How is exclusion challenged, and what new exclusions emerge in the process?

In this context, it is worth noting that race is often involved in how the archive is ordered and constituted. Stoler (2009), for example, discusses how it was through colonial archives that the otherness of non-whiteness was (re)affirmed. The bureaucratic technologies that begat the collation of data on ever-larger scales, argues Ian Hacking (2005) ran parallel to the imperial projects that reified racialised difference. The exclusive presence of racialised bodies in colonial registers through to their over-representation in police DNA databases (Skinner, 2013) speaks to the resonance of race in the archival setting. As a primary social category in the world, it is hardly surprising that it slips so easily in the ordering of archives. But there is, as Bowker suggests, another dimension to the presence of the exotic or the other, which I consciously group with the ‘ethnic minority’ that so often constitutes our archives. He argues that there is something about the mundanity behind the Western drive to aggregate information that makes it unattractive in the archive. There is, he suggests, the perception of...

‘...a great divide between our knowledge, which is timeless and without a past trajectory (it is always already there) and other folks’ knowing, which is tied oh-so-closely to their environment and their traditions. We need to preserve their memories and their diversity

precisely because we are the ethnos without memory: particularity is always already other.’ (Bowker, 2005: 225)

In the case of the selective collection explored in this thesis race is also central, as might have been assumed by its thematic prevalence in the last chapter. It is therefore an interesting point of exploration to think about how the archive can operate in relation to race. How are decisions of inclusion shaped around race? How is the archive’s order informed by race?

This speaks to an important point that merits its own exploration here. Order is at the heart of the archive. Classificatory systems, argues Beer, ‘order the content, make it retrievable and searchable, place it, categorise it, and give it meaning’ (2013: 41). It is through naming, and classifying, that ‘we bring order to chaos. We tame the wilderness, place everything in boxes’ (Duff and Harris, 2002: 282). Accordingly, where there is something deemed unworthy of the archive, there is a framework that must at some point have excluded that something. Archives, then, rely on criteria of classification, ‘grids of specification’ (Foucault, 1972: 46). As Derrida puts it, there can ‘be no archiving without titles ... without names ... without criteria of classification and of hierarchization, without order’ (1996: 40).

Importantly, though, the technical structure of an archive is the overriding determinant of what can go in it. Derrida ponders, in an example of the two overlapping concerns of his work *Archive Fever* (Freud, and the protean notion of “the archive”), what the psychoanalytic archive (see Appadurai, 1996; Marcus, 1998)² would have looked like if Freud and his contemporaries had used computers,

² Marcus notes that those working in an academic discipline can view the literary corpus of their discipline as an archive, suggesting that anthropologists all produce ‘personal ethnographic archives’ due to the accumulation of material from the field. An anthropologist himself, he notes that each of his colleagues in one way or another ‘is an archivist of his or her own career’ (1998: 53). Appadurai’s introduction to *Modernity at Large* (1996) similarly makes continual reference to the anthropological corpus as an archive, whilst a similar point

teleconferencing and email instead of letter writing. The ‘geo-techno-logical shocks’ of these novel communication forms would, he contends, have altered psychoanalysis unrecognisably.³ More broadly, he notes that archives are not simply:

‘...the place for stocking and for conserving an archivable content of the past which would exist in any case, ... the technical structure of the archiving archive also determines the structure of the archivable content even in its very coming into existence and in its relationship to the future. The archivization produces as much as it records the event.’ (1996: 16-17)

Here, Derrida is arguing that the archive is not some passive container that holds whatever people at the time think is worth retaining. The archive is a product of technological *context* as much as the archived *content*. Derrida’s point here is vital. Conceivably, anything might be archived if the technological conditions facilitate and merit it. Accordingly, archival strategies and methods ‘over the past centuries, and from here on into future centuries’ are ‘constantly evolving, ever mutating, continually adapting’. Cook explains that this is because of the often radical changes not only in small institutional shifts, but ‘the wider cultural, legal, technological, social, and philosophical trends in society’ (1997: 20). Similarly, Bowker notes that every novel medium ‘imprints its own special flavor to the memories of that epoch’ (2005: 26). The medium thus produces a qualitative *change* in the archive. The

is made by Foucault in *The Archaeology of Knowledge* in the chapter ‘The Unities of Discourse’ where he unpicks the notion of an author’s *œuvre*, to wit, self-referential archive.

³ It is also worth qualifying Derrida’s remarks in the light of Joanne Yates’ monograph on the transition into modern bureaucratic practice in American business. Given the ‘weaknesses of the pen’ (1993: 36), the emergence of the typewriter ‘transformed the production and use of documents’ (*ibid.*: 44). It is therefore very likely that a typewriter would have produced a geo-techno-logical shock all of its own for the early psychoanalysts even without the advent of email.

identity of the record is produced by way being stored in, saved on, and recorded via, the given medium.

Instability, it has been argued by Cook and co-author Schwartz, is an inevitability of any endeavour of record keeping, which is a pursuit facilitated by technology and ‘moulded by organization culture’ (Schwartz and Cook, 2002: 13). Elsewhere, the same authors argue that the nature of archives themselves – spaces that require content that necessitate subjective, interpretative knowledge – impose seemingly rational, stable systems of record management that are ‘inherently chaotic’ (Cook and Schwartz, 2002: 176). They argue that novel technologies or discoveries (indeed, we might include *any* kind of change) can be the catalyst of disassembly for entire archival strategies and methodologies.

It becomes apparent, then, that what Brothman calls an ‘Edenic order’ in a piece in which he imagines the archive as a tended garden with a particular ‘archival ecology’ (1991: 80) is not a naturally occurring thing. Records do not have, he argues, a natural place in the archive. It is instead an ‘imposed socio-historical order’ (*ibid.*: 85). It makes sense to look at STS scholarship on classification and ordering at this point, particularly that of Geoffrey Bowker and Susan Leigh Star. The basic point made by the authors is that there is much to be learnt from infrastructures. By performing what they authors call an ‘infrastructural inversion’ (Bowker and Star, 1999), it is possible to ‘unearth the dramas inherent in system design creating, to restore narrative to what appears to be dead lists’ (Star, 1999: 377). We might, then, spend time looking at the ‘practices that make up [an archive’s] unspoken order, its rubrics of organisation, its rules of placement and reference’ (Stoler, 2002: 94). How are those orders developed, and do they ever change? If so, how and why?

As Bowker notes, ‘any information infrastructure ... aims by its nature to contain all and only the information that is needed’ (1997: 126). But there is, Bowker adds elsewhere, ‘no foretelling what information will be relevant’ (Bowker and Star, 1999: 116). Any and all information *could* be useful, but one cannot know until it starts being used. As he puts it, ‘you won’t know what makes a difference until you have built up a body of knowledge that relies, for its units of data, on the classification scheme that you have not yet developed’ (Bowker, 1997: 131). This is

because, as Waterton reminds us, knowledge itself is ‘chronically performative, contingent, and emergent, interacting with a world which itself is in an eternal process of becoming’ (2010: 654) which speaks to Bowker’s claim some years earlier that, in light of this quality, ‘naming mechanisms tend to break down’ (2000: 654) in archives. To the extent that a classification system and the matter that fits within it can be open to determinations of outdatedness, irrelevance or insufficiency, an infrastructure (or, at least, those to be of future use) cannot be finished. Star argues that though infrastructural revisions may have been made speedier in the contemporary moment, the ‘heated, but invisible, discussions’ persist, their shapes and arenas simply having changed (2002: 111). Energised discussion about the form and operation of classifications within archival spaces has not disappeared with the advent of new technologies.

For this reason, ‘a perfect archival system is a chimera’ (Bowker, 2000: 670). Classificatory systems are incredibly unstable, shifting with professional and technological preference. Archivists, we know, engage with material through evaluative lenses peculiar to the archival field of interest. But, given Bowker’s point, these lenses must be forever liable to tiny or, occasionally, seismic recalibration. In respect of this, Bearman argues that archivists might better think of themselves as managers of a ‘process that sets known benefits and current costs against future, long-term and unknown risks’ (2002: 326). Notions of order change, and so archives must be pliant with this. Archives must contend with the possibility that something within the archive may no longer be required. To maintain order is a big job, and it requires the identification and removal of things that ‘no longer “fit” within a preordained social/ archival order’ (Brothman, 1991: 81). Once such items are removed, they no longer enjoy the “status” of the archive (Mbembe, 2002).

Order, then, ‘is constantly threatened with disruption’ (Brothman, 1991: 80). The borders of the archive (that which it will receive, and that which it refrains from collecting) and the classificatory frameworks used to manage the matter within those limits, are always potential ‘sites of disagreement’ (Beer, 2013: 43). Without the capacity for these conversations, though, ‘archival credibility will suffer ... Irrelevance will loom’ (Cook and Schwartz, 2002: 179). With this in mind, *obsolescence* (a term that brings to life the temporal quality of irrelevance) is a risk

that cannot be effaced. However, it can be managed. What happens, then, when the archive becomes irrelevant, or when some of the matter within it loses applicability to future users? An important question emerging from this is *how* such risks are managed.

Risk, of course, presents itself in myriad ways. Derrida argues that there is ‘no archive without outside’ (1996: 11). One cannot archive without consigning the archived thing to an external place which, by way of its exteriority and vulnerability, ‘menaces with destruction’. Dramatically, he closes his idea by suggesting that the archive ‘always works, and *a priori*, against itself’ (*ibid.*: 12). He makes the point again in a paper some time later:

‘You need the exteriority of the place in order to get something archived. Now, because of this exteriority, what is kept in the archive, of course can be erased, can be lost, and the very gesture which consists in keeping safe – in a safe, so to speak – is always, and from the beginning, threatened by the possibility of destruction.’
(2002: 42)

Featherstone argues that discussions about the archive are usually interested in how it changes over a period of time, even though ‘the archive has a spatial history too’. In drawing attention to the spatiality of the archive, he describes how archives developed in one space could be transferred to another space, such that Haiti’s national archive resides in France. Archives can physically ‘be destroyed, stolen, purchased and relocated’ (2006: 592). It is worth keeping this in mind. Whilst Derrida is not referring to literally quaking earth when he said that deconstruction would cause the archive concept to be ‘shaken by an earthquake’ (1996: 5), archives dealing with physical material are, like the rest of the physical world, vulnerable to the world’s proclivities. Floods, fires and earthquakes could literally destroy the archive. To return to Derrida’s etymology from earlier in the chapter where he raised the issue of the archive as a guarded space, we can begin to ask questions about how the archive protects itself from such material risks as destruction. More broadly, we might combine these issues of risk (obsolescence, physical destruction) to ask how the archive can sustain itself, in light of the diverse risks it faces.

2.7 Blood in the Archive

In the next chapter, chapter three, I explore the methods employed in the data collection and analysis, and reflect on the intertwined experience of producing a conceptual understanding alongside the production of empirical data. I treat this methodological exploration as a kind of audit of the different elements that occurred on the way to producing the thesis. Accordingly, I explain how I became familiar with the scientific underpinnings of umbilical cord blood, and how I initially orbited towards the All Party Parliamentary Group that acted as a useful means of locating the relevant participants who I went on to interview. In this chapter, then, I also explain why and how I undertook qualitative interviewing, and how I then analysed the data emerging from these encounters alongside the various documents – policy documents, reports, and so forth – that I also used as data.

The fourth chapter, which is the first of four empirical chapters, adopts an archival lens to consider the empirical data in reference to the issues of *order* in the archive. I explain how the archive in question – the UK’s publically available collection of umbilical cord – is ordered along explicitly racialised lines. I explore here how the archival goal of representativeness is worked towards in this instance by encouraging stem cell donation from Black and minority ethnicity donors. One of the key elements of this chapter is thinking through how race is used to bring order, but is itself a chaotic classification that proves challenging to wrangle into a classificatory schema that makes sense universally. The actual use of ethnicity data by those who use the bank – practitioners – is minimal, as they instead rely on the molecular tool of Human Leukocyte Antigen (HLA) typing.

Chapter five explores the archive as an *exclusionary* space, plotting out the dualism of public/private that has come to define projects of UCB collection. Public, as I touch upon in this chapter, implies particular communitarian sentiments of access to donation whilst in practice, the capacity to donate to this public archive has a variety of limits in terms of resources and geographies. This chapter, then, explores the tension between the moral admonishment of ‘waste’ avoidance through UCB donation and the privation of access to donation faced by so many in the UK. In addition to this it also explores the racialised differentiation of bodies through

encouragement of particular communities to help others from within the same group. How does the appeal to community spirit have the potential to invert itself such that people will donate only for particular recipients?

The focus of the sixth chapter is around *use* in the archive. Here I am interested in exploring how the clinical standards that determine what stem cell source might be selected inform how the archive comes to be managed. An important caveat I highlight here is that use in the archive cannot be fully understood without comprehending how the archive comes to be used. For that reason, I explore the different registers of judgment (the rational and affective strata insofar as they can be divided) that bring the archive into play for clinicians. Here I focus on one feature of the umbilical cord blood stem cell unit – its Total Nucleated Cell (TNC) count – to highlight the responsive shifts in archival practice in accordance with user preferences. The chapter is concerned with how and why these archivists respond to their users' preferences.

The final empirical chapter, chapter seven, is broadly engaged with the various *risks* faced by the archive. Its first concern is the way in which archivists come to think of their collections as different 'generations', as if learning from previous iterations of practice. What, I explore, does this reveal about the archive as an inherently dynamic space? In addition to this, the chapter engages with what happens when users' selection criteria and preferences shift. Matter stands to travel out of relevance, and the archive – without addressing this – faces the death knell of obsolescence. How is such risk dealt with? Risk, though, takes on other guises. What physical challenges does the archive come up against? How might we come to understand the industry's concern with 'resilience' within an archival framework? Finally, how do archivists anticipate future challenges and absorb those within their strategic project of development?

Finally, the concluding eighth chapter lays out the arguments made throughout preceding chapters. Rather than just a summary, the chapter draws out something of these critical threads to frame some of the key problematics that the thesis brings into relief. This chapter also offers an opportunity to reflect on the methodological and theoretical limitations of the doctoral research presented here. Finally, I use this last

chapter as an opportunity to put forward some future pathways of enquiry that can begin to address these limits and also build upon the critical offering provided in this thesis.

Chapter Three: Methodology

3.1 Introduction

In this chapter, I set out to explore the methods employed in collecting and considering the data I offer in the following chapters. In a way, the chapter acts as an account of the coiled relationship between the theoretical and empirical work in this thesis. Far from a linear process, data collection, analysis, and the production of a theoretical understanding were intertwined. This chapter, then, acts like an audit of the various tasks I undertook on my way to writing the thesis.

I begin by explaining some of my early familiarisation with the scientific literature. I then explain my early interest in the All Party Parliamentary Group (APPG) on Stem Cell Transplantation, and the UK Stem Cell Strategic Forum (SCSF), which are names that appear fairly regularly in chapters to come. I describe my early intentions to observe APPG meetings, before introducing the body of policy documents I analysed. After this, I describe why I approached particular people for qualitative interviewing and how I undertook this part of my data collection. Here, I reflect on my own experience of developing fluency in expert knowledge. I also describe the ethical approval process and, in particular, the issue of maintaining participant anonymity in a field where many participants seemed to know one another.

3.2 Before Data Collection

In an effort to prepare myself for data collection (particularly to develop the beginnings of a literacy, if not fluency, in the scientific nomenclature of the field I had anticipated needing to know about), I undertook a review of the scientific literature that relates to UCB. I reflect later on in the chapter on the issue of developing this kind of expert fluency but it is worth explaining here how I benefited from this early exercise. Firstly, I read through the most widely-cited journal articles on umbilical cord blood stem cell storage and transplant in the leading journals of the field (*'Blood'*, *'Bone Marrow Transplantation'*, *'Transfusion'*, *'New England Journal of Medicine'*). Reading these through gave me a sense of the shifting landscape of UCB storage and transplantation, and familiarised me with some of the

terms that I would later come across in data collection. At this stage, I also familiarised myself with undergraduate immunology material. This was useful not least because it allowed me to see how the field of immunology (and tissue transplantation science) conceptualises and visualises the theories it relies upon. Then, I undertook an internet search for UCB studies that made reference in some way to either the 'race' or 'ethnicity' of donor/recipients using key word searches.

Ethnicity classifications usually appeared in tables of data and were generally only discussed beyond any tabulated appearance to specify statistical significance in the given research. Often ethnicity was not mentioned at all in this way and its presence in the table was unquestioned even though it often held no statistical significance in research findings, implicitly re-inscribing the 'variable' of ethnicity as a necessary, yet silent, point of data collection. I was interested here in how these categories shifted, unfolded, got reduced and magnified. A number of ethnicities might appear in one graph only to be reduced to a white/non-white binary in another (see, for example, Ballen *et al.*, 2006). It interested me that race could be reduced like this, as I had understood race to have use only when used for specificity.

These slippages, to refer back to Bliss's (2011) term, were interesting, though, and highlighted for me the difficulty of pinning down durable classificatory frameworks. This issue came to the fore during data collection and analysis. An Australia-based study includes 'Australian aboriginals' and 'pacific islanders' (Samuel *et al.*, 2007) in order to correlate with the Australian bureau of statistics, whilst these categories are unsurprisingly absent in other studies, where different specificities emerge. In a Singapore-based study, for instance, "Malay" and "Asian Indian" categories are used (Tang *et al.*, 2007). It became apparent here that race categories had to have some local meaning, perhaps even had to fit into political classificatory frameworks like censuses, which themselves have an interesting locality and history (Hacking, 2005), to be useful.

This exercise was invaluable in developing my methodological approach because it produced a more articulated awareness that race had use, but that it was a very difficult thing to classify consistently. To that extent, I also realised that I had to have some consistency myself. Through this exercise I decided a few things. Firstly, I

have chosen not to use the term ‘non-white’. To me, it infers a *lack* of ‘white’. It also positions the non-white identity around whiteness, a point that resonates with Dyer’s (1997) suggestion that white people are somehow *free of* colour, the point in reference to which all ‘othered’ bodies should be understood. I use terms like Asian, Black or minority ethnicity in this thesis to describe a group or a body racialised as such. I do this in the main because these are terms used by minority activist groups working in the field (see National BAME Transplant Alliance, 2012). They are imperfect terms as they do not fully capture the heterogeneity of the bodies that are minoritised by way of their racialisation (see St. Louis, 2005). But I want to understand why and how race is enrolled, and talking *about* race cannot be done *without* race (Warmington, 2009).

As the famous post-racialist Gilroy noted in 1998, it is important to ask ‘what that trope “race” lodged in the body might mean in the age defined by ... molecular biology’ (1998: 843). So too is it important, I think, to keep asking what this ‘trope’ might mean more broadly across contemporary scientific discourses related to human bodies and populations. But for the sake of consistency, I do not use the word ‘race’ a great deal in the thesis that follows. I use the word ‘ethnicity’, which I freely agree with Murji and Solomos is used here ‘as an inference of race’ (2005: 4). I hope though, that Carter and Dyson would appreciate that although I recognise their argument that the seemingly benign term ‘ethnicity’ might allow some to talk about ‘race’ without having to actually say such a ‘disreputable’ word (2011: 966), they would recognise that I choose to use the word, whilst conscious of its variable meanings, for consistency and clarity.

3.3 Observation and Documentary Analysis

In this section, I consider the inclusion of particular data sources into my analysis. The first of these, and the most minor, are parliamentary meeting observation notes. In September 2013, I attended an APPG at the Houses of Parliament. Although this meeting was open to the public, I requested to the secretariat that my name and affiliation were published on the minutes. The APPG report has been an active space for political discussion about the establishment of HSC usage in the UK and its potential both for clinical, industry, and research purposes. The topic of the meeting I

attended was the needs of patients from ethnic minority backgrounds. I took observation notes in which I wrote down, with as much speed as possible, the relevant points of presentations and discussion. The determination of relevance of course represented my own positionality (Mulhall, 2003), but data collection by this means was cut short. One meeting was postponed at short notice, and because of the room size for the following two meetings, the APPG was closed to public audience.

Another opportunity arose for observation, this time in Madrid. This occasion was of a different nature, and involved a visit to a public umbilical cord blood processing unit and bank. The access negotiated by the European Commission action, *Bio-objects*, permitted access through the entire complex of the municipal blood centre, where regular donors give blood, and where an entire district of Spain's blood supplies are stored in their separate components to retain their use for as long as possible. Behind all of this lay a much quieter laboratory, where a single man and two female operatives oversaw several freezers full of stem cells from Spanish donations of umbilical cord blood. This visit included a small group of STS scholars including myself and Nik Brown, with whom I have since co-authored an article exploring our observations here amongst other things (Brown and Williams, 2015). On this visit, I was able to collect a significant amount of visual data (some of which I offered as context in chapter one). During this trip, I spent time in industrial cold storage units, observed the careful work of scientists fractionating and measuring bloods, and processing UCB units ready for storage. It is important to note that whilst this visit took place abroad as part of a European network and so may not appear to have direct relevance, it was particularly useful in drawing my attention to the physical aspects of resilience engendered in the design and management of these spaces, not only in Spain and the UK but globally. This is a significant concern of chapter seven.

As Ball (2011) notes, the unobtrusive nature of locating public domain literature makes them a particularly useful source of data. As will be seen in the chapters that follow, use is made of these different sources as I explore the data. They offer a peculiar insight into what the secretary found fitting to document, or what a presenter found the most useful way of visualising their point for an audience. Fortunately, minutes and presentations from the two APPG meetings that preceded my project,

the set from the meeting I attended, and the two that took place after this, were made available in the public domain on the APPG website for anybody with an interest. These documents were incorporated into data analysis (n=5). Where made publically available on the APPG website, I have also incorporated presentations into analysis which includes both PowerPoint presentations and verbatim scripts provided by speakers (n=16). Some interviewees were also APPG speakers, and I make this clear in the following chapters wherever I think it will be useful for the reader.

Most bureaucratic institutions 'are awash with ... forms, memos, monthly, quarterly and annual reports, procedure manuals, spreadsheets and records, as well as policy and mission statements' (Prior, 2011: 98). Accordingly, policy documents were also included in data analysis. This was, again, another means of unobtrusive data collection that permitted great insight into the rationales, aims, and rhetoric used by the various institutions I was interested in. Importantly, though, these data were not used to 'supplement' that collected from interviews as a means of validating them. Rather, the documents analysed as part of this project themselves formed a rich, invaluable source of readily available data that complement, rather than simply 'prop up', the other data appearing in the following chapters. Appendix C outlines those documents (n=12) included in the data analysis. Covering a wide range of sources, these are government policy documents, incident reports, and operation/classification guidelines. I came across these various documents at different points. Some were found well before interviews began, some were considered in response to the recommendation of interviewees. More still came to my attention during data analysis and were incorporated at this point.

Along with this, I also included parliamentary discussion in my data analysis. The reason for this is because the establishment of the Stem Cell Strategic Forum was mandated in parliament by a government minister. A number of other MPs have also raised motions about UCB's role alongside adult volunteer donation in parliament. Though all these individuals have all been involved in the APPG in some way, it was apposite that the parliamentary discussion itself be incorporated into data analysis because they demonstrate an official, transcribed documentation of the political emergence of the issue of umbilical cord blood in the UK. Using the online archive of the UK parliamentary record of what was said in parliament, Hansard, which

thematically indexes discussions in the House, I selected all instances of the discussion of UCB in parliament. The extracts (n=4) from Hansard include all statements, questions and answers made in reference to the initial speaker's motion or bill. The first discussion of umbilical cord blood in the House is in 2008, and is followed by further instances in 2010 and 2011. Hansard extracts, downloaded verbatim from the Parliamentary publications website, include a first and a second reading of a bill regarding the donation of umbilical cord blood, and two motions regarding umbilical cord blood banking facilities in the UK.

3.4 Why Qualitative Interviews?

So far, I have described the foundational work I undertook in preparation to begin data collection. I have also outlined the various documents and materials included in data analysis. At this point, then, I want to consider the role of qualitative interviews in this study. It was recognised from the beginning of the project that I would need to speak to those involved in the production of policy. Talking to the individuals would allow me to complement my other data collection, not least because interviewing is an 'interactive, situational and generative approach to the acquisition of data' (Mason, cited in May, 2002: 225). Generativity points to something beyond the fact that interviews yield data. They also generate new pathways of exploration that analysis of documents alone cannot provide. Writing about their methodologies in studies on biotechnology regulation, Prainsack and Wahlberg (2013) note the same. Assuming there was no coherent order, they sought to move beyond the tailored policy documents to see the messiness behind the order. Qualitative interviews stand to shade in the tidy policy with the dominant voices, receded suggestions, the consensus (and lack thereof) that could have shifted an entire policy strategy in a different direction.

Interviews, of course, will never '*unearth* the relevant data ... because the phenomenon under research does not have a static decontextual ... existence' (Mason, cited in May, 2002: 227, original italics). But as a generative tool, the interview encounter stands to reveal complexity, enriching data analysis and key findings. To this end, much of the data in the chapters ahead were the product of a semi-structured approach to interviewing. This entailed the development of a brief

list of headings that were prepared in advance, and tailored to the participant's position and access. In Appendix D, I provide a list of general themes and example questions related to these that are indicative of what interviewees were asked. This is by no means an exhaustive list. Questions were highly dependent on a participant's previous responses and varied depending upon that own person's involvement in the broader area. A briefer indicative list of thematic avenues for questioning is outlined below.

Table 2: A list of thematic avenues for qualitative semi-structured interviews

The individual participant's involvement in the APPG, SCSF, and/or the WMDA	Particularities of the role of the APPG, SCSF, and/or the WMDA	The collection and use of ethnicity data in the UK and internationally
The development and current state of Total Nucleated Cell (TNC) count thresholds	The development and current state of HLA typing resolution consensus	The economic dimensions of UCB banking and clinical application
Particularities of the role of the individual participant's charity	The individual participant's knowledge of UCB technology	The consensus on a relationship between HLA and ethnicity
The historical and current relationship between UCB and adult HSCs	The recommendations of the Stem Cell Strategic Forum's 2010 report	Specific queries related to particular documents with which the individual participant has been involved in producing
The clinical emergence and uptake of UCB	The choice of UCB collection sites across the UK	The role of private banking in the UK

When undertaking interviews, I found that considering what themes to discuss in advance ensured that key bases of inquiry were touched upon in such a way that participants were still able to etch the conversational flow. Structure, then, was

useful. But *too much structure* in the interview would not lend itself to the ‘sensitivity to context and particularity required’ (Mason, cited in May, 2002: 231) in this research setting. A more inflexible method such as the structured interview, usually invoked because of the researcher’s ‘need to standardize the way in which an interviewee is dealt with’ (Bryman, 2008: 437) would be at odds with this need for unanticipated avenues of exploration. Of course, though I had decided *how* I wanted to interview, deciding *who* to talk to would require its own consideration.

3.5 Who is an Expert?

In this section, I want to consider how I decided who to approach as a participant. I would, on reflection, call this one of those dilemmas of trying determine ‘expertise’, a debate that many STS and Science Studies scholars have engaged in (see Rip, 2003). I describe here how I began by searching for the ‘core set’ of scientists involved before extending my search into the broader sphere of policy production to include those speaking or involved in chairing parliamentary meetings, those contributing to the key policy documents. Developed by Harry Collins (1981), the core set approach is a means of determining who to involve in the participant group in those communities involved in the production or use of generally emergent technological or scientific processes. The overarching determination of whether something can be considered a core set comes through considering whether the common interest of the ground is defined by controversy, disagreement, and potential upheaval. The core set, then, is that ‘small group of experienced and qualified persons who actively contribute to scientific debate’ (1988: 740). Controversial science, in Collins’ formulation, is an important element in determining the existence of a given core set.

From its instantiation, umbilical cord blood has been involved in controversy. Significant concern has been raised about the claim that UCB donation is harmless for the woman and baby involved. This discussion tends to coalesce around the potential problematics of early clamping, particularly for neonates who may stand to benefit from late clamping of the umbilical cord, rather than the early clamping required to sequester stem cells for storage (American College of Obstetricians and Gynecologists, 2012). Consequently, this controversy stands to have an impact on

whether parents decide to store stem cells or delay clamping for other potential benefits for their own neonate (Brown, 2013).

UCB also takes a place in those discussions about the morality of scientific interventions that use stem cells. As a potential point of political controversy, those working with cord stem cells have taken pains to ensure UCB stem cells' definitional differentiation from controversy-ridden embryonic stem cells. In scientific research literature they described as having 'embryonic characteristics' (McGuckin *et al.*, 2005) or being 'embryonic-like stem cells' (Alvarez-Gonzalez *et al.*, 2013). In *New Scientist* magazine, it was similarly asserted that UCB contained "'ethical" embryonic stem cells' (Coghlan, 2005). This hints, perhaps, to 'moral pathfinding' in which 'a number of negotiations and an amount of reconceptualisation work' take place around potentially controversial, perceivably embryonic, tissue (Svendsen and Koch, 2008: 95). By way of explaining how the controversy was managed by interviewees, consider the quote below from one of the interview transcripts.

There was this business of what was embryonic and what was adult? And of course, cord blood often gets mistaken as being embryonic and it isn't. It's adult stem cells. Well actually it isn't either ... the cells in cord blood are derived from foetal stem cells. ... But it's not embryos and the ethics and all the rest of it around that. And so it's quite easy to see how people get confused. So, in terms of ethics, cord blood is adult stem cells.

But public controversy – the 'people' who 'get confused' – is not the only kind of controversy that has come to define this domain. Some members of the 'core set', argues Collins, 'will not necessarily interact frequently with one another, for some members may be enemies' (1981: 8). A dramatic description perhaps, but it does ring true with some of the sentiments expressed by interviewees, such as in this quote from a participant. Here, they describe a conference attended by those involved in producing professional guidelines, including several people I interviewed:

It was funny because it wasn't a discussion. It was an argument, a total argument. About "it was better for the mortality, the TRM

[tissue-resident memory cell count]”, “it’s better if there is a mismatch.” ... It was an argument between two different groups ... fighting about what was wrong.

As Collins notes, a core set can be determined by asking individual participants ‘who else they think has made a significant contribution to the debate’ (1981: 9). Frequent mention of important names signals inclusion in the core set, argues Collins. Not unlike the much more commonly found approach of snowball sampling, all interviewees were asked to recommend other people I might be able to speak to. Those I interviewed also occasionally mentioned other individuals during our discussions as in these examples, which are taken from transcriptions with participants.

So xx would be your man because he has the criteria now that people use and he’ll be able to tell you exactly what different people are doing.

Have you spoken to xx yet? ... I’ll send your email to him. He’s really spending his whole life now in building these models in costing and all that.

However, the challenge here, as Collins and Evans have termed it, is one of ‘extension’ (2002). The core set approach makes space for the possibility that it might have to make space for more than the few qualified scientists undertaking esoteric work. The core set should only include those who are ‘reasonably scientifically qualified and/or experienced’, but Collins explains himself here:

‘This is only to say that on matters scientific ... we prefer our technical opinions ... to be formed by the outcome of debates among the wise (whether these outcomes turn out to be correct or not) rather than by the first impressions of John Doe or “the man on the Clapham omnibus”.’ (Collins, 1988: 740)

If indeed a fairly well defined group of scientists could be approached, was that enough? How far beyond that, if at all, might I extend? And in what direction? As Rip puts it, ‘the state-of-the-art (i.e. our knowledge) in a domain derives from the state-of-the-debate’ (2003: 374). My conviction from the start of this process was that I wanted to talk with those people involved in the discussion about the role of umbilical cord blood in the UK’s stem cell provision services. Though this included scientists, it did not end with them. As such, invites were extended to those who had been involved in APPGs and those who had contributed to particular policy documents. I use the word ‘contributed’ rather than ‘authored’ as in some cases, authorship was credited institutionally whilst all contributors are listed within the document. The policy documents I used were reports produced by the SCSF (UK Stem Cell Oversight Committee, 2015; UK Stem Cell Strategic Forum, 2010a, 2010b) and the APPG (2012).

For this study 28 potential participants were contacted via email which included an information sheet and informed consent form (see appendix). In total, 18 were interviewed. Of the ten who were not, two felt that their expertise was not relevant to the research because they had moved away from working in the area of umbilical cord blood. One told me they were too busy to meet with me (although I did clarify that I was able to visit them at any time over the months I was collecting data). One had retired and no longer felt they were in the position to talk to me, one had moved into a different role and helped to organise a meeting with the colleague who had taken over their job. One email address had become inactive presumably because they had left the institution, and a search for their replacement was fruitless. Three were entirely unresponsive to emails, and one agreed to a telephone interview but eventually became unresponsive, presumably because other commitments had taken precedence.

Data saturation, of course, is never an easy thing to determine (Francis *et al.*, 2009). As Collins notes, the core set’s ‘exact membership is not a thing to be agonized over’ (1981: 9). However, participants (unaware of who I had already interviewed) started to recommend those who I had already approached. As such, by the end of data collection all of those recommended to me (and who I then checked were appropriately involved in the study context) had been approached. Along with this,

there was also the issue of relevance. Was it worth ‘swelling the numbers’ to ensure validity, or would validity have suffered? Should I have invited those who were not suggested to me, or who were perhaps ‘less’ involved in the field? The answer to this question, I decided, was no. This was particularly apparent when I began to analyse interviews and found the data thematically rich and conceptually fertile. I expand on the process of data analysis shortly, but it is worth firstly giving some detail about the interview data I collected for this project.

3.6 The Participants in This Study

To contact participants, email addresses were found through an internet search. I also arranged meetings at the APPG, and at the annual conference of the World Marrow Donor Association (WMDA) in London where I met with two participants. A standard template explaining the project and tailored to their particular involvement was emailed to them all individually, and was sent out to a few participants at a time. As most of these individuals were based in London, I had hoped for practical purposes to combine as many interviews into each visit as possible. Inevitably, practicality was not on my side and I was soon quite familiar with the National Rail advance train booking process. Indeed, on one occasion I was halfway down to London when I received an email from the participant telling me they could were ill and could not meet. Interviews took place between October 2013 and November 2014.

The table below presents information about those who were interviewed. In total, I undertook 21 interviews with 18 participants. Some interviews (n=4) were done over the telephone, and in 2 of these cases I followed up the telephone interview with a further face-to-face interview as phone interviews tended to be shorter (~40 minutes) whilst the average face-to-face interview lasted around an hour and a half. In one of the cases, the telephone conversation was a ‘follow up’ after undertaking some initial data analysis as I outline later in the chapter. In the column below where I describe their relevance to the study, I refer to their membership to different groups or forums. These are the UK Stem Cell Strategic Forum (SCSF), the All-Party Parliamentary Group on Stem Cell Transplantation (APPG), the World Marrow Donor Association (WMDA), the Cord Blood Working Group of the British Society of Blood and

Marrow Transplantation (BSBMT) and NetCord, an international cord blood bank accreditation and advisory group.

Table 3: A list of individual participants interviewed for this study

Means of communication for interview	Participant's anonymised identifier	The participant's relevance to this study
In person	Participant 1	Involved in APPG, SCSF and BSBMT Cord Blood Working Group
In person	Participant 2	Involved in APPG
By telephone		
By telephone	Participant 3	Involved in APPG
In person		
In person	Participant 4	Involved in APPG and SCSF
In person	Participant 5	Involved in APPG, SCSF and BSBMT Cord Blood Working Group
In person	Participant 6	Involved in BSBMT Cord Blood Working Group and WMDA
By telephone	Participant 7	Co-author of recommendations for international best practice; also involved in SCSF
In person		
In person	Participant 8	Involved in APPG, SCSF, BSBMT Cord Blood Working Group and WMDA
In person	Participant 9	Co-author of recommendations for international best practice; also involved in NetCord and WMDA
In person	Participant 10	Involved in APPG and SCSF
In person	Participant 11	Involved in APPG
In person	Participant 12	Involved in APPG
In person	Participant 13	Involved in APPG and SCSF
In person	Participant 14	Involved in APPG
In person	Participant 15	Involved in APPG

In person	Participant 16	Co-author of recommendations for international best practice; also involved in NetCord, SCSF, and WMDA
In person	Participant 17	Involved in WMDA
By telephone	Participant 18	Involved in APPG and SCSF

During the course of interviewing participants, I came across an issue that I had – to an extent – anticipated. This was the development of fluency in expert knowledge, which others have tackled by *assuming* the role of a status subordinate (Delaney, 2007) who can essentially *perform* a lack of knowledge that prompts elongated answers from participants. Elsewhere, this has been described as the exploitation of outsider status (Herod, 1999), or playing the role of unthreatening supplicant (Desmond, 2004). As Morris (2009) notes, these methods permit deception and manipulation in the interview encounter. Before I began interviews, I had – as I have outlined above – spent a considerable amount of time familiarising myself with the scientific literature. I studied undergraduate texts on basic immunology, and learnt a great deal from the initial science literature review. These were revealing exercises in that they familiarised me with concepts, methods and measures commonly employed during collecting, processing, measuring and freezing UCB. Nonetheless, terms came up during interviews that I had not come across. For example, a participant said GIAS (pronounced guy-uss) several times during our discussion. They felt it relevant enough to say it, so I asked them what GIAS stood for.

Graft Identification Advisory Service ... the hospital will send us the [patient] details and we will then make the decision on who [which volunteer donor] to do the extended typing on... and as much as telling you who it's good to tissue type, it will also tell you who you should definitely not further type because they'll say "this person, no they're not going to be nearly what we want" ... So it's really good. It helps to unlock the part of our register that, beforehand, was locked basically ... it means that we can reduce the number of people that people have to do confirmatory typing on which will ... hopefully speed up transplant as well.

This clarification uncovered something vital. The above quote illustrates the idea that older data could somehow be ‘locked’. In this case, tissue typed in the past at a lower resolution of molecular specificity must now undergo ‘confirmatory typing’. It was only through asking for clarification that a thread that runs through the final empirical chapter, obsolescence, really started to come alive in my mind as an important point in the practice of storing and registering HSCs.

In Welch *et al.*’s discussion of interviewing those in senior positions in business, they advocate knowing abbreviations (2002: 624). This point resonates with my own experience. When working with scientists and those who come into contact with the scientific language they use, it was effective to practice what I have started to call *acronym awareness*. I mean this on two levels. Firstly, acronym awareness can be thought of as the preparation of knowing terms, abbreviations and basic ideas beforehand so the interview’s flow is less frequently hindered by requests for clarification. It has been argued that preparation can ‘establish trust with the interviewees’ (Mikecz, 2012: 487). Perhaps it also allows for interaction that can only take place when the interlocutors are talking in the same “language”. Secondly, it advocates alertness for acronyms and abbreviations. If I did not know one, it was worth finding out what it stood for. Put simply, terms are not abbreviated unless they are being used a lot. If somebody abbreviates a term, it must be in fairly frequent use and therefore have some relevance to the day-to-day practices I am interested in.

Considering this diverse assembly of data sources, I would suggest that the project rests on what Prainsack and Wahlberg call an ethnographic sensibility. Not an ethnography, but not reliant only on interviews or on policy documentation, I have tried to move past analysis only of ‘tailored narratives found in policy documents and policy-makers’ accounts,’ instead paying attention ‘to the practices and narratives “on the ground”’ (Prainsack and Wahlberg, 2013: 340). In their respective studies of Israeli stem cells and Vietnamese complementary medicine, the authors collected data by a variety of methods.

‘Spending time in our respective countries of study, interviewing experts, being in laboratories, gathering and analysing policy papers, discussions from e-mail lists, and other relevant documents,

speaking to lay persons, ‘hanging out’, and reading newspapers was what brought insight...’ (*ibid.*: 341)

In this thesis, I have sought data through an array of methods to bring insight to a system that, on reflection, I would argue cannot be appreciated without some attempt to ‘broaden methodological scope’ (*ibid.*) beyond a single approach. As I have described here, I undertook qualitative interviews, analysis of a diversity of documents, meeting observation, spending time in a UCB and blood processing unit, and following published updates in clinical and scientific consensus. Data and reflections from all of these sources appear in the empirical chapters that follow the current one, offering what is intended to be a rich and dynamic exposition of the complexity that underwrites the context of interest here.

3.7 Ethical Considerations

In light of the data collection methods I decided to use for this study it was necessary to secure ethical approval from the ELMPS (Economics, Law, Management, Politics and Sociology) sub-committee of the University of York’s Ethics Committee. In application for approval, I laid out the rationale behind, and good practice for, data collection. I explained, for example, how I would undertake observations at APPG meetings (which, as I explained above, became less integral as a data collection point as the research progressed). To do this ethically, I would notify the secretariat that I was attending and ask them to ensure that my name and affiliation were written down in minutes. Because of my decision to focus on the production of policy and not look specifically at the treatment of NHS patients, I did not require NHS ethics approval. Similarly, my research did not set out to explore work undertaken by NHS-employed staff members in the course of contracted employment duties. Accordingly, NHS research and development approval was not required.

I outlined my approach to qualitative interviewing which centred mainly on the issue of anonymity. Anonymity has been termed the operationalisation of research confidentiality and is a central facet in the production of social research (Wiles *et al.*, 2008). One of the largest challenges I had anticipated in this study was maintaining confidentiality of participants both during, as well as after, my data

collection. As Collins notes of many involved in a core set, individuals are ‘linked biographically and occasionally bibliographically’ (1974: 171). In short, they often know one another. Those involved in policy discussion, scientifically trained or experienced in the field outside of the laboratory (for example, charity leaders who were *au fait* with the science though not themselves ‘scientists’) did tend to know one another, having met many times before. Collins’ point resonates with my own experience, as people I had already spoken to would be suggested by others as potential participants. Here I was faced with a decision. On the one hand, I could reveal one participant’s identity to another. On the other, I could prevaricate, jot down the suggested name and feign an intention to pursue it further. I found the second option to be the only choice.

In this context it is perhaps unsurprising that one of the biggest decisions made in writing this thesis was made to maintain the anonymity of participants. I am talking here about the omission of information about their locality, their gender and – as best as possible – the specificities of their role beyond their involvement and membership in the groups that have come to constitute this core set. Consider this hypothetical participant who exemplifies the plurality of interests, expertise and capacities that defined my various participants.

A trained immunologist who used to work in an adult donor registry in Europe but who now works for a UK-based charity encouraging cord blood donation in the Jewish community.

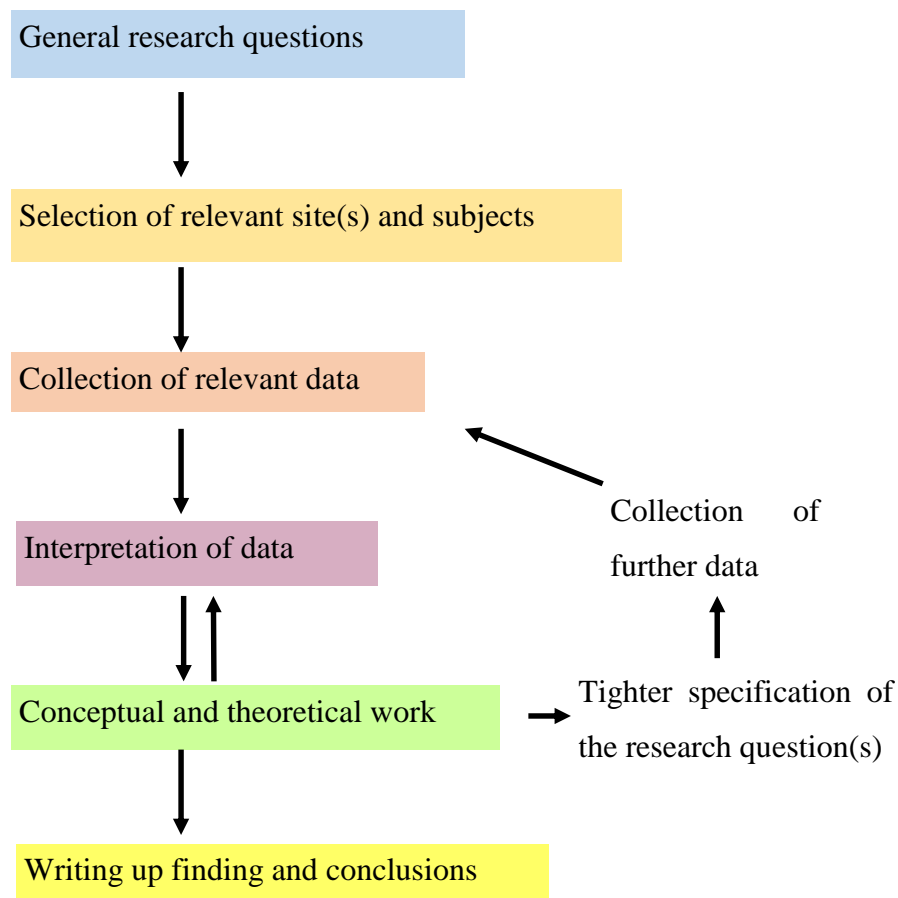
This would probably be a recognisable descriptor to the rest of the core set. As such, I offer biographical or professional context beyond core set affiliations at junctures in the chapters that follow. But I only do so when I feel it enriches data analysis. Though every effort has been taken to anonymise these individuals who have kindly offered their time to be involved in the study, all were provided with the information sheet and signed informed consent forms to confirm their recognition of the potential that, even after this anonymisation, there was still the possibility of identification. Being explicit about the issue and thus allowing the participant to decide if they still wished to take part was, as the Research Ethics Committee agreed, the only option available for this research with the core set.

3.8 Data Analysis and Theoretical Framework

I transcribed all the audio recordings of interviews myself using transcription software made available by the University of York. I did so as a means of familiarising myself with the collected data ahead of analysis (Bird, 2005). I undertook each transcription once I had finished the interview and had returned to my office. I then listened to the audio and read the transcribed document simultaneously so as to ensure consistency between the two sources and remove errors. I selected to transcribe all audio data verbatim, and removed conversational pauses and fillers. I did this to maximise clarity of the transcribed data, both for me during analysis and for the reader in the upcoming chapters. It is also worth noting that in the data used in the following chapters, there are often recollections of conversations. This is particularly so when I ask participants to reflect on the production of a particular policy document or a discussion in a particular meeting. Of course, ‘accounts of accounts’ and ‘versions of versions’ are a quotidian feature of everyday life (Potter and Wetherell, 1987: 4). As such, I use grammatical conventions to clarify where the interviewee is referring to somebody else’s speech or a statement they made in the past in their own account in the present.

To analyse the data, I used the QSR NVivo qualitative data software package and ‘coded’ all interview transcripts, policy documents, APPG minutes and observation notes, and Hansard excerpts. I grouped relevant portions of data into ‘nodes’ which represented various themes. I did this without a pre-existing thematic schema, permitting the data to ‘speak for itself’ given the semi-structured nature of interviews to allow expansion into new conversational terrain, and the broad array of data sources. It is worth noting, though, that I did not depart on theoretical analysis from the purely inductive starting point of grounded theory. Rather, by the time that this phase of research began I had already started thinking about the economic and geographic tensions within the field of research which I explore elsewhere (Williams, 2015). My analysis was also inflected by the historical context that I lay out in chapter one. Along with this, my awareness for the enrolment of ethnicity in this context also played a role in selecting what I found to be ‘node-worthy’ in the initial analysis stage.

Figure 4: Bryman's steps of qualitative research projects



Although I had already become familiar with the key policy documents from the SCSF and the APPG, I began data analysis after I had undertaken 10 interviews. This is because during transcription, which is one of the first interpretative interactions with interview data (Bird, 2005), I had started to notice emerging issues of selectivity in collecting umbilical cord blood tissue, and in deciding what best to include in UCB collections. In analysing these first interviews and the bulk of the other documents listed above, I was making an attempt to engage with the data in a recursive manner as demonstrated in the image above, which I have recreated based upon Bryman's (2008: 384) depiction of the qualitative research process. Notice further down the diagram that the interaction with earlier-collected data can be useful in collecting later data.

Through the initial data analysis, I developed a fairly thematic framework built around notions emerging in my theoretical explorations. These were, broadly speaking, the themes of risk, materiality, order, classification, standardisation, use,

race/ethnicity, identity, inclusion, exclusion, selectivity, rarity and usefulness. For example, 'classification' became a key node, with sub-nodes emerging from it that included 'inter-institutional data collection alignment' and 'difficulty of mixed-race classification', the latter of which related back to another key node: 'race/ethnicity'. In a bid to try and understand these various key nodes and how they fitted together, I came upon the literature on the archival paradigm that I elucidated in chapter two. It was in this phase of 'conceptual and theoretical work' from the diagram above that the archival lens began to take shape. From this point, I returned to the field to undertake the remaining interviews. The questions did not diverge much from the thematic matrix outlined earlier in the chapter. However, my lines of enquiry around particular issues became more prominent, including my interest in the selectivity over inclusion in the banks (around HLA types, a UCB unit's cell count, a donor's qualities, and the geographic limitation of collection sites), and the difficulty of stabilising classifications in the management of the UCB collection (for example, HLA typology which, as I noted in chapter one, is subject to frequent update).

3.9 Conclusion

In this chapter I have outlined the methodological considerations that underwrite this thesis. I began by plotting out some of the preparatory work I undertook before collecting data. Doing this kind of ground work, I noted, was useful in both situating myself moving forward but also in developing a familiarity with the language of HSC transplantation. In this chapter I also introduced the documents I analysed, along with APPG meeting minutes and Hansard extracts. These, I explained, complement the other element of my data collection which is qualitative semi-structured interviewing. An interesting aspect of this facet of data collection was deciding who I should approach to participate. For this, I turned to the work of Harry Collins (1981, 1988) whose conceptualisation of the core set guided me in trying to select those experienced and/or qualified individuals who are engaged in the discussion about UCB in the UK setting. It is in the context of this discussion that I move into the first empirical chapter where the data takes a central stage.

Chapter Four: Order in the Archive

4.1 Introduction

So far, we have seen a number of questions emerge from the context of HSC banking explored in chapter one. In the second chapter, I laid out the theoretical underpinnings and thematic structure of how I would approach an empirical exposition. The data and analysis of this chapter, then, speak to how we might understand *order* in the UK's umbilical cord blood collections. We have seen that all archives are predicated on a particular kind of order (Brothman, 1991). That order will be specific to the users and managers of the given collection and, whilst it might make little sense to outsiders, it forms the basis of how they understand and conceptualise the collected matter.

Order in the umbilical cord blood banks, as this chapter explores, coalesces around donors' racial identities. If all archival content is selected for inclusion with reference to a concern for representativeness (Jimerson, 2009) then it is important also to explore how ethnicity – or 'groupness', as Brubaker (2004) calls it – is enrolled and deployed in decisions about archival inclusion. The chapter begins, then, by considering how the goal of archival representativeness is manifested in the context of the UK's umbilical cord blood banks. By unpacking the life-saving purposes of the bank, as set out in parliamentary debate and discussion, I offer a foundation out of which we can begin to see how a supposed underrepresentation of black and minority ethnicity donors in adult donor registries provides the impetus for encouraging the collection of UCB within underrepresented demographics. The chapter therefore positions ethnicity as a central element in coming to understand the issue of archival order as it exists within the UCB bank.

I consider how archival order, including its technologies of classification, have been developed both to conceptualise the bank *as it exists now* and to *develop it for the future*. Following on from this, the chapter plots out how ethnicity data collection is a practice marked by disorder. Drawing on interviews, I demonstrate how ethnicity data (if indeed it is even collected) can be a highly inconsistent practice across different banks, adult registries and international networks of stem cell exchange.

This, I suggest, can be read as an inherently chaotic practice of translating classifications used in different contexts that mean different things to different constituencies in different spaces and places. The chapter then turns to an important division between *molar* and *molecular* differentiation of bodies. I focus on the assumption that racial differences can be reduced to genetic composition to show that the actual use of ethnicity data is not in the clinical decision-making space. Rather, the molecular HLA match between donor and recipient becomes the fulcrum of clinical selection. Ethnicity is instead found to be useful in determining what should be included in the collection in the first instance.

4.2 Towards a Representative Ideal

In what follows, I want to explore the notion that, in deciding to include certain things in an archive, those doing so work towards some normative point of *representativeness*. By this, I mean simply that those working in archives tend to have a sense of what constitutes representativeness in their context that they try to build their archive in reference to (Jimerson, 2009). In the UCB bank, I want to consider if, and how, this might be the case. To what extent is the decision about what to include driven by a concern that the collection should be – in some way – representative of something. How might that representativeness be understood?

The account below is taken from an interview with a policy maker. In it, they offer an account of the situation for UK ethnic minority patients requiring stem cell transplantation.

...one area that we've certainly looked at is the number of Black and ethnic minorities because that's – it's a bit better now, but it's still a scandalous situation ... just because you happen to be born Black or Asian or whatever ... you stand what is a massive difference in terms of your chances of finding a donor. And then there's the whole mixed raced issue as well which is, if your father's black and your mother's Chinese, you've had it.
(Participant 15)

In this participant's account, they describe a 'scandalous situation' in which ethnic minorities writ large ('black or Asian or whatever') face a 'massive difference' in their chance of locating a suitable stem cell donor. This brief statement echoes a similar one made in an extract in chapter one, from a news article about a minority ethnicity toddler. This 'massive difference' is put down to the fact that the bulk of adult volunteer donors self-identify as 'white' or, as this chapter will shortly demonstrate, whichever equivalent category is made available to them when they are asked to select an ethnic classification for themselves. As Brown *et al.* note, this is in part because adult registries enjoy 'strong historical penetration amongst advantaged middle class blood donors but recruit less well beyond the mainstream demographic' (2011: 1117). Many groups are excluded from the composition of the adult volunteer registry because of this historical penetration in particular demographics. The resulting demographic deficit of the adult donor registries in part explains the UK's motivation to collect umbilical cord blood. The quote below comes from a policy maker involved in the SCSF.

*Obviously the whole aim of setting up the cord blood banks was to address the, redress the balance of underrepresentation of Black, Asian and minority ethnic donors on the adult registries.
(Participant 10)*

Here, they explain that the purpose behind banking in the UK context was 'obviously' to redress a lack of ethnic minority donors in the alternative source of HSCs (adult volunteer donor registries). Tellingly, this participant conceptualises this in terms of an 'underrepresentation,' which necessarily implies a normative point of representativeness that the aggregated collections of HSCs (both from UCB banks and in adult registries) should strive for. This normative point, or optimum level, of representativeness is crucial here. Waterton writes that archives 'are technologies for making representations of the world' (2010: 649). The idea of finding a resolution for 'underrepresentation' is important because it demonstrates how this collection, like many archives, is expected to be 'representative'. Take, for example, an extract from notes taken at an All-Party Parliamentary Group (APPG) meeting of what was said during a presentation on the composition of the UK's umbilical cord blood banks and adult donor registers, and a quote from an interview with an interviewee involved in the APPG.

There is an element of underrepresentation on the larger registers [which] don't necessarily ... match the census data [on] the percentage of an ethnic minority in the UK population. (APPG notes, September 2013)

...the Nolan and the NHSBT focus collection of cord blood in hospitals which have a diverse ethnic mix ... So you get cord units in that are more reflective of the population ... it was part of the policy of the Stem Cell Strategic Forum. (Participant 5)

In the first quote, we again see the notion of ‘underrepresentation.’ The presenter implies that underrepresentation comes about because adult registries do not ‘match the census data’ available on the ‘percentage of an ethnic minority in the UK population.’ From this account we might glean that representativeness is tantamount to reproduction of the UK census data. This is even more telling in the practitioner’s choice of words in the second quote, above. Here, the participant mentions a collection ‘focus’ on particular hospitals, a point that requires separate unpacking and one to which I will return in the next chapter. Importantly, though, the reasoning behind collecting with a ‘focus’ is to collect units ‘that are more reflective of the population.’ The aim to be ‘reflective’ in this way again speaks to the idea that the ideal state of representativeness is a *mirroring*, or a reproduction, of the UK population. We see here, then, that those working in and with the different banks and registries are informed by the goal of reflecting or representing the ethnic composition of the UK population.

By matching the percentages of the population’s ethnicities, the inventory can be said to ‘represent’. Archives are tools of representation. To recall the words of Carolyn Steedman, ‘a whole world, a social order, may be imagined by the recurrence of a name in a register, through a scrap of paper, or some other little piece of flotsam’ (1998: 76). Waterton argues that archives ‘order the world, both in terms of a world past ... and in terms of future worlds’ (2010: 652). The work of those involved in developing UCB in the UK looks towards producing a representative collection. But developing a sense of how close or far the collection is to that representative ideal requires the given collection to be measurable in some way. That is, to have a metric

by which the collection can be seen as moving towards that state of representativeness. What, then, is that metric? If the UCB collection is intended to address the lack of adult volunteer donors who identify as anything other than white, then the bank must to an extent be understood in terms of – and be measurable by – the ethnicities of donors. Order in this archive, then, can be seen to orbit around the idea of ethnicity. But how does ethnicity work in practice? How is donor ethnicity measured? How, as Bowker and Star (1999) might ask, is the work of classification done? And what use, then, might ethnicity data collected through this serve?

4.3 Producing Useable Ethnicity Data

We have seen how umbilical cord blood banks in the UK have been developed with the aim not only of saving lives, but of saving the lives of people who are more at risk of not being able to find a match through existing HSC sourcing avenues. Those individuals are defined as ethnic minorities. But how are those working with the UCB collection able to tell they are addressing the need they perceive to exist? That lies, I suggest, in the order of these archives. Here, then, I want to consider how ethnicity can be ‘measured’ in this instance. The quote below comes from a practitioner involved in the APPG and the SCSF. Here, they explain the usefulness of having information about current volunteer donors’ ethnicities:

Well it would be useful at the end of the day to tell us where we’re not finding donors ... But at the end of the day, it tells us what we would need to do more of, where we would need to collect, et cetera. (Participant 1)

The quote demonstrates their understanding that ethnicity information about the current register would be useful. If it were available, patterns of requirement might emerge. If those working to find matches for patients knew – through some metric of measurement – that this group struggled to find matches, they could infer that they as managers of a collection of UCB ‘need to do more’ in terms of locating suitable stem cells for those patients. It is through having information on the ethnicity of volunteer donors that those working in the field can be confident in what they ‘would need to collect.’ Having ethnicity data is considered useful within the framework of

archivists constructing a collection that represents and thereby provides for the population adequately, because, as a result of asking individual volunteer donors for their ethnicity, the gaps can be more clearly seen. During a presentation to the APPG, a UCB bank administrator explains how this kind of information fits into the planning about how they are going to compose their collection of UCB.

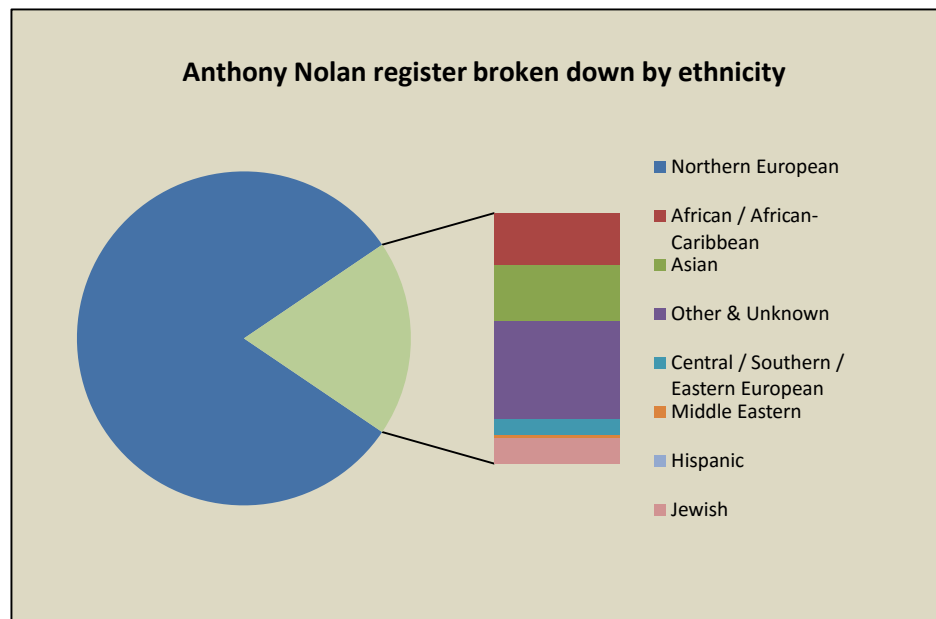
It's more difficult to make decisions as to where we need to be in terms of percentages ... until we know what we're dealing with. (APPG notes, September 2013)

Decisions about 'where we need to be in terms of percentages' – from which we might infer, the composition of the UK's stem cell inventory – are made more difficult by the dearth of information about 'what we're dealing with' in terms of the current volunteer donor pool. In the minutes from the same meeting, the secretary makes note of the 'questions' at the end of the discussion where the contributors explain to MPs the difficulty of the situation.

[The presenter] said that NHSBT and Anthony Nolan are working with DoH [Department of Health] and the Stem Cell Supply Group to review the current inventory needs. [The presenter] stated that until the unmet need for BME patients is quantified it would be difficult to plan an accurate BAME stem cell provision strategy. The British Society of Blood and Marrow Transplantation does collect some data but it lacks the resource to do this to the standard required for these purposes. [Another presenter] agreed and admitted that identifying the best places to recruit can be challenging without the data highlighting what the need is. (APPG Meeting Minutes, September 2013)

The 'unmet need' has not been 'quantified,' and so 'accurate' planning for provision is challenging. Making decisions about the *future* rests upon what the requirements can be said to be in the *present*, but without adequate data from the moment a volunteer donor was registered at some point in the *past* makes this difficult. The pie chart below is reproduced from a presentation at the same APPG.

Figure 5: Anthony Nolan adult donor registry ethnicity composition reproduced from APPG presentation



As its title notes, the chart offers a particular visualisation of the registry, wherein the whole database is represented by the full circle, and the segments represent the segmentation of volunteer donors by ethnicity. Over three quarters of this registry is composed of data from volunteer donors who self-identify as ‘Northern European’, whilst the other categories are congealed into the remainder. Reading along the archival grain is what Stoler (2009; 2002) calls those efforts to understand the rubrics through which any given archive is organized. In this instance, we can see how this archive is thus considered as a singular whole that one can ‘break down by ethnicity’. As an archive, the database is informed by a particular order (Brothman, 1991). The order in this particular visualisation is an ordering by ethnicity. One can be Northern European, Asian, or so forth. The category ‘Other & Unknown’ is home to those volunteers with the restive bodies that perhaps do not fit in a single category because of their mixed-ness, or because they did not feel at home in a particular category when given the options.

It has been argued that self-identification can offer otherwise-passive biomedical research participants some agency. As sociologist Brett St. Louis points out, ‘voluntaristic modes of self-racialization’ unsettle the argument that biological population groups are simply externally ascribed (2005: 43). Of course, it is

unavoidable that taxonomies delimit the choices from which the subject may select, obliging people to identify within a rigid framework that might not accommodate personal preference (see Root, 2003). The ordering system that Anthony Nolan uses for adult volunteer donors was presented to the APPG audience. This new classificatory framework, reproduced below, was developed for use from October 2012.

Figure 6: Anthony Nolan's ethnicity classification framework reproduced from APPG presentation

Ethnic group		
Give the best description of your ancestors' origin. This is not necessarily your nationality. Please tick only one.		
UNITED KINGDOM & IRELAND (WHITE)	OTHER (WHITE)	<input type="checkbox"/> Eastern Russia, Kazakhstan, Uzbekistan, Mongolia
<input type="checkbox"/> England	<input type="checkbox"/> Australia, New Zealand (Northern European descent)	<input type="checkbox"/> Other Asian (inc. Mixed Asian)
<input type="checkbox"/> Scotland	<input type="checkbox"/> Other white (inc. Mixed White)	OTHER
<input type="checkbox"/> Wales	AFRICA AND CARIBBEAN (BLACK)	<input type="checkbox"/> North Africa & Middle East
<input type="checkbox"/> Northern Ireland	<input type="checkbox"/> Caribbean Islands	<input type="checkbox"/> Jewish
<input type="checkbox"/> Republic of Ireland	<input type="checkbox"/> Africa (excluding North Africa)	<input type="checkbox"/> South America
<input type="checkbox"/> Mixed UK & Ireland (e.g. Welsh Mother, English Father)	<input type="checkbox"/> Any other African or African-Caribbean (excluding North Africa)	<input type="checkbox"/> Central America, Mestizo
EUROPE (WHITE)	ASIA (ASIAN)	<input type="checkbox"/> Any other Non-European
<input type="checkbox"/> Austria, Belgium, France, Germany, Netherlands, Switzerland	<input type="checkbox"/> India	MIXED ETHNICITY
<input type="checkbox"/> Scandinavia (e.g. Denmark, Iceland)	<input type="checkbox"/> Pakistan	<input type="checkbox"/> Mixed White & Asian
<input type="checkbox"/> Italy, Portugal, Spain	<input type="checkbox"/> Bangladesh	<input type="checkbox"/> Mixed Black & Asian
<input type="checkbox"/> Turkey	<input type="checkbox"/> Any other South Asian family origins (e.g. Nepal, Bhutan)	<input type="checkbox"/> Mixed White & Black
<input type="checkbox"/> Greece	<input type="checkbox"/> Japan, North Korea, South Korea	<input type="checkbox"/> Mixed White & Other
<input type="checkbox"/> Other Balkan States (e.g. Serbia, Bulgaria)	<input type="checkbox"/> China, Taiwan	<input type="checkbox"/> Mixed Black & Other
<input type="checkbox"/> Eastern Europe (e.g. Czech Republic, Baltics, Western Russia)	<input type="checkbox"/> Thailand, Indonesia, Burma	<input type="checkbox"/> Mixed Asian & Other
<input type="checkbox"/> Other Southern or Eastern European descent, or a mixture of those	<input type="checkbox"/> Malaysia, Vietnam, Philippines, Cambodia, Laos	<input type="checkbox"/> Any other mixed origins
<input type="checkbox"/> Other Northern or Central European descent	<input type="checkbox"/> Any other South East Asian	<input type="checkbox"/> DON'T KNOW
		<input type="checkbox"/> DECLINED TO ANSWER

This table of tick boxes is a means of bringing order to this collection, a technology of classification. It is designed to collect data in the most useful way, as I go on to explore immediately below. The 'ethnic group' classification scheme instructs the volunteer donor (who is also the box ticker) to 'please tick only one.' The request, emphasised with bold letters, confirms that one cannot possibly tick more than one. Of course, the extensive 'Mixed Ethnicity' options are doubtless intended to capture all of those who would feel they could conceivably tick two or more boxes. It asks the volunteer donor to 'give the best description of your ancestors' origin.' Let's give it a try. My paternal grandfather was born in Jamaica, whilst all my other grandparents come from Bolton in Lancashire (or Greater Manchester, depending on your generation). Had I also been born in Jamaica, I could have ticked 'Caribbean Islands,' but I sit more feasibly in a 'Mixed Ethnicities' category. As a consequence, I lose specificity. I am 'Mixed White & Black' – no longer English and Caribbean.

The specificity of my personal whiteness and my personal blackness is lost. During an interview with one participant, I asked about the classification framework. The interviewee explains that they were involved in producing it. They describe a meeting where it had been a topic of discussion.

It was [the recruitment team] versus the researchers. We've got these major categories, and then we've got minor categories underneath them. So we've got mixed within each. British Irish, Asian, Northern European, and then mixed within that. So you could be Mixed Pakistani and Indian and you come up as Mixed Asian. And we also have, like, Mixed British Irish. So if you have a Republic of Ireland mother and a Welsh father, you're Mixed British Irish. So we have mixed within those and then we have also more major categories! And that was the bit where I was like "Look, we're doing recruitment events here!" ... In one of these meetings, we were talking about 'what do you think is far enough back to get a true identity?' and one of our medical people was like, "it's grandparents." I can't run recruitment events where I say to people "where were your grandparents born?" It's just not feasible. That's not the way that it works. (Participant 2)

In this account, the administrator's adult donor recruitment team stands in contrast to their scientific colleagues. The recruiters want to run events where they can encourage as much registration as possible. 'Look,' they describe having said, 'we're doing recruitment events here!' The account makes clear a level of exasperation with long lists of ethnicity options produced for the level of specificity required by researchers and clinicians. Having an extensive list of major and minor categories, with a profusion of 'mixed' options represents a barrier, making it more challenging for a donor to locate themselves. The participant even struggles with the idea that somebody would need to select their ancestors' origins. They explain that asking for somebody's grandparents' place of birth is 'just not feasible' because recruitment events do not allow for the team to spend their time explaining this in detail. From the researcher side (if we follow the path of the previous account which describes

recruiters and researchers in opposition) there is a similar amount of dissatisfaction with the manner in which the data is collected.

...it's very hard to actually be sure that people know what ethnicities – in genetic ways – they actually belong to. You sometimes have the case that you have a great grandfather that was Chinese and due to that fact the whole family regards itself as being Chinese which is not necessarily true when all the other guys are basically some other race because after two generations, the racial indicator is gone ... then when people answer and say 'ok, I belong to that ethnicity' due to some cultural feeling which is not really reflected in their genes you get answers for the genetic way that do not necessarily really reflect the true ethnicity. (Participant 17)

A person might struggle to 'know' their ethnicity 'in genetic ways'. A great grandfather's ethnicity is 'not necessarily true' for the generations that follow him because the 'indicator is gone.' There are threads of biological reductionism that might be picked up from this statement – particularly the idea that 'some cultural feeling' cannot be 'reflected in their genes' which equates to their 'true ethnicity'. But more pertinently, this quote speaks to Lee's claim that even if self-identifications do not stray far from 'good approximations of ancestral origin' (2009: 1184) there remain concerns over reproducibility and consistency using the methodology. Along with this, scientists in individual projects producing their own taxonomies may be 'reducing biomedical rigor' (Bliss, 2011: 1024) which consequently could hamper comparability between different projects (see Bradby, 2003). Order, then, is not easily achieved. What one participant views as 'feasible' in the interaction with a potential stem cell donor, might not be the classification framework deemed most useful by the scientists enrolled to produce these frameworks. Order, which is needed to be able to determine the archive's current state and its future direction ('what we need to do more of'), is not quite as easy to produce in this archival endeavour.

4.4 ‘Everybody Records It Differently’

We have seen so far how having ethnicity data on donors is framed as something that would be strategically useful in determining what should be included in these collections of umbilical cord blood. For that reason, donors are asked to identify their ethnicity when they donate. Having this information about the collection *as it exists* is seen as something that can help those working with the collection to decide the direction they need to take as they move forward and develop the bank. But if those working with the collection do not know the ethnicity of the patients – the constituency that we can think of here as the *archive user* – then is the usefulness of donor information limited? In what follows, I want to develop the discussion of how order is brought into this particular archive, by thinking specifically about how those working in this collection try to understand the patients who will receive the material stored there. The following quote below comes from an interview with a practitioner who participates in the APPG.

So ... if we had this all beautifully recorded you could say we searched for 100 Afro-Caribbean patients and found this many donors. So that sort of information would be useful. (Participant 1)

In this account, the ‘beautifully recorded’ patient data are viewed as a tool to make determinations about likelihoods of finding matches. In the example here, by knowing that 100 patients who could be defined as ‘Afro-Caribbean’ found a hypothetical number of matches, a determination of chance could be produced. That data would be ‘useful,’ we infer, because without it such claims cannot be evidenced. In this context, it makes sense to ask how patient data is collected. To begin exploring this question, I want to consider a quote, reproduced below, from an interview with a senior immunologist.

...the whole collection of ethnicity data has not been easy. But we’re lucky we can collect it. In France they cannot by law. It’s illegal! ... So we managed to start collecting data. And the NHS approved that, and we have been collecting data on the donors for the past – I think – 10 years? But not on patients. ... in the forms

for Search we ask for the ethnic origin of the patient. But it's only this year we started collecting it. A big achievement because it's the only way we can actually see the unmet need. The only scientific way of doing it. Before, we suspected. (Participant 9)

That collecting user data had been a struggle speaks to a concern of archival theorist Sundqvist who states that the users of archives 'are often defined in a deductive and perhaps speculative way, not explicitly underpinned with empirical data' (2007: 635). Capturing this data is difficult, and the scientist vocalises their feeling of luck that they can collect it at all. In their example, France, it is illegal to collect ethnicity data at all. To the extent that data are still limited, 'speculation' (in Sundqvist's terms) or 'suspecting' (in the above participant's) is necessary. One APPG contributor reflected on their work as a practitioner, showing me a tissue request form their clinical nursing team uses for patients. On it, ethnicity was an open field entitled 'Ethnic Origin. Be Specific.'

...ethnicity's a big problem, because everybody records it differently ... so this is what we fill in when we take the blood tests. But as you can see here: "Ethnic Origin. Be Specific." ... there's no doubt it would be useful information ... So, it would be very useful to have an accurate ethnicity. I asked the girls and they said they virtually never fill it in. (Participant 1)

In the quote preceding the one above, the scientist laments that ethnicity data collection 'has not been easy'. Similarly, in the account directly above, the practitioner sees it as 'a big problem.' For the participant, this is because 'everybody records it differently.' They offer an example from their own practice. When faced with a form that requests ethnicity data, 'the girls' (revealing something of the gendered dynamic of the nursing team) 'virtually never fill it in.' Inconsistency (or, perhaps, *disorder*) lies at the heart of the issue in this account. The 'Ethnic Origin. Be Specific.' is an open field that could as easily demand a narrative answer or some kind of patient genealogy instead of a singular word of identification. Nonetheless, it exists to bring the possibility of some semblance of order. It is by their omission that these clinical nurses do not advance the cause of order. Nonetheless, the

classificatory imagination (Beer, 2013) is apparent in the extract below where the practitioner advances another possibility for data collection.

From the minute they come into hospital as the patient, we need to have a drop-down box of ethnicity categories. Whatever it may be, and it shouldn't be too complicated. It should be what's scientifically useful ... I'm sure the scientists could group these for us. And have a tick box that we use that ticks the same tick box the donor people use, and the same tick box that the government members use, so we're all talking about the same thing. So we know exactly where we have donors, and where we don't have donors. (Participant 1)

The practitioner is clear that 'we need to have a drop-down box.' One of the caveats of this is that it 'shouldn't be too complicated' which echoes the concerns of the APPG presenter who describes a situation in which the scientists offered a classificatory scheme with *too many* ethnicity options. And yet, whilst the avoidance of complexity is important, a balance must be struck. The drop-down box options must still be 'scientifically useful.' Here, the clinician defers to the 'scientists' who could do the labour of grouping. The ideal classification system would be used by all stakeholders (the patient care team, the stem cell donor). Ideally, it would tally with what the government uses, 'so we're all talking about the same thing'. However, this account reveals that the participant equates the 'scientifically useful' classification scheme with one that would be meaningful beyond that sphere – for example, in government ethnicity classifications. Yet the interviewee quoted earlier expresses a fundamental fissure between 'cultural feelings' and scientific or 'true' ethnicity. As such, the balance of usefulness and accessibility is a difficult one to strike. But the commensurability of language, consistency and order, are constructed here as the ideal. This is a point that I will return to shortly. Briefly, though, it is interesting to note that as the practitioner continues in their imagined scenario of data capture (exercising their classificatory imagination, as Beer might say) they run up against the confounding problem of mixed race-ness.

Participant 1: And then, of course, you've got mixed race and it gets even more complicated.

RW: Would a drop-down box suffice for that?

Participant 1: Well you'd have to tick two probably. Mum and dad. And I guess, yeah ... well it has to be clever doesn't it? Yes... it's a tricky one. How you'd actually do that.

Here, the participant highlights the issue of 'mixed race.' They do not specify patients or donors, thus implying that it is the broad identity category of 'mixed raced' which is so 'complicated'. As archival theorists Cook and Schwartz note, systems of record management that appear rational and stable are 'inherently chaotic' (2002: 176). Within the framework of maternal and paternal antigens, it makes sense to the participant that one would actually need to capture both parents' ethnicities. Suddenly, a drop-down box that would capture data of scientific use becomes perhaps *too* complex. This is the quandary of mixed raced data capture and the logic of having to regress to predecessors to meaningfully make sense of one's molecular individuality (Anderson and MacKay, 2014). It speaks to the inflexibility of ethnicity classifications that, by way of their rigidity, make no space for the restive bodies that refuse to fit into one category.

The practitioner struggles to picture a means of data capture that would account for such instances. The classification would have 'to be clever', but it is 'tricky' in practice to answer 'how you'd actually do that'. The challenge of order is complex and problematic given that the data of interest are patient and donor ethnicities. This point is particularly pronounced when we zoom out a little. Referring back to the practitioner, even if one collection is nicely ordered, how do we know that 'we're all talking about the same thing'? We have considered the complexity inherent in donor and patient data collection, but what happens when that data is put to work, or when classifications and their attendant classificatory imaginations clash?

4.5 Translating Classifications

Donors and patients are important constituencies to know in terms of their ethnic identities. We have seen this point emerge out of the accounts of those involved in trying to collect such information. The data would be useful, having some role to play in determining the strategic direction of the collection. But we have also seen how challenging it can be to collect such data. From the design of a classificatory framework, through to the point where data might be collected, there are divergent purposes (encouraging registration versus collecting specific and useable data) and barriers to collection (the omission of data, or the practice of not collecting at all). Importantly, though, the UK's UCB banks, as we have seen, exist in part to address a lack of adult volunteer donors of minority ethnicities. As such, it makes sense to ask if the system of order that *determined* this lack in adult donor registries is the same system of order than UCB banks use to determine whether they are successfully *addressing* it. The quote below, from an interview with a scientist working in one of the cord blood banks, demonstrates the complexity of order in this context.

And to be funnier ... between labs, recruitment, cord blood, we didn't have the same ethnicity codes ... It was crazy. We were uploading our units in [our central database], in our register and we were trying to translate our ethnicities to the ethnicity codes that we had already in the register. It was like, "excuse me, we are not specialists in ethnicity!" I cannot ask my lab scientists to figure out what this means! So, we talked together. We agreed to ethnicity codes. We were working with the different maternities we have in the program. Because NHS – at the different trusts – they had ethnicity codes as well. We found them really interesting to use. We agreed with one of them, we worked with H&I people.... and we agreed an ethnicity code. And now we wish to have the same ethnicity codes with NHSBT... (Participant 6)

As the quote above explains, even within a singular institution's interrelated operations (UCB collection, adult donor recruitment and laboratory diagnostics work), the ethnicity classifications are different. This is far from the 'edenic order'

that selective collections strive for (Brothman, 1991). The suggestion on the part of the participant that this situation was ‘funny’ or ‘crazy’ speaks to the nonsensical collection of data that, by way of its initial collection design, has limited use for the people who work with it. Expanding on this, the participant notes the practical challenge of having to make sense of often contradictory, and always variable, ethnicity classification systems. Across the different British UCB banks and adult registries, ethnicity data were being captured differently. In the same quote, the respondent describes how their laboratory staff had been given the job of trying to input data from one classification system into another, so that all tissue and donor data could be searched for on their central database. The suggestion that being a ‘specialist in ethnicity’ is a requirement for this task is telling. It speaks to how challenging (both practically and, it might even be said, epistemologically) bringing different classification schemes together stands to be. According to the scientist, this is an expertise that none of their staff had. A charity spokesperson summarises the quandary differently.

Transplant centres, even registries, aren't using the same ethnicity codes. If you're not using the same codes, how are you – one's an apple, one's an orange but you think they're both the same. They're not the same ... [Registries and hospitals should be] getting their acts together, and being consistent. In terms of using the right codes to decipher what racial aspects of people you use. (Participant 4)

The interviewee gives a similar account to the scientist. ‘Transplant centres, even registries’ are seen to employ inconsistent ethnicity codes. In referring to the well-known ‘apples and oranges’ idiom, the participant implies that these different ethnicity codes are incommensurable. Thus, no aggregation or comparison of data sets in terms of ethnic composition can be made whilst, as the same participant explained during an APPG presentation, the parties are not all...

...talking the same language about what is ‘black’, what is defined as ‘white’, what is defined as ‘mixed race’. (APPG notes, September 2013)

This speaks to what Brubaker calls the ‘ever-recommencing definitional casuistry’ of ethnicity (2002: 167). It demonstrates the challenge of trying to pin down sufficiently *durable* ethnicity classifications which are scientifically and culturally meaningful across time. Expressing the need to align different data collection practices across British institutions, one participant briefly described a discussion with their counterpart in a different institution, explaining why it would be useful.

Every time I see [them], it's like “we need to do this ethnicity code together” ... WMDA [World Marrow Donor Association] ask us for ethnicities, and sometimes we don't have the ethnicities from the patients. So when we need to do the reports for stats, we cannot provide these data ... If we had all the ethnicities recorded, we could do also analysis ... Information is power. And HLA is totally related with ethnicity so why not have it if it is not difficult. If NHSBT is working together with Anthony Nolan, let's agree the same ethnicity codes, then move on to the transplant centres to agree the same ethnicity codes. (Participant 6)

Even between institutions, there is a recognition that they ‘need to do this ethnicity code together’ so both are using the same classificatory imagination (Beer, 2013). In the account above, the participant also makes reference to international pressure to provide relevant data when the ‘WMDA ask us for ethnicities.’ If both the NHSBT and Anthony Nolan could ‘agree’ (a word that could as easily evoke the sentiment of *compromise* as it does *harmony*), the field would be in a position to provide a more comprehensive set of statistics to the World Marrow Donor Association which attempts to produce a global picture of current stem cells stocks. The participant does not mention whether this would then rely on the UK’s stem cell inventories (if they somehow compromise/harmonise) employing the same classificatory imagination as the WMDA. Since 2011, the WMDA has provided ethnicity codes to advise for global registries (World Marrow Donor Association, 2011 - see Appendix E). The organisation’s quality and regulation working group website explains its codes, reproduced below, in the following terms:

‘Race/ethnic information is increasingly relevant to unrelated donor search strategies ... Global registries are enhancing communications using electronic systems to exchange information. As a result, it is increasingly important to achieve a common standard of ethnic definitions. [WMDA] worked towards a WMDA Dictionary ... to allow stem cell donor registries that capture race/ethnicity data on donors and/or cord blood units to incorporate these into their [electronic messages to WMDA]’ (World Marrow Donor Association, 2015)

The ‘common language’ they were aiming for, which relies on consensus between the WMDA and the array of registries they work with, has yet to be matched in the UK. This is clear simply by comparing Anthony Nolan’s current classification scheme (reproduced earlier in the chapter) with WMDA’s directly above. The lack of consensus over classification and categories is commonplace across archives. The taxonomies used to manage archival matter are always potential ‘sites of disagreement’ (Beer, 2013: 43). They are, as Derrida evocatively notes, ever at risk from being ‘shaken by an earthquake from which no classificational concept ... can be sheltered’ (1996: 5).

Bowker asks an interesting question in this respect. ‘Why does the best standard not always win?’ The answer he posits speaks to the issue at hand here, that ‘no node is an island’ (2005: 112). In other words, it is difficult to make one classificatory standard win no matter how good it is if it is being put to work in a wider context in which everybody else is already using their own classificatory standards in their own context. This issue, I would argue, is compounded by the contingency of a socially salient, spatially, temporally transient notion such as ethnicity. Interestingly, the suggestion in the WMDA codes’ very existence is that ethnicity is a language of some kind which has the capacity to be translatable in different geographic contexts. In this case, everybody needs to speak the same ethnicity language, or at least use different languages that exist in the same epistemological family so they can be ‘translated’ across frameworks.

The ability to translate the meaning of different ethnicity languages across such frameworks is held as a holy grail, but seems almost impossible given the importance of the *locality* in which classifications are defined. The WMDA, being an American organisation, includes in its classification framework a North American ‘broad race’ code, which is absent from Anthony Nolan’s classification. Its ‘Europe’ section is much briefer than the more in-depth Anthony Nolan classifications. The context from which classification emerges explains these differences. These classifications articulate geographically specific ways of knowing bodies, but also the different interests served which may include expediency at the point of donation or, on the other hand, durable scientific usefulness. For this reason making sense of different classifications, particularly internationally, potentially moves beyond translational challenge to translational impossibility.

4.6 Molar and Molecular Differentiation

So far, we have explored the view that ethnicity data are useful for ordering the UCB collection, but that these data must be collected so that they are either directly applicable to, or translatable to, other collections. Given this, it is tempting to ask how the practice of HSC transplantation happens at all if the collection of such a seemingly useful sort of data is so erratic. With that in mind, it is worth considering how practitioners do their work with such inconsistent – perhaps even inexistent – data. To explore this, it is useful to remind ourselves of that link between ethnicity and tissue type that was touched upon in chapter one, and to consider how the strange, congealed relationship between these ostensibly molar (ethnicity) and molecular (genetic) bodily distinctions works in practice. The quote below comes from a policy maker involved in the APPG.

But Asians are much more susceptible to diabetes. I went to one of the meetings ... I said to one of the doctors, why is this? He said, there’s something in the genes, they think. So genes, you see ... Different people ... I wonder how different Caribbean blood is to blood in the Orkney Islands? ... They found years ago with spina bifida, that it’s more prevalent in South Wales and the Orkney

Islands in the north of Scotland. Why? It's probably because they were short of something in their make-up. (Participant 12)

In this quote the policy maker gives an account of how a person's ethnicity can determine their susceptibility to different kinds of illness. Importantly, an Asian person might be more vulnerable to developing diabetes because 'it's in the genes.' Similarly, the participant claims there is higher prevalence of spina bifida, a gestational spinal development disorder, in South Wales and in the Orkney Islands. 'Probably,' the participant suggests, this is due them being 'short of something in their make-up', by which the participant infers the notion of genetic make-up (or composition). They describe blood as 'Caribbean', positing its difference to blood 'from the Orkney Islands'. In this account we witness the reduction of ethnic identity, and illness experience, to the nebulous notions of 'genes', 'blood', and 'make-up'. This quote demonstrates how this prevalent model of the relationship between genetic composition and experience of health, mobilises ethnicity as the intermediary in the causal chain. Somebody has diabetes so, because they are Asian, they must have something 'in their genes.' Spina bifida is prevalent in North Wales which is populated with people of a particular descent or ancestry, so they are 'short of something in their make-up.' To the extent that the molar category of ethnicity is invoked simply as an indicator of a deeper molecular state, its use is necessarily limited. For example, the quote below is from an interviewee responding to a question about whether clinicians would ever use donors' ethnicity data when making a selection for their patient.

No, because the ethnicity tends to be the thing that determines the HLA type ... the importance of ethnicity is only in the HLA type. So your HLA types are inherited, obviously, so certain populations have certain HLA combinations. So that's why it's so important. Um, but yeah, as soon as you – I'm not aware of any data, but as soon as you've the HLA match, it's quite likely that they're from the same ethnic group anyway. (Participant 5)

In this account, the reason given for clinicians not using donor ethnicity data is 'because the ethnicity tends to be the thing that determines the HLA type'. Again,

ethnicity becomes a causal intermediary. This time, not between the *event of illness* and molecular composition, but between the *event of the match* and the molecular composition. If ‘you’ve the HLA match’ then you are ‘likely’ to be part of ‘the same ethnic group.’ The participant notes that there are no data confirming this, but conveys a surety that a match *within* an ‘ethnic group’ ‘tends’ or is ‘likely’ to be the case. I asked a practitioner involved with the APPG the same question. They reflected on their own experience in response:

Participant 1: So we would take it [ethnicity] into account, but there are other things that matter before. So we’d match for HLA type ... We match for viruses they may have seen. We match for blood group. There’s all sorts of things we come down. So ethnicity could be in there if we had the information. I have never had information, I don’t think, on the ethnicity.

RW: Ok, but if ethnicity is something that matters—

Participant 1: Well it’s already there.

RW: in the HLA?

Participant 1: Yeah, exactly.

In a similar account, this practitioner notes that they ‘have never had information’ about donor ethnicity. If they did, they ‘would take it into account’ but this would be lower on the list of criteria considered in the process. I will consider this list of ‘all sorts of things we come down’ in depth in chapter six. But importantly, this account suggests that ethnicity (a datum that the practitioner never has) is not as important as HLA typology. How the clinician chooses to describe this is telling. Ethnicity is ‘already there’ in the donor’s HLA type. In the preceding quote ethnicity ‘determines’ HLA. In this one, ethnicity is folded into HLA. HLA is crucial, and ethnicity takes on what I have described elsewhere (Williams, 2015) as an almost *metonymic* position as HLA’s less specific, molar stand-in. A clinician would not select a donor for their patient based on ethnicity alone. Ethnicity sits somewhere in

the list of useful information of those working with and in these collections, but contends with other data for priority. As an example, the participant below is a scientist who presented at the WMDA annual conference, working to analyse the prevalence of different HLA types in registries across the world. I asked them whether they would find it useful to have ethnicity data in HSC collections around the world.

Participant 17: You might think “okay this data could be better for scientific evaluation,” ... but I think this is a very luxurious demand in the context that we’re working in ... It would be nice to have them all always HLA typed at the best level ... which we try to do but of course it's timely and a costly process.

RW: That’s a priority over having everyone’s ethnicity data?

Participant 17: Yeah, of course. I mean the ethnicity data is nice to have and if you could get it then it’s alright. But it’s not anything that I could imagine we would phone up someone and ask people for that.

Having ethnicity data is a secondary ‘luxury’ compared to other factors such as HLA typology which have more utility. In this context, improving the consistency of racial and ethnic categories, prioritised by respondents above, instead starts to look like an unnecessary luxury compared to having tissues ‘always HLA typed at the best level.’ The molecular composition of available HSC cells is information that is useful to have. Talking about a new working group established in their workplace, one participant explained the use of doing analysis not with donors’ ethnicity data but with their HLA data.

Participant 17: We have all this wonderful, beautiful data about HLA and you can do an analysis like “what is the matching probability of an international exchange” and that kind of thing and, since we have the data, we’re doing it.

RW: And this makes the registry more efficient?

Participant 17: That's the offspring of course.

Here, the scientist describes the work they are involved in using HLA data taken from international collections of HSCs. In this account, they describe the kind of question they might calculate an answer to. These are questions of 'matching probability.' By collating all the information on the HLA combinations of each donor in one collection, and doing this with all the collections they have data for, the interviewee can then see whether a potential patient HLA type would correspond to a match. If a person has x combination of HLA alleles, they stand y chance of finding a match. HLA, then, is now being used to give a sense of the chances of making matches internationally. This work is done by collating data of present registry donors to construct a sense of what the international system of HSCs is able to provide. This work is being done *without* comprehensive ethnicity data.

This prompts an important question. If ethnicity is not useful in the quotidian practice of *using* banked HSCs, why is it so central to strategic planning? Or, to refer to Brubaker, for what purpose is racial 'groupness' enrolled here? The beginning of the answer is embedded in the consensus on a relationship between one's ethnicity and one's genetic composition. But this understanding does not fully explain *why* ethnicity is enrolled. Why talk about something like a donor's ethnicity (which is thought to be scientifically less useful or truthful, as we have seen) when we could simply talk about a donor's tissue type? The rest of the answer can be found by referring back to the archival paradigm. The beginning of this chapter opened with Kaplan's argument that all 'archivists do what they do so that others ... now or in the distant future, can do what they do' (2002: 217). As a conceptual 'proxy' for genetic composition, ethnicity offers a socially salient and – importantly – molar point of reference for those working to make the UCB collection as useful as it can be by being able to guide collectors to the bodies perceived as most relevant to the collection.

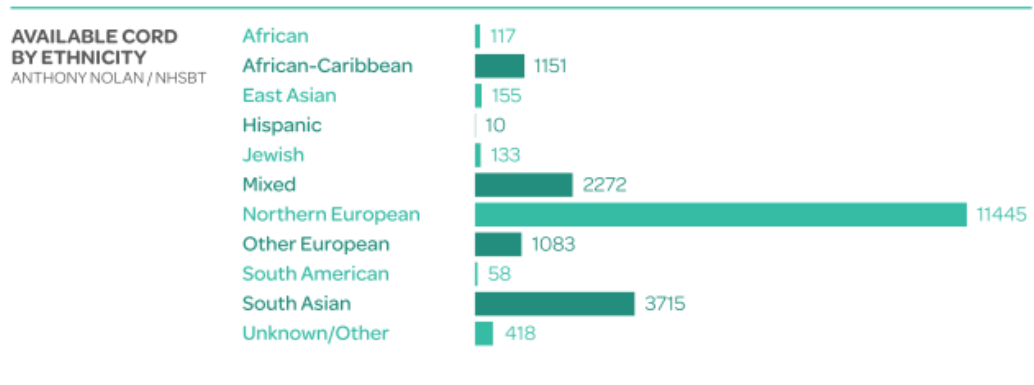
The ethnicity/genetic relationship claim has cache in this space and there is an understanding that minority ethnicity individuals are less likely to find a tissue match

(although this is a claim, as we saw, based on assumption). As such, ethnicity can be enrolled in the strategic efforts of the collection managers. You cannot encourage donation by asking people of a particular tissue type to come forward (because none of us off the top of our heads would know what our tissue type *is!*). However you *can* collect umbilical cord blood in the maternity wards that serve more Asian and Black women. Ethnicity is thus the focal point around which practical strategic work coalesces. This work is undertaken by everybody in the chain. This includes the scientists constructing the infrastructures of their ethnicity data collection, the donation drive organisers collecting donor ethnicity data and the volunteers who offer it. Ethnicity can also be seen as central when the clinical nursing teams find time to ‘be specific’ about their patients’ ‘ethnic origin,’ or when the women who consent to donate their umbilical cords are requested to tick the box that would ‘give the best description of [her] ancestor’s origin.’ The quote below comes from a public bank administrator.

*...going out to a population going ‘we need more of you to join the register because we have – well we don’t know how many patients we have.’ ... When we’re trying to do quite accurate modelling of what our bank needs to look like, it’s really difficult when you’re not 100% clear – you’re doing it a bit by, almost, instinct.
(Participant 8)*

The administrator uses adult donation as an example of the need for ethnicity data, suggesting that encouraging donation in a particular group or ‘population’ by saying ‘we need more of you’ is a difficult claim to uphold if the number of patients is unknown. Likewise, it is challenging to know what the UCB bank ‘needs to look like’ if those managing it aren’t ‘100% clear’ about the requirement, and thus have to rely on ‘instinct.’ To this extent, being able to make claims about the ethnic composition of the bank goes some way towards knowing the limits of the bank’s capacity for provision. Ethnicity data may not be useful in the clinical practice of trying to match a patient and donor molecularly. Yet not having the data can be equally perilous to the telos of managing the UCB collection in the first place (that is, making it representative). The chart below, from Anthony Nolan and NHSBT’s annual inventory report (2014: 21), demonstrates this.

Figure 7: UK cord inventory ordered by ethnicity reproduced from the 2014 annual inventory report



This chart depicts the ethnicity data of all cords available in the UK’s two main UCB banks. They are broken down by donor ethnicity. Donor ethnicity data collection allows those managing the bank to know what it looks like and – within the framework in which ethnicity is connected to genetic composition – what it needs to look like *as it develops*. This information does not have utility in the clinical decision-making process of the practitioner because they do not receive this information about the donor. But it has utility as a means of demonstrating the bank’s current position in terms of what is deemed to be an important referent (ethnicity) and as a tool through which those working in the collection can make decisions about moving forward. Ethnicity, then, means little in the practice of using this archive, whilst having a great deal of resonance in terms of how archival inclusion is conceptualised and planned out.

An important point to make at the end of this chapter, though, is that the molecular individual as she is understood today is only a product of the most recent consensus of what constitutes the self. My point here is that HLA as a standard nomenclature is itself constantly under review, being challenged to absorb new alleles into its ontological paradigm of what constitutes the self. This is, of course, hardly a surprise given, as Mackenzie *et al.* (2013: 703) point out, ‘the essential thing that a standard needs – an unchanging attribute – is, it seems, precisely what the biological essentially lacks’. This is to say that even HLA typing standards change. Even in not bothering with a messy register like race, fixed standards like HLA must be updated regularly to keep up with the pace of change in what constitutes the molecular

individual from year to year. I will unpack this more in chapter seven, but the point here is that we should be wary in suggesting that the exclusive use of a molecular register in ordering any archive could ever be a final act of ‘consigning chaos to oblivion’ (Bowker, 2005: 70).

4.7 Conclusion

This chapter explored how those working with UCB collections in the UK decide what will be included in these collections. I began this chapter, then, by plotting out the purpose and the order of the collection. This revealed much about the difficulty of trying to gather data about individuals’ racial or ethnic identities. So too did it begin to reveal how inclusion in this collection hinges on ethnicity. Speaking broadly to the difficulty of trying to capture socially salient but formidably transient categories like ethnicity (Bliss, 2011), the chapter demonstrates how order in this collection is something desperately strived for but not so easily come by. This, I suggested, prompts important questions about how ethnicity is translated across different collections that are drawn together as a wider pool of HSC resources for the UK’s public. If they do not order their collections in the same way, what use can the order have overall? This concern steered the chapter towards exploring what use – in clinical practice – ethnicity has. As we see, in quotidian clinical selection of tissue, the answer is clear. Here, ethnicity has no use at all. Put differently, clinicians receive no information regarding the tissue donor’s ethnicity. Ethnicity has use only so far as those managing the collection can conceptualise where their collection stands, and what they need to do (in accordance with immunological understandings of ethnicity as a genetically meaningful category) to ensure the continuing usefulness of their collection.

I suggested that ethnicity is a tangible means of strategising – more so than invisible, molecular markers of difference. You can focus collections in maternity units where there are more Black and minority ethnicity women. But as soon as a person donates, their ethnicity matters little in the specific task of matching a donor and a recipient together. As such, whilst this archive must focus its wider strategy on a broad concept like ethnicity, the day-to-day small-scale matching of tissues requires no less than the intensely molecular HLA typing that negates the need for ethnicity. This

relationship between the molar and molecular registers of ethnicity and HLA type, then, highlights the importance of understanding not only *how* but *why* we are asked to situate ourselves and our bodies (as well as our identities and potential clinical usefulness) within a broader, ‘genetically diverse’ population.

This, perhaps, is what Nikolas Rose was pointing towards in his discussion of how, in the contemporary moment, race has come to signify ‘an unstable space of ambivalence between the molecular level of the genome and the cell, and the molar level of classifications in terms of population group, country of origin, cultural diversity, and self-perception’ (Rose, 2007: 161). As a tool of individuation, a person’s HLA type will discern them from everybody else. Placed side by side, two HLA types can be compared for similarity or “compatibility”. But in the archival space, where tissues are stored so that this comparison may one day take place, ethnicity (which this chapter has demonstrated remains an indeterminate register) is thought to be a more useful ‘ascertainment strategy’ for locating the potentially useful stem cells in the first place (Kittles and Weiss, cited in Rose, 2007: 159).

As a pivotal centrepiece of the inventory’s strategy, ethnicity means everything. As a contingent and context-specific social category in a world of molecular allogeneic tissue matching, ethnicity begins to lose all meaning. The decision of what to include in the collection orbits around a category that paradoxically, means everything and nothing at once. We can, I would conclude, be assured that the purpose of using ethnicity to encourage donation has an emancipatory biopolitic at its core that demonstrates a clear departure from historical uses of ethnicity in a medical setting (Rose, 2007). And yet the inability to “pin” ethnicity down in durable and universal classificatory frameworks, or to make race meaningful beyond ordering this archive tells us something. Ethnicity in a biomedical setting – even if used with the most beneficent intentions – offers a jarring molar indeterminacy as compared to the extremely specific forms of molecular information now available to us. It is important to trace if, how, and why ethnicity persists in such settings as the capacity of tissue typing technology inevitably develops and the molecular dimensions of individuation proliferate and deepen.

Chapter Five: Exclusion from the Archive

5.1 Introduction

In the last chapter we explored the notion of order as it relates to the context of umbilical cord blood banks. Moving on from this, and drawing on the exclusion of archival practice that I highlighted in chapter two, I want to explore the extent to which can we understand UCB collections as exclusionary spaces. The fact that traditionally, UCB banks are dualistically posited as either *public* or *private*, adds another vector this discussion. As such, the idea of the public, the universal, or the national resource, is one that this chapter engages with in some depth. In doing so, it moves towards a considered critique that though titularly public, these systems are anything but inclusive and universal. Indeed, private – in terms of the *privation* of access – seems to make sense as a way of thinking of such ostensibly ‘public’ selective collections.

With this in mind, the chapter begins by considering how archives are always limited, if only by the fact that they rely on ‘resources’ to be sustained and developed. By considering empirical data from interviews, and analysis of policy documentation, I first plot out the incredibly limited state of provision of donation opportunities for UCB across the UK. Out of this come several threads of discussion, focusing around the different limitations of resources (where there are either stipulated criteria of how resources might be used, or there is simply not enough money). This practical arrangement exists alongside the enrolment of the claim that undonated UCB is waste. What is to be done with this moral indictment of irresponsibility, if somebody cannot donate even if willing? For this, and the broader notion that donation is a communitarian act, I turn to the work of Roberto Esposito (2011), which opens the chapter discussion out to consider how even in hospitals that allow public donation, not all women will qualify to do so. As it transpires in the chapter, then, a universal resource is not universal in terms of its donation, which allows us to reconsider briefly the role of the ‘private’ banking system in this context.

But beyond this, I am also keen to explore the fallout of the desire for the archive to be representative – to give, as Achille Mbembe writes – an ‘illusion of totality’ (2002: 21) which, as Derrida provocatively argues ‘is never without violence’ (1996: 3). The chapter, then, looks to consider in detail how the demand for HSCs donated by minority ethnicity mothers translates into focused collection practices that concentrate on maximising such donation. This produces particular kinds of exclusion of its own. Enfolded into this is a question that has to be asked. What happens, I begin to explore here, when groupness is invoked (Brubaker, 2004). If particular ethnicity groups are responsabilised to donate for the good of *their own community*, what becomes of the universal tenet that holds up this system?

5.2 Limited Resources

To begin this chapter, it is apposite to think about the notion of resources as it relates to the archival space. ‘Many archivists,’ writes Jimerson, ‘remain constrained by external forces, including ... resource allocators’ (2009: 297). ‘Resources’ here is a handy euphemism. It congeals various issues enfolded into the notion of having enough money. Here, I want to unpick how resources in the context of UCB collection are indeed limited. Consider, for example, notes below from an All Party Parliamentary Group (APPG) meeting, where a policy maker asked a question at the end of the group session. The question was directed at those present involved with the Stem Cell Strategic Forum (SCSF). The policy maker asked if there was an optimum number of UCB collection sites. The response came from an administrator of one of the umbilical cord blood banks:

... that boils down to simple resource issues ... we had identified the need for 50 million pounds of resources ... to put all of the recommendations into place ... we've been looking at an annual figure of the last three years of four million. (APPG notes, September 2013)

The number of UCB collection sites ‘boils down to simple resource issues.’ Though a grand figure of £50m would have been useful, the SCSF secured only £4m. A lack

of capital, put simply, puts limits on the number of UCB collection sites. In this context, consider the quote below, from an interview with a policy maker.

...providing funding to NHS Blood and Transplant and to the Anthony Nolan directly to implement specifically the recommendations around aligning the stem cell registry ... about half the funding has gone to the cord blood side of it if you wanted to put a figure on it. We've provided 12 million over the last three years. So that's our role... we obviously work closely with [the institutions] in determining the best way for allocating the funding to get the best results... [They] are obviously under pressure as well to make sure that they use funding they get in the most appropriate way as well. (Participant 10)

In this account, the policy maker describes a situation in which the institutions in receipt of this funding must determine the ‘best way for allocating’ it ‘to get the best results.’ The funding is not unlimited, and so the managers of the UCB collections must give considerable consideration, and ‘are obviously under pressure’ that the funding they receive be used ‘in the most appropriate way.’ This raises interesting questions around what constitutes appropriateness in this context of limited resources. What, here, is the ‘best result?’ It is not, I will preface the rest of the chapter by stating, a scenario in which any pregnant woman in the UK is able to donate her HSCs when she gives birth. According to Redshaw *et al.* (2011), as of 2010 there were 289 maternity units.⁴ Out of these, only fifteen offer the option of donation to women giving birth in the unit. Eight of these sites exist in London. The remaining seven are dotted in different cities across England. Of the eight collection sites in London, six are run by the NHSBT (the other two are managed by AN). An

⁴ The figure of 289 maternity units comes from Redshaw *et al.*'s report focusing on maternity provision in England in 2010. This number included Obstetric units, and Adjacent and Freestanding Midwifery Units (next to, and separate from, hospitals respectively). This number has likely changed slightly though no more recent audit exists.

immunologist who has worked on professional guidelines for tissue selection explained the situation in an interview.

We could move to some other places. It's easier for us to have all our collection centres in London because [of] resourcing, staffing ... All the units are assessed [in London] ... If they fulfil certain criteria they are then sent to Filton [in Bristol] where they are processed and stored. (Participant 9)

In this account, the interviewee concedes there *could* be NHSBT-led collection centres in 'some other places' but due to 'resources, staffing,' it is 'easier' to have all the facilities (from collection through to assessment) in London. The suggestion that 'resources' demand this concentration of collection centres is important. It reveals that practical exigencies preclude expansion and, thus, inclusion. This was an issue that was recognised in the SCSF report.

Logistically, maternity units collecting cord blood are best managed in clusters, allowing staff to move from hospital to hospital to ensure 24/7 attendance to maximise the number of units collected. (UK Stem Cell Strategic Forum, 2010b: 35)

The policy document can be seen here to rationalise the concentration of collection centres within a single city (in this case, London) by framing it 'logistically.' Such language connotes an almost militaristic operation of efficient procurement and supply with the thought-out movement of personnel. Collection sites are 'best managed' by being selected as 'clusters.' Such planning permits the movement of staff which can allow their constant ('24/7') presence. The intention of all this is to 'maximise' collection. What this suggests, of course, is that maximisation is not the same as expanding collection sites, but encouraging a selective focus on a concentration of collection centres. A similar account was provided by a speaker answering questions at an APPG regarding the state of Anthony Nolan's decision to extend staffing provision across existing collection sites rather than open new ones.

There wasn't that much money in the pot ... the best way was to sweat, for want of a better word, our existing assets to 24/7 collection centres. (APPG notes, September 2013)

Instead of the euphemistic limited resources, this account quite directly notes that there was not 'that much money in the pot.' This APPG speaker explains that with the limitations as they stood, it made sense to 'sweat' their 'assets' to day-and-night provision in individual wards where shift-worker collectors take over from one another so that there is always a qualified collector at hand for any delivery. They are, then, deriving as much value as they could out of their investment and paying collectors to stay in participating maternity units all day, every day of the week. As such the speaker's account explains how Anthony Nolan, like the NHSBT, rationalises its choice not to widen the scope of collection by placing staff in different maternity units, instead focusing their staff in maternity units in which they are already based. Both institutions can thus be seen to work within a logic where efficiency is equated with focus and selectivity. Any other state of matters, for example opening up in a number of units dotted across the country, and with less than constant staffing, would seem *inefficient*. This is an issue that the SCSF picks up in its 2010 policy document.

'A 'postcode lottery' exists for prospective cord blood donors outside London who are currently unable to donate.' (UK Stem Cell Strategic Forum, 2010b: 84)

The notion of a 'postcode lottery' enrolled here implies a sense of randomness to a woman's (or a 'prospective' donor's) likelihood of giving birth in a maternity unit where somebody works to collect the UCB tissue. The sense that this is determined by chance belies a complexity of reasons that have produced and closed off opportunities to donate UCB in UK maternity wards. Those managing the UCB collections, then, are limited by their resources, which resonates with Jimerson's (2009) point that all archivists face the decision of making the best of what resource allocators allow them. More than this, though, what begins to emerge here is that selectivity inevitably begets exclusion. Who, in other words, are the losers of the postcode lottery?

5.3 ‘The Kind of Funding We Have’

There can be too little funding for the managers of these UCB collections to fulfil every goal they may wish to fill. They have to work with what they have and ‘sweat’ their assets (to borrow from one participant, above). Resources, then, can be *limited*. But beyond this, resources can also be *delimited*, a word I use here to convey funding that states quite specifically how the money is to be used. Here, I want to consider how the *kind* of funding that the institutions secure can limit the spread of staffing for collection in maternity wards. This speaks to our broader concern in this chapter, which is to develop some understanding of how UCB banks, as selective collections, might be necessarily exclusionary. Delimited, rather than limited funding, is a particularly acute issue for Anthony Nolan. The charity had to secure government funding to expand its collection units across areas other than London. As well as the funding from the Department of Health, Anthony Nolan’s available resources for collecting UCB are boosted from the government’s Regional Growth Fund. The quote below comes from an interview with a scientist. Here, the scientist explains which maternity ward they are selecting to staff with UCB collectors.

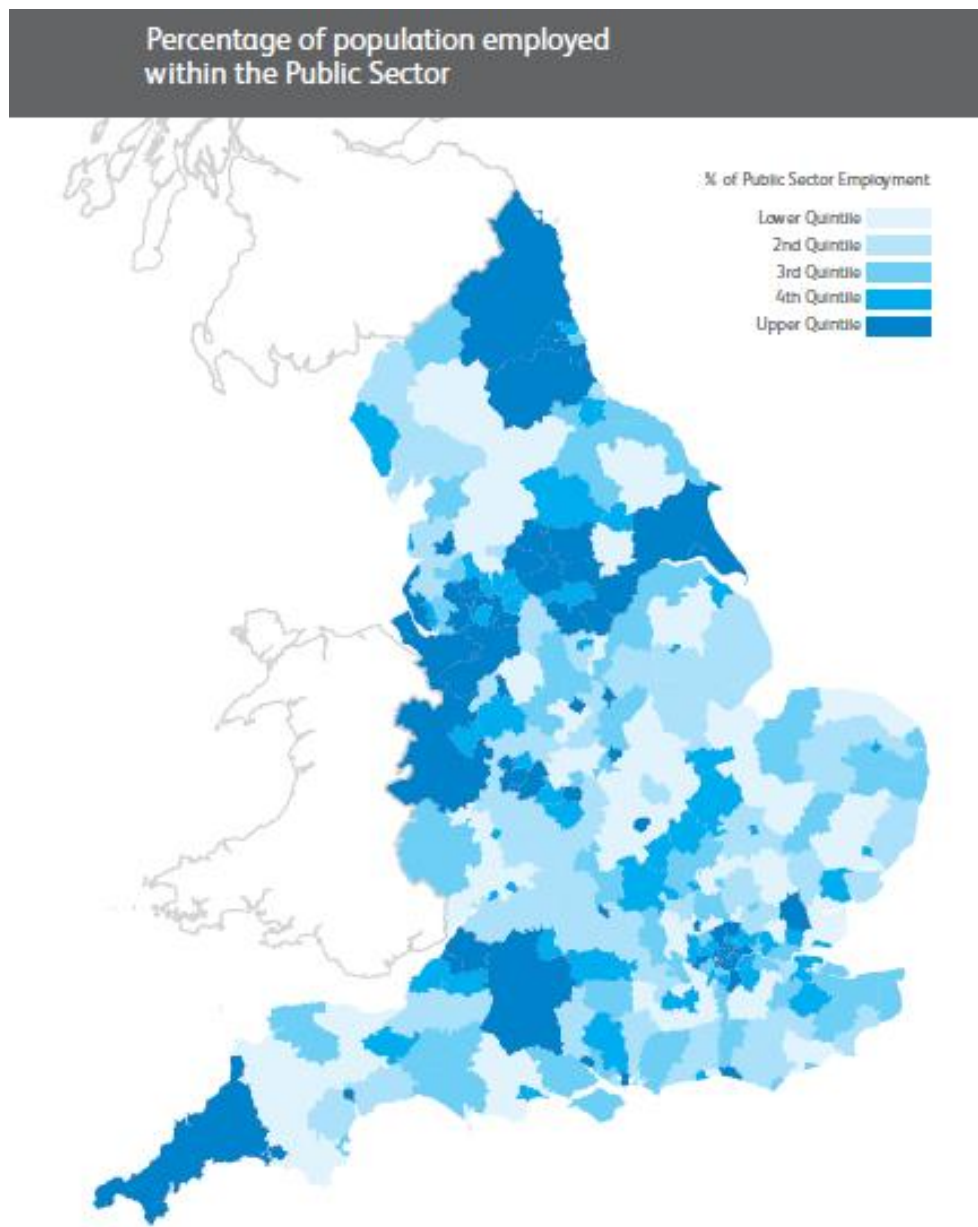
Hopefully it will be Nottingham ... QMC [Queen’s Medical Centre] and City Hospital, and hopefully Newcastle ... And then, if Newcastle doesn’t want, or it’s too difficult to open it, we will go to Manchester, because we need to do it in the North because of the kind of funding we have. (Participant 6)

The funding that the scientist refers to in this account is the governmental Regional Growth Fund (RGF) which the charity bid for and was awarded in 2013. The growth fund, awarded by the Department for Business, Innovation and Skills (2013) under the auspices of ‘UK Stem Cell Provision’, to an extent dictates which maternity units in which geographical areas the charity is permitted work with. As the scientist notes, the caveat of the funding is that they ‘need to do it in the North’. As the Department for Business, Innovation & Skills’ annual RGF report explains, the fund is designed to ease the transition of areas ‘dependent on the public sector ... to sustainable private sector-led growth’. The report notes that bids from those areas ‘where there is

a vibrant private sector' may struggle to be successful for this kind of funding (2014: 8).

By using this source of funding, the charity precludes itself from operating in particular spaces deemed unsuitable within the government's normative neoliberal framework of prudent investment (see Bentley and Pugalis, 2013). In the map below, reproduced from the same annual report (2014: 9), public sector-reliant areas (dark blue) and private sector-reliant areas (light blue) are mapped out.

Figure 8: The UK's public sector- and private sector-reliant areas reproduced from the 2014 RFG annual report.



Segments of low public sector employment (thus, less eligible for the use of RGF funding) are not on Anthony Nolan's list of collection site options. But the cities of Nottingham and Manchester, 80 miles apart, *are*. Swathes of pale blue, private sector-led England once again miss the cut because of the resource limitations of the institutions providing UCB collection, which are compelled to stay in the concentrated cluster of London hospitals or focus their energies on particular cities.

Practical limitations like funding, staffing and proximity are central to the limited number of maternity units that collect UCB, and thus the limited opportunity for women to donate their umbilical cords. The institutions cannot collect at every maternity unit, and *choosing* where to invest funding is based on determinations of what is both practicable and efficient. The point of this is that those managing how UCB is collected must be *selective* in their broader strategic decisions. This speaks to the point made by archival theorist Terry Cook. He writes that those working in archives will choose, 'in eras of limited resources ... which systems, which functions ... and which related records, will get full, partial, or no archival attention in all archival processes, from system design requirements to appraisal and acquisition' (2013: 102). When an archive is purported to exist in the national interest whilst its staff practices selective acquisition of matter, a tension must inevitably arise. With government funding, the public UCB banks operating in the UK are collections of matter that exist primarily for the UK's public health, to save the faceless lives of the unnamed patients past, and the imagined patients future. What tensions arise between this required exclusivity, and the enrolment of national interest and community? The quote below comes from a public bank administrator.

It's not a right. It's not a right! We do play on this a little bit because when we're persuading the hospitals to let us do cord collection we do sort of say, "This is a service that you're offering your mum. Your mum, given a choice, if she is quite passionate about this, and she's completely ambivalent between two hospitals she wants to go and have her baby in, she might choose to go." There's plenty of evidence and examples of women who've said, "I'm going to have my baby in that hospital because I can donate my cord" ... So it's like a service but really it shouldn't be looked

at as a service because we're not offering it as a universal service.

(Participant 8)

In this account, the administrator describes a situation in which hospitals are approached to be collection sites. The interviewee explains that convincing a hospital can require the bank workers to 'play on' the idea that donating cord is 'a right.' They are offering 'a service' to mothers who are 'passionate about' donating, and who might make their choice of hospital based upon the availability of an opportunity to do so. Crucially, though, the administrator states the UK UCB banks do not offer a 'universal service,' a service available to all, equally. Even within a collection site, as I will touch up shortly, some women are favoured over others. There is no guarantee that because you deliver in one of the 15 collecting maternity units, that you will actually have your cord collected. Donation, therefore, is sometimes made to look like 'a right,' an adherence to some kind of moral principle, though it is not. In this context, it would be useful to explore this disparity between the invocations of universalist rhetoric of everybody's right to donate, versus the actuality of selective practice.

The discussion resonates with Roberto Esposito's work on the notion of community. The originary Latin *communitas*, he argues, is rooted in the notion of the *munus*. This can mean a gift, or an office. Importantly for Esposito, it can also refer to an obligation. *Communitas* expresses not a common wealth or interest, but the common *obligations* of the community bond. Consequently, community can imply a 'diminishment of one's own goods and ... of oneself' (2006: 50). Thus, when the notion of community is used, it is suggestive of a duty of the individuals that comprise it to give of themselves to fulfil the duty of the bond. Community is an unsettled indebtedness, an absence that must be filled or recompensed. The invocation of community might be seen to produce the sense that people have 'a right,' or a moral compulsion, to give of themselves.

It is worth noting that this account confounds sociological understandings of community as 'a valorized alternative, antidote or even cure to the ills that the social had not been able to address' (Rose, 1996: 332). Such a community furnishes individuals with affective attachments to a shared identity. Community here is

something to which we might belong, but which also *belongs to us* as an entitlement. Esposito contends otherwise. Community is actually driven by this perpetual deficit of obligation and so is a source of constant tension. The decision to focus cord blood collection has outcomes that do not necessarily speak to the perhaps illusory sentiments of community that prop up ‘public’ donation systems. Take, for example, the quote below from an administrator working with one of the adult donor registries. Here, they reflect on their organisation’s trouble with would-be UCB donors.

People get so offended when told they can’t give blood ... they look at this sort of donation like it’s a right. Same with cord blood donation ... people say, “Well I couldn’t do it at my local hospital” ... Sometimes altruism completely overrides the need of the patient ... there’s a fine line between altruism and selfishness. (Participant 2)

Healy argues that ‘the gift of life, the dignity of donation and the rhetoric of community sit uneasily with the bureaucratic administration of procurement’ (2006: 112). Here, he is writing about the donation of blood, to which the administrator quoted above draws a comparison with UCB donation. People, the administrator asserts, ‘get offended’ by the inability to donate, as if donation were ‘a right’. In the account, this ‘altruism’ which implies a sense of selflessness, of giving out of concern for the welfare of others is not far away from ‘selfishness’.

This resonates with a point made by Brown who notes that UCB banking in its public valence is promoted in reference to the ‘solidaristic moral economy of gift and altruistic participation in imagined community and nationhood’ (2013: 98). Brown goes on to note a particular discursive emphasis on the *wastefulness* of not donating. The system of procurement is propped up by an altruistic tenor that

‘...succeeds only if the discursive framework of waste is accepted by donors or depositors and works on the basis that UCB has limited value outside its clinical usefulness in UCB banking. Waste, as a classificatory status, imposes a moral injunction not to squander something potentially precious’ (*ibid.*)

With Brown's point in mind, it might be suggested that it is as though the concern of *communitas*, reciprocating their indebtedness to the community, folds over on itself in a harmful way when women feel a compulsion to donate that cannot, in actuality, be fulfilled. This highlights the problematic construction of the UCB bank within a framework of universal donation, where the moral admonishment of waste is invoked to encourage the act of donation.

The bank instead is built and developed on the platform not of *creating* access to donation but actually *closing access off*. By appealing to the spirit of *communitas* and the obligation to give of oneself, archivists construct a debt which *all* in the community should feel a responsibility to repay, but which very few actually *can*. In this context, recall the requirement of banks to 'cluster' their collecting, rather than expand it. The quote below comes from an administrator who oversees the collectors of UCB. Here, they reflect on the situation in the collection site in Leicester, run by Anthony Nolan.

There are women who are unhappy if they can't donate because they're not delivering in the right place. We have women who are having home births ... we have a stand-alone centre in Melton Mowbray. If they deliver there then we can't do it [collect the cord]. We explain that we're a finite service and we can't be everywhere, we have to concentrate where most babies are being born, which is here. (Participant 11)

The interviewee above describes a situation where the city centre maternity ward does not host all the births in the area. If a woman has a home birth, they are not 'delivering in the right place' to permit collection. 14 miles out of the city limits is a small rural town called Melton Mowbray, and it is a similar story there. The town is famous to most of us for its eponymous pork pies, but probably not so well known for its rate of umbilical cord blood donation, which is zero. 'If they deliver there', explains this participant, 'we can't do it'. Again, people are 'unhappy if they can't donate,' which echoes preceding quotes. But the implication here is that *there is no rationality* to this unhappiness because the collection site is a 'finite service'. The notion that the collectors cannot be everywhere is suggestive of the selectivity of the

practice of collecting and banking UCB tissue. This theme is explicit in the quote below from another administrator.

You get a lot of women who hear about cord blood banking in the UK and think “Yes, I want to do that” ... Ours is a focused collection model ... Based on the targets, we don’t really need to expand into huge amounts of collection sites. (Participant 8)

In this account, the ‘focused collection model’ does not allow for the women ‘who hear about cord blood banking’ and decide they would like to participate. The foundation of this model of collection is the *targets*. ‘Based on’ these, there is no ‘*need*’ for expansion to allow the many women of the UK to donate their cords. To refer back to Esposito, there is no requirement for these members of the community to fulfil their *munus*, or duty, even though they ‘hear about’ the possibility of contributing to a life-saving resource for their community, and decide they want to participate in it. Importantly, though, even if a woman *did* deliver in one of the eligible maternity wards, with staff employed to collect cords to send onwards, there is still no guarantee that their cords would be collected for the bank.

5.4 ‘We Wouldn’t Collect from Them’

As we have seen so far, funding, limited and delimited as it can be, forces those working with these collections to make decisions about where they will collect UCB. As a consequence, they are also making decisions about where *not* to collect. Whilst ‘playing off’ the claim that the bank offers a service to donors, this is (as Healy (2006) notes of large scale tissue collecting projects) not so much a donation system as a *procurement* system. We can learn more about UCB collection and its exclusivity by recourse to literature on blood donation systems where questions of exclusivity through selectivity are central. Valentine (2005) notes the propensity to morally valorise the selfless blood donor whilst some are ineligible to donate even though they have the capacity to. The particularly old and young, the anaemic, those who have engaged in sex work or who have ever injected a non-prescription drug, any man who has had sex with another man in the last year, anybody who might have

recently travelled to a malarial zone. All of these people are ineligible to partake in blood donation, the vital act of citizenship.

We can thus see how the *private* existences of people (their sexual partners, a lack of iron-rich food in their diet, their last summer holiday) are transposed onto their (in)eligibility for participation in the vital public. By extension, they are also denied access to an avenue for addressing their debt to the community through the act of giving. The onerousness of sustaining one's relation to the community in this way demands ascetic self-denial (Copeman, 2009). The policing of eligibility therefore problematises an understanding of blood donation as a 'participatory space of belonging' (Valentine, 2005: 115). We are challenged to rethink public blood donation beyond an act both of, and for, community because it is 'a public practice ... that certain kinds of public are precluded from' (*ibid.*: 116). It is institutional safety regulations in blood donation that produce these 'categories of people' who risk the safety of the national supply of blood (Busby *et al.*, 2014: 89).

These frameworks of value are also applied in the realm of blood stem cell donation, and they become clear when considering UCB banking through an archival lens. *All* archives, suggests Mbembe, are 'primarily a product of a judgment' (2002: 20). The archival reason (Osborne, 1999) in this instance can be found in trying to gauge the *safety* of the cord blood unit. Tests are undertaken once the cord blood unit has been retrieved and sent to the laboratory, but the judgment inherent in archival practice is present even earlier on in the process of collection. Whilst all women in a maternity unit with collectors could donate their UCB and *then* have tests completed on all, resources get in the way of this too. The quote below comes from an interview with the individual who co-ordinates the regional collections of cord blood units for one of the public banks.

Participant 11: We have to give verbal information about the program, and this reviews it. They have to tick all the boxes to agree. There's a screening form. If they say 'yes' to any of the things above that line then we don't accept. This is our exclusion criteria basically, that we work with. And anything else - if they've got any sort of formulating infection, or if the placenta's smelly, we

wouldn't collect from them because we wouldn't want to put anybody in danger.

RW: A lot of that looks like the blood donation–

Participant 11: It is. Almost word-for-word, it's the same thing...

According to Richard Titmuss, successful blood donation systems rely on consistent donations from regular donors. In turn, blood *safety* relies on knowing 'the state of health, the health history, and the social habits of the donor' (1970: 162). The personal integrity of a donor was so important, according to Titmuss, because 'one man's untruthfulness can reduce another man's welfare' (*ibid.*: 163). The conception of 'safety' provokes a logic of surveillance, of policing the boundaries of donation. In the UCB context, the archival reason embedded in the early stages of the individual unit collection process is brought into sharp relief. The archival reasoning can be found in these checklists, verbal scripts, and even smell checks. The cord blood collector employs a 'discriminating gaze' (Featherstone, 2006: 594) from the point of procurement. In the account below, the same participant guides me through the pages of a cord blood collectors' advisory guide.

...So if someone has got Oral Herpes – fresh lesions they must not donate. "If lesions are healing, accept"... They might have a condition such as diabetes, which lots of women have. If they're a Type-1 diabetic or some other autoimmune condition then they won't be considered as being clinical in the future, so that would be one you wouldn't go for first. You'd go for your straightforward woman with no medical conditions. So there are some choices you can make... (Participant 11)

The guidelines of eligibility state that if a woman has oral herpes, she is ineligible. But if the contusions in the mouth are in the healing process, the collectors may 'accept' the donor. Similarly, 'lots of women have' diabetes, one of the autoimmune conditions that render them ineligible to donate a cord that will be 'clinical in the future.' The implication of this is that the cord would be suitable for research

purposes, but that this donor is one that the collector ‘wouldn’t go for first’. The ‘straightforward’ woman who does not present any of these conditions is the one ‘you’d go for’ first. ‘Choices’ can, and must, be made. As Beer (2013) argues, the archive’s politics live in the processes of such decision-making. This is particularly evident in the account below. Here, the same participant describes how having IVF prevents women from being able to participate in donation and, importantly, the women’s reactions.

*...we have to say no maybe because they’ve had IVF ... If they’ve had a human product such as a hormone which women will generally have had in their treatment then we’re not able to collect. It’s like having a blood transfusion. CJD. That’s the problem really. So they get upset, they can be very upset. We just try and thank them very much, you can help in all sorts of different ways. You can tell all your friends, spread the word. That’s what we need people to do. It doesn’t, you know, they’re disappointed...
(Participant 11)*

The comparison of the situation of IVF users coming into contact with ‘human products’ with Creutzfeldt-Jakob disease (CJD) is telling. Variant CJD (vCJD) is a fatal neurodegenerative disease caused, it is believed, by consuming the meat of cows contaminated with Bovine Spongiform Encephalopathy (BSE). As a 2013 report commissioned by the Department of Health explains, it is thought that up to 1 in 2,000 people in the UK present an indicator of vCJD because of the presence of BSE in the UK food chain in the early nineties. From 1999, all blood donations have had the white cells removed ‘in order to reduce any vCJD infectivity present’ (Bennet and Daraktchiev, 2013: 2). The paper also describes how from 2004, anybody who had received blood components would thereby be ‘excluded from donating blood, in order to prevent vCJD ... being “recycled” within the population’ (*ibid.*).

In the UCB domain, collectors must similarly ‘say no’ to the women who have received IVF treatment. These women who are rejected become pregnant using new reproductive technologies. These are the ‘happy’ rather than ‘hopeless’ narrative

category of IVF treatment stories (Franklin, 1990). As Throsby puts it, ‘the desperate infertile woman ... functions as a cautionary tale’ in the pursuit of IVF success where the divorcing of female existence from motherhood is anathema (2004: 64). And yet, IVF treatment precludes UCB donation. The successful entry into the feminine injunction of motherhood by way of IVF blocks the path to successfully complying with the moral injunction not to waste the precious stem cells within one’s umbilical cord (Brown, 2013).

Questions over the quality of donations, then, lie at the heart of exclusionary blood donation practices. In a similar way, the exclusion of men who sleep with men is directly related to HIV infection via blood transfusions in the United States, where, between 1982 and 2001, 14,262 people have been diagnosed with HIV or AIDS because of their use of blood products donated in the US (Donegan, 2003). As a social group thought more likely to have HIV, closing access to donation for the constituency becomes a method of *quality assurance*. As Titmuss argues, it is because of the risk to safety that blood collection services ‘have stressed the great importance of maintaining the most rigorous standards in the selection of donors’ (1970: 162).

This rigour, enrolled by collectors of UCB as they employ their archival reason, amplifies the exclusionary tenor of the system of procurement. The women excluded because of the discriminating gaze of archival practice ‘can be very upset’ or ‘disappointed’ if archival reason dictated that they were not donors considered to be eligible. Their would-be donation is thus rendered one of the ‘unimportant, irrelevant, worthless things [that] remain in the profane realm, beyond the archive’ (Groys, 2003: 179). This clashes, as we will see, with the expectations of individuals who might have hoped they could donate. One participant suggested that would-be donors’ concerns might be assuaged by a better understanding of who could benefit from the donation.

Basically donating cord blood in a hospital down the road, it goes to a bank that’s available to everyone and that’s something we have to make sure the message gets out. That the bank doesn’t

serve them, the hospitals they came from; it's a national resource.
(Participant 10)

The act of donating in a hospital 'down the road' (we might infer, a hospital local to the donor) is not the purpose of the bank which 'doesn't serve' the donor, or their hospital. Rather, the bank is a 'national resource' 'available to everyone' to use. Trying to disentangle the notion of a public cord blood initiative from a universal donation structure would rely on a reconstruction of cord blood donation away from the moral language of waste avoidance (Brown, 2013). Instead, accounts would need to be redirected towards a frank assertion about the reality of the initiative. That is, most women cannot donate. In this light, might we also need to reconsider the idea of the private banking model? Accounts given by interviewees, all connected with the public sector of cord blood banking, aired concerns over the quality of the product offered by private banks, but not necessarily *the notion* of the product itself. Below are quotes from two different interviewees.

The private banks have this sort of network of collection, so if you think about the national banks are only in certain hospitals, so you have to give birth there otherwise you can't store them, whereas private banking accesses women who give birth anywhere in the country. (Participant 5)

So from her point of view, she's thinking "well this is unfair!" and the private banks will say, "well, yes. But we offer it everywhere." ... Private banking is something else ... It's a different offering.
(Participant 8)

The first account asserts that private banks are seen to offer a 'network of collection'. If you wish to donate publically, you can only do so 'in certain hospitals' whilst the private network allows women wishing to preserve their cord to 'give birth anywhere in the country'. The reflections in the second quote resonate with this point. The interviewee suggests that, from the potential donor's point of view, the inability to donate is 'unfair'. In this way, private banks can be more universal, because they are able to offer the service 'everywhere.' The private bank can be conceptualised as an

avenue for those women who cannot donate to participate in the act of stem cell storage which stands to challenge the private/public binary offered by sociological accounts that pitch, as Brown *et al.* put it, ‘a solidaristic ethos of community inclusion against the atomistic seclusion of the self’ (2011: 1116). The capitalistic motivations of private banks overshadow individuals’ motivations to bank privately, which stand to be produced out of the exclusionary practices of public banking.

5.5 Ethnic Exclusivity

The practice of collecting UCB into banks for public use is, as we are beginning to see, clearly exclusionary. A lack of funding might stop expansion into more hospitals. Particular kinds of funding might demand certain qualities of the area in which the collection site is to be placed. The pregnant women who wish to donate, but are not able to attend the chosen maternity unit, are excluded. We also see resonances with other kinds of tissue collection practices, particularly blood donation, in that even if a woman *does* attend a chosen maternity unit, she might not be a safe enough donor. There is even more to be considered in terms of understanding the UCB collection as an exclusionary space. As we saw in the last chapter, adult donor registry data come mainly from volunteers who self-identify as white. Briefly, I mentioned that the focus on ethnic minorities has been employed to try and augment their donations in UCB banks. Here, I want to consider how that focus plays out in practice, and how it produces another vector of archival exclusion. Take, for example, the quote below from a participant involved in the APPG.

We want to focus on hospitals which have a high birth rate. Preferably a high birth rate of diverse ethnic mothers and that’s what we’re focused on. So Mrs Jones out in little Bollock-on-the-Wold going into her local maternity hospital? She doesn’t have access to that. (Participant 8)

Here, the administrator offers an example which alludes to how donors’ ethnicities enfold into decisions about which maternity units are to be selected as collection sites. The hypothetical Mrs Jones resides in the coarsely-named, fictional Bollock-on-the-Wold which is reminiscent of the similarly hyphenated Cotswolds town of

Stow-on-the-Wold. Mrs Jones, her whiteness duly inferred by a traditional rural residence and one of the most common British surnames in the UK census (McElduff *et al.*, 2008) is not in the scope of ‘focus’. Instead, this is placed on hospitals where there are ‘diverse ethnic mothers’. It is not too much of a stretch here to see the inference. The participant seems conscious of the fact that selecting urban hospitals with high concentrations of minority ethnicity women closes off access to white women in rural areas. Whilst whiteness is only implied here, rural areas in Britain traditionally have a much smaller concentration of ethnic minorities than do urban centres (Garner and Bhattacharyya, 2011; Parkinson *et al.*, 2006).⁵

To make sense of this, it is worth returning to our archival lens. Featherstone notes the tensions at work in archival decision-making, writing that ‘the archive should be as exhaustive as possible’ (2006: 593). By and large, archivists believe that they should incorporate a diverse breadth of matter into the archive, thus readying themselves for the unknown future. Groys calls this a ‘mandate for completeness’ (2003: 182), in that there is an onus on archivists to ensure that they offer a comprehensive and representative range of matter to users. Why spend one’s resources on banking what are believed to be common, ‘white’ stem cells when there is a lack of rare, ‘minority’ stem cells that could be addressed through focused collection?

This is, I would argue, not unlike Bowker’s point that in the effort to produce biodiversity databases, a spread of diversity across the archive is preferable to ‘preserving a large number of species *within* a spread of genetic difference’ (2005:

⁵ Parkinson *et al.* assert that the dimensions of Black and minority ethnicity (BAME) geography has ‘a clear urban-rural gradient’ (2006: 52). They also note that the distribution is heavily weighted towards London, but that other large and small cities across England saw an increase in BAME residents and a decrease in white residents between the 1991 and 2001 censuses. This is, as Garner and Bhattacharyya assert, because ‘of original settlement patterns around London and the larger industrial bases throughout the Midlands and the North of England’ (2011: 5)

207, my italics). Maximising diversity is key in the database. Accordingly, an understanding of HLA diversity as linked to ethnicity (see Williams, 2015), for instance, is instructive in where UCB is collected. Collection sites not only need to meet funding criteria, but must fit within this logic where ethnicity is seen to be important. The quote below comes from interviews with two individuals involved in the APPG.

A petition went on in Manchester by the MP ... to have a collection site opened there and that's why we've ended up in Manchester. Again, another place with lots of babies and good diversity. (Participant 11)

...we collect at King's ... because King's has a huge number of ethnic minorities ... You basically target the region because that's where there are lots of mothers of ethnic minority groups. (Participant 1)

In the first quote, the interviewee explains that a collection site in Manchester is a rational choice not only because of the density of births – ‘lots of babies’ – but also the high numbers of women coming from ‘ethnic minority groups.’ Echoing this, the second quote notes that King’s College Hospital (one of the London collection sites) is a similarly attractive collection site. The hospital has a ‘huge number of ethnic minorities’. Ethnicity, and the consensus on its connection to tissue-type rarity, is pivotal in how the archival mandate for completeness is understood.

It is worth noting that the construction of rarity in minority ethnicity tissue might be seen as rooted in a particular and problematic history. Titmuss was attuned to it, cautioning his readers to remember the ‘contemporary world-wide phenomena of racial prejudice and its association with concepts of blood impurities, ‘good’ blood and ‘bad’ blood, untouchability and contamination’ (1970: 20). I would argue, though, that what we see here is a kind of inversion of this. Black UCB and Asian UCB (the most useful, molar categorisation for otherwise molecular distinctions) is imbued with a kind of value *because of its rarity*. It becomes vital that such tissue be

collected and stored away. How, then, is this understanding put into practice at a policy level? Consider this extract from the Stem Cell Strategic Forum, below.

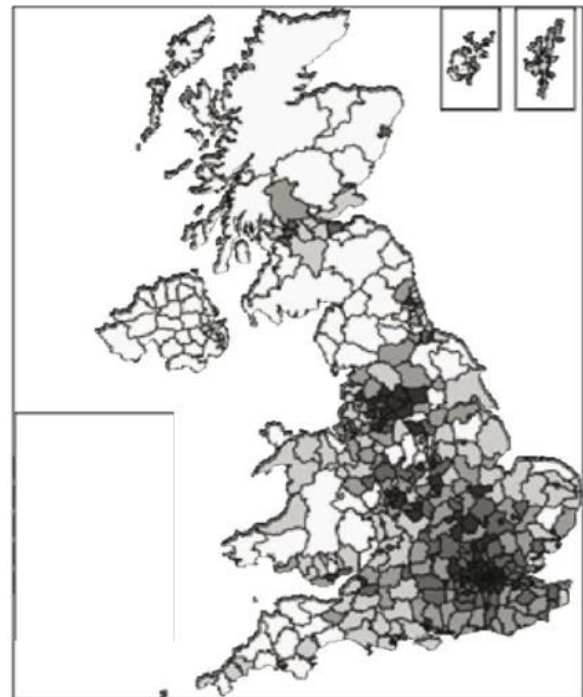
‘Since 45% of ethnic minority individuals live in and around London ... it follows that an ethnically diverse cord blood inventory may best be achieved by collecting cord blood units primarily from London hospitals with maternity units with over 5000 births per annum.’ (UK Stem Cell Strategic Forum, 2010b: 35)

As the extract explains, nearly half the ethnic minority population of England lives in London and its surrounding areas. To evidence this claim, it refers to a visualisation of the spread of ethnic minority people (and their inherent bodily resources) by mapping census data from the 2001 census (UK Stem Cell Strategic Forum, 2010b: 35), reproduced below. In the map, darker areas represent a higher presence of minority ethnicities

Figure 9: The distribution of minority ethnicity people across the UK reproduced from Stem Cell Strategic Forum report (2014b)

Key.

6.4% to 60.4%
2.5% to 6.3%
1.5% to 2.4%
1.0% to 1.4%
0.2% to 0.9%



Through the use of census data, a means of measuring the population, the collection managers attempt to combat the underrepresentation of minorities. They do this by focusing more intensely on those excluded bodies. By focusing in this way, their work actively excludes particular locations and the people in them. Mrs Jones over in the Cotswolds has no place in this plan (because she is already represented in the adult registry), whilst minority ethnicity status is enrolled as a target for the bank. To use Achille Mbembe's words, this is an archival 'montage of fragments'. The archivists wish to mirror the country's population, but they can only do so in a fragmented and partial way. And yet, as Mbembe goes on to say, this effort creates an 'illusion of totality and continuity' (Mbembe, 2002: 21). This perceived need to focus gives imprimatur to the geographic exclusion of large parts of the country, and speaks directly to Stoler's suggestion that the work of the archivist tends more toward 'an extractive enterprise than an ethnographic one' (2002: 84).

Discussing blood donation systems, Titmuss recognises the possibility 'that because one's blood is rare or unique,' an individual might be made to feel a 'particular responsibility to make it available to others who may need it' (1970: 263). This onus to make their vitality available can manifest in what Titmuss calls the 'captive voluntary donor' who, if they choose not to donate, risks the shame of 'the relevant social group' applying moral pressure (1970: 96). Although Titmuss is talking about blood donation rather than stem cell donation, the point is echoed in a quote from an individual involved in an organisation that encourages adult volunteer, organ, and cord blood stem cell donation amongst ethnic minorities.

...whether it be bone marrow, cord blood, organ donation [our organisation is] highlighting ... how race is important in terms of matching ... we are the vanguard of this movement of getting ethnic minorities, especially Black and mixed raced people to realise: take your health seriously, especially when it comes to cancers and especially when it relates directly to race. You need to be ready to try and help someone else because you never know when you might need it yourself ... That's a very specialised message that's got to be ... couched in a way that will resonate with families and mothers-to-be when they hear it. (Participant 4)

In this account, the interviewee positions their movement as a ‘vanguard’. The militaristic inference is suggestive of being on the frontline of a battle in bringing ethnic minorities to a realisation. The military tactic could be seen as an invocation of the *munus*. The participant puts this quite bluntly, stating that one must be ‘ready to try and help someone else because you never know when you might need it yourself’. This network of *munus*, the insatiable obligation to others in the group, must be ‘couched’ so that it will ‘resonate’ with the potential cord blood donors. This affective resonance is a central element in the augmentation of donation. Awareness raising is therefore not simply about highlighting the illness and the statistical probabilities, but of highlighting potential donors’ responsibilities to the community.

This sentiment is explored by Kierans and Cooper (2011), who consider the manner in which organ transplant policy reproduces notions of racialised genetic difference. They argue that this discourse of difference constructs the issue of organ donation as a cultural one that falls beyond the remit of medicine, and which thereby racialises the responsibility to donate by placing the onus onto these ‘different’ communities themselves. Tensions emerging from community-led campaigns to promote adult donor registration speak to the same concerns that Kierans and Cooper have of similar organ donation campaigns which ‘amplify the idea that donation is the collective responsibility of biologically, socially and culturally distinct and distinguishable communities’ (2011: 14). In this context, consider the quote below from the same patient activist as above.

Because we’re talking about life and death. We don’t take any prisoners on this, we are hard hitting. We won’t compromise – especially with the black community – on pussyfooting around these subject matters ... For many years, our motto was a quotation from Malcolm X. Our motto was “by any means necessary” ... And we are probably now as hard on our community ...than ever before. So we don’t compromise at all on this.
(Participant 4)

This language – ‘We don’t take any prisoners’, and a motto from the Muslim minister and Black luminary Malcolm X – indicates a sober resolve to highlight both

the community's difference. It also indicates a consciousness of some obligation to itself that, remaining unfulfilled, amounts to what Ruha Benjamin has elsewhere called a kind of 'civic defection' (2013: 44).

This racialised difference-making lies at the centre of Kierans and Cooper's argument. They argue that by highlighting difference, one risks the 'further entrenchment of such difference' (2011: 14). This entrenchment becomes problematic when, as Kierans and Cooper explain, the microcosmic reproduction of Titmuss's original advocacy of intercorporeal generosity along ethnic lines actually comes to 'contradict the wider communitarian and inclusive vision of society upon which this view was originally built' (2011: 11). *Communitas* is perversely inverted. Communities *within* the larger population are indebted to one another inside the same reified ethnic circle. This risks challenging, at least in spirit, the notion that donors should not be given the option to prescribe their potential recipient's characteristics (Titmuss, 1970). One interviewer touched upon this when they reflected on the state of adult donor registries in the nineties.

So I was involved in the very early days, when we just didn't have any Afro-Caribbean patients. And it's quite interesting because they used to do, even in those days, some early drives. And you quite often got Afro-Caribbean donors coming forward saying "we'll donate but only to an Afro-Caribbean child" ... sort of very ethnically driven ... quite frequently people would say that.
(Participant 1)

In this account, the participant points out that minority donors would come forward with a caveat that their stem cells only be used by another person with the same ethnicity as them. The idea that donation was 'ethnically driven' is interesting, but perhaps not so surprising with the kind of messages enrolled in encouraging the donation in the first place. By reproducing a racialised difference in encouraging donation, accounts of the *munus* or indebtedness coalesce around this same ethnic line. The onus to help then becomes sealed *within the differentiated community itself*. If donation systems enforce an image of a sealed ethnic community that must help

itself, as Kierans and Cooper suggest, then indebtedness and the drive to give only *within* said community makes sense.

But with this in mind, it is perhaps worth remembering that as well as having the ability to reify categories of difference, transplant technologies can effectively *transcend* them. In Beck's account of the unified stem cell donation system of Cyprus, he describes the biopolitical unification of Turkish- and Greek-Cypriot bodies that come to embody a 'vital public' distinguishable from the 'political public in the classical sense' (2011: 113). This highlights the need to consider how both group-specific and nation-wide appeals to *give* belie 'the complex layering of myriad networks of individual association, action, and intention that animate the social and moral worlds in which people actually live and die' (Simpson, 2014: 6).

5.6 Conclusion

In response to the last chapter's concern with inclusion, this chapter has picked up the threads of exclusion produced out of a demand for the UCB bank managers to ensure their collections are representative. This empirical chapter, then, has been broadly concerned with what kinds of conditions preclude the act of UCB donation. The limitations (and delimitations) of resources decide to an extent how many collection centres there are and where they should be. The ethnic composition of the area served by a maternity unit also has some bearing on this, whilst the choice over which units will be collected within that already lessened pool of potential donors is made in reference to other selection criteria that further filter the access to donation.

What do we learn from having critically explored the state of play regarding access to UCB donation? Firstly, we get a sense of who is excluded, along with *why* they are excluded, which gives us some sense that the jussive force of this archive is at work. This force, as Bowker writes, 'operates through being invisibly exclusionary. The invisibility is an important feature here: the archive presents itself as being the set of all possible statements, rather than the law of what can be said' (2005: 14). To my mind, what Bowker is saying here speaks to what we see happening in the UK context of public UCB donation. It works in the system's interest for those involved in the management of UCB collection and collections to portray what they provide as

a universal service. At its visible level, public UCB collection is surely a great thing, a communitarian giving of self to fulfil the insatiable debt of the commons. Every woman's donation awaits its entry to the 'set of all possible statements'. At the invisible level, public UCB donation is not something just any woman can do. If one is lucky enough to live in the right city (eligible for funding, sufficiently composed of minority ethnicities, and therefore chosen to have a collection site), there's scope (though, as we have seen, no guarantee of) donation. The various vectors of exclusion that make up archival practice in this instance are thus Bowker's 'law of what can be said'.

Secondly, what we see here despite all the donors and all the donation, is a system of procurement (to use Healy's (2006) phrasing). Indeed, my own use of such terms (and the challenge I have found it to employ any other word than 'donor') bespeaks the prevalence of the framing of these systems as ones of donation. As irritated, upset, or guilty as anybody might be made by what we see here, the scenario is borne out of the fact that those in charge neither want nor require every unit that could potentially be collected in the UK. It is the discriminatory gaze and the exclusion it produces that defines the practices here. In our context, producing a useful collection for the public's use ironically requires preclusion of public contribution to it.

Chapter Six: Using the Archive

6.1 Introduction

In the last two chapters, we have explored the roles of order and selectivity within the UK's public UCB collections. Here, I want to explore how these collections come to be used. In the spirit of the archival lens, it might be said that this chapter offers a contribution to the literature on archival 'user studies', an area that those writing about archives often lament as remaining fairly underexplored (Conway, 2010; Johnson, 2008; Sundqvist, 2007). What I want to plot out in the following discussion is the way in which the umbilical cord blood banks in question stand to be used (or indeed overlooked) in users' efforts to find what they are looking for. How, put simply, is use made of these archives?

To begin exploring this question, this chapter considers what might be thought of as the standards of medical practice that have been produced to guide clinicians in making their selection of HSCs. The British *donor selection algorithm* (Shaw *et al.*, 2009) is a professional, published consensus statement designed to recommend particular treatment paths in a given scenario. In what follows, I consider how this tool that guides potential users to the archive, requires regular updating itself to keep in step with technological advances in tissue matching, before looking at the important local, idiosyncratic (Knorr, 1979) iterations of such standards. What emerges here is that, alongside the more rational register of decision-making in the scenario of HSC selection, is a considerably more affective layer in which particular clinicians are comfortable using particular kinds of HSCs, something which I conceptualise as 'clinical comfort'.

Throughout the chapter, I tackle how those working with these selective collections operate in light of these changing standards and subjective preferences. How, I consider in what follows, does their desire to encourage archival use (Kaplan, 2002) actually manifest in a space governed to an extent by both an experiential layer of affect and a stratum of continually transforming standardisation. With this in mind, I look at how clinicians are drawn to the archive, or are compelled to take the risk with UCB which is, to them, a new and risky technology. As I demonstrate, subjective

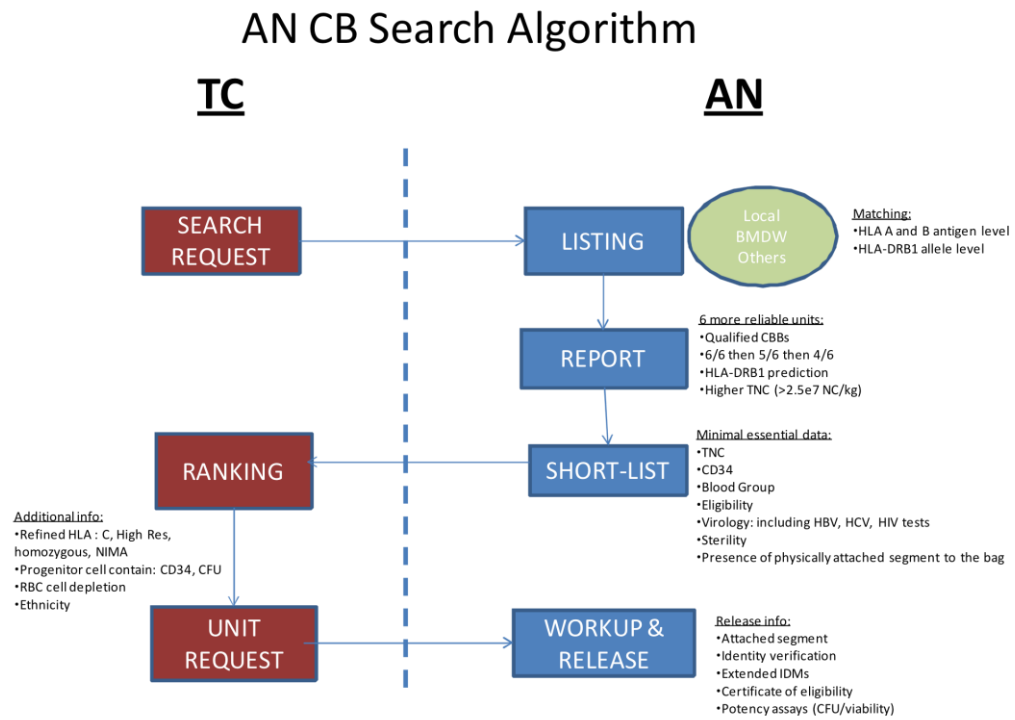
preference governs interactions well beyond opting to search for cord. This preference also emerges when it comes to the task of selecting which cord to use. To anchor the exploration, I focus on the issue of a unit's Total Nucleated Cell (TNC) count. Recent data suggest that larger TNC counts, or cell doses, are a feature of more successfully engrafted units. Clinicians' preference for these units has changed the kind of demand the UCB archive is experiencing and, thus, what matter the archivists are collecting and putting into the collections for future use. The chapter concludes by making a case for appreciating that UCB collections, like all useful archives, can only be understood in reference to the demands of their users.

6.2 Professional Standards and Local Idiosyncrasies

To preface the discussion that follows in this chapter, it is worth plotting out the *process* of how a UCB unit travels from the freezer to the clinic. Figure 10, below, taken from the publically accessible Anthony Nolan Operation Guide (2012: 5), plots out a sort of UCB unit search process ideal type. The image divides transplant centres (TCs) and the charity that performs the tissue search, Anthony Nolan (AN). It represents the manner in which a UCB unit is requested, located, chosen and dispatched. It is a representation used to visually describe the process of search and selection to anybody interested enough to read it – perhaps clinicians, charity workers, or policy makers. Unsurprisingly, it does not (and, I would argue, *can* not) convey the complexity of the actuality of unit selection. Its use lies simply in demonstrating the key moments in any instance of a search.

This is a fairly straightforward process in which a 'SEARCH REQUEST' prompts those at the bank to undergo three blue boxes' worth of archival searches. All pertinent units are located (LISTING). The archivists then produce a list (REPORT) then filter that list based on the relevant figures (set out next to the blue boxes). The archive workers then produce a set of results (SHORT LIST) sent to the clinician to be ranked (RANKING). This colourful image is suggestive of a rational, processual task of archival use, guided in the main by the archivist (in the case of Figure 10, 'AN') who does most of the work then gives the final choice to those at the transplant centre.

Figure 10: Anthony Nolan's cord blood 'search algorithm' flow chart reproduced by Anthony Nolan Operation Guide (2012).



The process of a search is succinctly laid out and demonstrates how the ‘archivist, as digitizer, system builder, and interface architect, plays a fundamental mediating role’ (Conway, 2010: 427) in how their selective collection will be used. Indeed, we could leave the chapter at that and have a fairly clear sense of the basic way in which use is currently made of these umbilical cord blood banks. That is, a search, a list, a choice, and a delivery. However, to end the account there would be to omit important elements enfolded into *whether* use is made of this archive at all.

Readers will recall the first sentences of the introductory chapter, where I posited a scenario in which your clinician suggested you had a chance of surviving your illness. This chance was some stem cells in a freezer. How, though, did your clinician know they were there? Why did they even think to look? To refer back to the colourful flow chart (Figure 10), why was that burgundy ‘SEARCH REQUEST’ made in the first place? The answers to these questions seem fairly obvious. UCB is an HSC source that clinicians know about and use to treat their patients. But, as I explore here, HSC was not always a source, not all clinicians are familiar with it, and

certainly not all of them will use HSCs from UCB in the course of care for patients who might benefit from them. As this chapter unpacks, it cannot be assumed that these collections will be used. As Conway notes in his study of those using photographic archives, different expert users of archives all have their own ways of choosing which archives to use and how to navigate them. There are different ‘modes of seeing’ archives that are informed by the highly variegated ‘distribution of user expectations’ (2010: 459). I want, then, to spend some time thinking about what user expectations might be black-boxed (or burgundy-boxed) in the first phase of archival use, the ‘RESEARCH REQUEST’. Put differently, to understand how use is made of these archival spaces requires us to think about why a clinician would even think to use one of them in the first place.

A good place to start looking for answers to this is the professional standards created to guide clinicians in their decision-making processes. Berg and Timmermans argue that such standards are an attempt to ‘rationalize medical work’, thus making clinical practice ‘more “scientific” by invoking formal technologies and by erasing unwarranted local variations’ (2000: 36). The British Cord Blood Working Group was developed by a group of scientists and clinicians interested in setting a protocol based on the knowledge produced in the course of their own practice, to offer guidance and a reference point for UK clinicians working with cord. A means of doing this was the production of a consensus statement and a ‘donor selection algorithm’, which I have reproduced below. This was published by Shaw *et al.* (2009: 10) and the algorithm was reproduced in the Stem Cell Strategic Forum’s report (2010b: 12), testament to its relevance as perceived by those planning out the future of clinical HSC provision. ‘We recommend,’ says the text accompanying the algorithm in the original journal article, ‘that the nationally agreed donor selection algorithms should be used’ (Shaw *et al.*, 2009: 10), in lieu – we might infer – of a *non*-nationally agreed, personal choice on the part of the individual practitioner.

Figure 11: Shaw et al.'s 'donor selection algorithm', reproduced from 2009 working group consensus statement.

Choice	Family donor	Volunteer unrelated donor	Unrelated cord
(a) Malignant disease: paediatrics			
1st	Matched family donor Matched cord (sibling)		
2nd		10/10	6/6
		9/10	5/6 ($> 3 \times 10^7$ TNC/kg)
3rd	$< / = 4/6$	8/10	5/6 ($< 3 \times 10^7$ TNC/kg)
			4/6
(b) Malignant disease: adults			
1st	Matched family donor Matched cord (sibling)		
2nd		10/10	
		9/10	
3rd		8/10	6/6
			5/6 ($> 3 \times 10^7$ TNC/kg)
4th	$< / = 4/6$	$< 8/10$	5/6 ($< 3 \times 10^7$ TNC/kg)
			4/H6
(c) Immunodeficiency/metabolic diseases			
1st	Matched family donor Matched cord (sibling)		
2nd		10/10	6/6
3rd		9/10	5/6 ($> 3 \times 10^7$ TNC/kg)
4th	$\leq 4/6$		5/6 ($> 3 \times 10^7$ TNC/kg)
			4/6
(d) Marrow failure			
1st	Matched family donor Matched cord (sibling)		
2nd		10/10	
3rd		9/10	6/6
			5/6 ($> 3 \times 10^7$ TNC/kg)
4th	$\leq 4/6$		5/6 ($< 3 \times 10^7$ TNC/kg)
			4/6

Before laying out the relevance of the table, it is worth briefly explaining how to read it. This table posits what we might think of as four illness scenarios. The first (a) is a childhood malignant disease. The second (b) is the same kind of disease in an adult. The presentation of metabolic disease is the third (c) scenario, and marrow failure (d) is posited as the fourth. The ranking of treatment options (1st, 2nd, 3rd, and 4th) make reference to the column headings, which represent the clinician's choices of source. The first choice is a 'family donor'. This comprises HSCs from a related donor, via either bone marrow or peripheral blood or by UCB taken during a sibling's birth. The second choice is a 'volunteer unrelated donor'. This would be HSCs taken from an adult donor via their bone marrow or from their peripheral blood and would be located via a volunteer adult donor registry. Finally, the 'unrelated cord' describes any anonymous UCB unit from an umbilical cord blood bank.

Positing an instance in which a patient presents with marrow failure (scenario *d*), we can see how the Cord Blood Working Group recommends we move forward. In the 1st instance, a matched family donor or cord is preferable. If this is not possible, the table then advises that the 2nd best option is to use HSCs from a volunteer unrelated donor. Simple so far, but if the ideal 10/10 unrelated donor match cannot be located, the 3rd option offers three choices:

- an unrelated, volunteer adult donor who can offer a 9/10 match, or
- an unrelated UCB unit with a 6/6 match, or
- an unrelated UCB unit with a 5/6 match, but with a Total Nucleated Cell (TNC) dose greater than $3 \times 10^7/\text{kg}$.

These three are equivalents in this table. We could *choose* any of these three. Indeed, these are only recommendations so we could *choose* to disregard the table altogether. In the scenario that a practitioner has all of these options available to them, they then have to *choose*. Choice, or selectivity *within* these collections, as we saw in the last two empirical chapters, is met with selectivity *beforehand* on the part of the collections' users. Clinical standards, in this way, can be seen as part of the selective prelude to archival use.

Choice permeates this archive. But what does the Cord Blood Working Group's attempt to order preference tell us? In understanding the pertinence of this table, it is perhaps useful to consider Harry Collins' discussion of scientific knowledge transmission. Exploring the ways through which knowledge is thought to be transmitted between individuals and groups, he posits the notion of *algorithmic* learning. This is the transmission of *knowledge* 'through information channels, such as scientific journals'. In this model, there is the implicit assumption that 'what there is to be known can be constrained in a set of discrete bits of information and logical instructions' (2012: 323). The table from Shaw *et al.*, it might be argued, represents the algorithmic model. It assumes that knowledge is best conveyed through logical instructions and so treatment options are ranked (1st, 2nd, 3rd, 4th) for a number of illness scenarios (a, b, c and d). Importantly the information is conveyed through a leading professional journal, *Bone Marrow Transplantation*.

In addition to this, the table can be seen as an attempt to bring order to the practice of tissue selection. This speaks to a point raised by Berg and Timmermans in their discussion of clinical decision-making devices. The logic that produces these models, they argue, necessarily posits *existing practices* as ones defined by disorder. Messy, non-rational practices are thus in need of replacement with 'scientifically established, rational, and universal modes of working and understanding' (2000: 31) that can be referred to so that practitioners can achieve optimal outcomes for their patients. In reality, however, these reference tools are prone to adaptation. Embodied in these tools is 'the never-ending need to tinker, to work around, to articulate loose ends' (*ibid.*: 51). Indeed, this point is made in the very publication in which the national consensus algorithm appears.

'It is unclear at this stage how the use of double UCB units may affect selection criteria. It was noted that data in cord blood transplantation were becoming available on outcomes when selection was based on other parameters (for example, CD34 counts) and that, therefore, these selection algorithms will need regular review and updating' (Shaw *et al.*, 2009: 10)

The potential increase in use of two smaller matching cords ('double UCB units), instead of one larger one, may change the algorithm down the line. New parameters – for example, different kinds of stem cells with the unit (CD34 cells in this instance) – may eventually be seen as more important than they appeared in 2009 and again cause the algorithm to change. This excerpt is an acknowledgement that selection criteria are likely to change in ways that are, in the present, 'unclear.' As such, written into the algorithmic transmission of knowledge is the inevitability of 'review' and of change, or 'updating'. As was noted in the first chapter, the field of HSC transplantation has always been something of an unknown terrain developed in research studies and small scale trials. The technology has, since its instantiation, been predicated on the understanding that there was more to uncover and know about how the treatment works. The quote below comes from a scientist analysing data of current international stem cell stocks.

We're basically curing because it works, not because we understand ... how the illness works ... since we don't have this global knowledge, well you have research that advances every year and thus introduces new aspects that you have been disregarding thus far. (Participant 17)

In this account, the scientist asserts that 'we don't have this global knowledge,' a knowledge perhaps presumed by the existence of donor selection algorithms like the one above. Indeed, practitioners operate with a limited understanding of 'how the illness works' and it is an area that comes to be defined by the gradual emergence of 'new aspects' so far not recognised as important in the field. These thoughts echo the reflections of Donnall Thomas, the transplantation scientist awarded a Nobel Prize discussed in the first chapter. Reflecting on the sporadic successes with the early animal models that his team was experimenting on, he noted that 'evidently it could be done - we just had to find out how' (1994: 341).

Transplantation can be thought of a domain defined by scientific research, by 'finding out how'. Patients treated with HSCs from a UCB unit may become a datum in a research publication whilst, say, a patient treated for a broken arm probably would not be. Practitioners are still learning about the immunological illnesses and

the technologies they can use to cure them. With this in mind, consider the interview quote from a member of the Cord Blood Working Group that published the selection algorithm. They explained how part of the group's function now was to update that consensus algorithm.

So part of the thing [we are] thrashing out is, if you have a patient, what order you should pick your donors in. And where cords fit into that ... even amongst cord experts there's differences of opinion. (Participant 5)

The notion of 'thrashing out' – exhaustive, vigorous discussion – resonates with the point made by Berg and Timmermans that 'messy, real-time work' (2000: 52) is required to sustain such decision making tools. Repair and refreshment are necessary to *make standards work* (Lampland and Star, 2009), as they are always at risk of 'falling apart under changing circumstances' (Timmermans, 2015: 80). Building on this, it is hardly surprising that it is not an easy task to produce the selection algorithm. Another quote from the same interviewee as above exemplifies this well.

As soon as I can get our experts to finally agree, because although everyone agreed in the room. The fine print – there's emails coming forwards and backwards, and then it needs approval for various things. But I would hope that that would be submitted for publication before the end of the year. (Participant 5)

The selection algorithm is essentially a composite of the preferences of a number of experts. The *production of* consensus and the consensus itself look nothing alike. The table above, for example, reveals nothing of the 'forwards and backwards' of emails. Its rational lists of ranks and ailments belie the effort of getting 'our experts to finally agree.' This quote echoes a point made by Bowker and Star. They argue that professional classifications, which are central in the management of many enterprises, are 'a contested site of great political significance' (Bowker and Star, 1999: 229). Perhaps tellingly, I interviewed the founder of the working group in November 2013. As of September 2015, the consensus statement has not yet been published. The inevitable review and updating of standards raises questions about

how archivists are supposed to respond. If recommendations are regularly changing what clinicians are advised to select, then these archivists must also have to adapt what matter they have to retain. Without doing so, they surely risk their inventories becoming obsolete – collections full of units that have lost their usefulness in reference to criteria that have changed around them. This is a point I want to return to in more depth in the next chapter, but for now I want to remain with the issue of use. The quote below comes from an administrator at a UK cord blood bank.

They're refining the consensus statement. The cord blood working group meeting has moved cord up the algorithm. So I think they're, we're making progress, but it's not just about us sitting in the bank saying "this is what they should be using." (Participant 8)

Those working at the bank, then, see important 'progress' in cord's movement 'up the algorithm'. This suggests an archival awareness of the importance of these kinds of standards in the use of these collections. Importantly, though, the administrator's account also implies an amount of exasperation as to the capacity of archivists to affect the decision of clinicians to become archive users. Harris, for example, suggests that those managing archives 'must go beyond merely servers of record users. They must become creators of users' (2002: 148). But in the actuality of collections administration in the bank as described in the account above, it is 'not just about us' telling clinicians that their collection is 'what they should be using'. So what else, or who else, might it be about?

The account bespeaks a complexity behind the changing clinical standards that cannot be addressed by simply *creating users*, to use Harris' term. Perhaps it *would* be this simple if there were profession-wide consensus about what is important or relevant to the process of tissue selection. However, Knorr argues that relevance and importance are never stably defined and never 'standardized throughout' scientific communities (1979: 361). Behind her argument is the notion of idiosyncrasy. 'Choice and interpretations,' she clarifies, 'are crystallizations of order in a local contingency space'. Her argument, developed in reference to scientific laboratory work, resonates in our context.

Figure 12: (below) A transplant centre's 'donor hierarchy' for paediatric leukaemia reproduced from APPG presentation

Donor hierarchy: paediatric leukaemia

Choice	Family Donor	Unrelated Donor	Unrelated CB
1st	MFD or matched CB		
2nd		8/8 7/8	6/6 5/6 ($> 3 \times 10^7$)
3rd	$\leq 4/6$	6/8	5/6 ($< 3 \times 10^7$) 4/6

Figure 13: (below) A transplant centre's 'donor hierarchy' for metabolic disease reproduced from APPG presentation

Donor hierarchy: immunodeficiency/metabolic disease

Choice	Family Donor	Unrelated Donor	Unrelated CB
1st	MFD or matched CB		
2nd		8/8	6/6
3rd		7/8	5/6 ($> 3 \times 10^7$)
4th	$\leq 4/6$		5/6 ($< 3 \times 10^7$) 4/6

For example, take the above images (Figure 12 and Figure 13) which are reproduced from the slides of a presentation at an APPG. During the APPG meeting, Participant 1 who presented these 'hierarchies' explained that they could be referred to in their transplant centre when a clinician was faced with a choice of clinical options, a situation they claimed was becoming more common. Importantly, these hierarchies

exist *in addition to* the national consensus algorithm discussed earlier in the chapter. By the simple fact of their co-existence we can see how, as Knorr puts it, ‘research sites develop *local* interpretations of methodical rules, a *know how* referring to what is meant and how to best make things work in the face of a codified literature’ (1979: 359, original italics), the codified literature being the guidance provided via the algorithmic transmission of a published donor selection algorithm. The practitioner described how they and colleagues at the transplant centre will ‘go through the boxes’ (observation notes, APPG September 2013), starting at the top and working downwards. They explained that the decision must take into consideration issues of availability, access and cost. I asked the participant to expand on this point in their presentation during an interview.

If you have a good matched adult or a good cord that’s fine. When you get to the mismatches, you see on the hierarchies you’ve got these choices ... you can use a mismatched unrelated ... you can use a mismatched cord. They’re all on the same band. (Participant 1)

Here, they describe the hierarchy. ‘A matched adult or a good cord’ is the ideal situation. But ‘when you get the mismatches’, that is – if you cannot find a matching family donor (an MFD, as the tables refer to it), the practitioner has ‘got these choices.’ Referring back to the hierarchies reproduced above, we can see how the clinician is talking about the *1st* choice, an MFD or a matched UCB unit. If neither of these options from the family is available, the next most preferable choice could then be considered. In this scenario, there are other options ‘on the same band’. Thus, the practitioners working in this hospital refer to this hierarchy and may *still* have to make a choice between an 8/8 matched unrelated adult donor or a 6/6 matched unrelated UCB unit. These hierarchies, like the algorithm, are tools of clinical decision making. Importantly, though, the quote reveals the centrality of choice *within* these seemingly rational tools. Berg and Timmermans similarly argue that the seeming order imposed by a tool like a transplant centre hierarchy actually *compels judgement*. They write that ‘logic has to be complemented with judgments devoid of rigorous calculation,’ (2000: 53) as if the more *rational* register of selection must run parallel to a different, perhaps more affective, repertoire.

6.3 Clinical Comfort

Given the contingency of archival use as it is so far emerging, the challenge of what Harris calls ‘archival outreach’ wherein collections workers ‘reach out to users and create new users’ (2002: 150) comes into sharp relief. Alongside tables of recommendations – both nationally and in hospitals – are the people who are using them. Each practitioner is a person, each having to make a decision for their patient in the face of circumstances peculiar to the given situation. In an interview, the practitioner who presented the transplant centre hierarchy at the APPG reflected on why, as is noted in the SCSF report (2010b: 73), some transplant centres are less likely to use UCB in HSC treatments.

We were quite slow to use cord. We used different sources. We used mismatched adults and parents, but just lately we’ve got much more into cord ... we’ve found new properties of cord that actually we think give us advantage over adult cells ... we have a lot of research going on around that as well. ... 2010 we did more cord transplants than adult, from unrelated donors. So that was very unusual for us ... different centres like doing different – and they’re better at doing – different [HSC sources]. (Participant 1)

In this quote, the interviewee attests that using a lot of cords was very ‘unusual’ for their transplant centre. But the shift in practice that they describe demonstrates that the status quo *can change*. In this account, we see how knowledge transfer thus need not be algorithmic, occurring through the traditional channels of output (Collins, 2012). To ‘think’ there is an advantage is, according to this practitioner’s reflection, sufficient for practices to transform. In the local setting, there has been a gradual ‘slow’ shift in practice in which UCB begins to be more frequently chosen and used. The research does not have to be published, but can be ‘going on.’ Indeed, Knorr (1979) argues that standard procedures such as publication are too slow for scientific practice. As Collins and Evans put it, ‘scientific knowledge takes a long time to make and therefore scientists are often pressed to make authoritative decisions on technical matters before there is an consensual knowledge on which to base them’ (2007: 8).

In addition to this, though, the different transplant centres will ‘like’ and be ‘better’ at using different HSC sources. The practitioner notes that at their transplant centre, clinicians have ‘got much more into cord,’ a phrase usually reserved for developing an interest in a new topic or hobby. It implies an almost Bourdieusian sense of taste in which one might *get into* hip-hop, *get into* yoga, *get into* the history of the Plantagenet kings. The account of this practitioner where they explain that one might *get into* cord bespeaks how preference works its way into a seemingly objective hierarchy. Broadly speaking, the archive itself is a noted space for the expression of taste (Good, 2013; Liu, 2007). But what we see here is slightly different. There is an affective register of ‘liking’ and ‘getting into’ that runs parallel to the rational register of standards and hierarchies that determine whether use is made of these selective collections. In this context, it is important to consider some of the consequences of the ‘parasite’ of locale-specific decision-making (Berg and Timmermans, 2000: 55) which, as we are beginning to see, incorporates elements of preference that sit uneasily with the move towards standardisation. The quote below comes from an adult donor registry administrator.

[A practitioner’s] experience will in some cases determine your outcome ... if you’re not a centre that does cord, or that has experience in doing cord, and if you’re not willing to gain the experience that you need or whatever – should you be sending your patients to other places to have their treatment done? ...people use terms like “postcode lottery”, but there is an element of that. You know, you’ve been doing this, you’re working on this, and I’m sure in your head, if I were to get leukaemia, where would I want to go?
(Participant 2)

In this participant’s account, transplant centres are bounded spaces in which only certain options are available. One hospital might not be ‘a centre that does cord’. The practitioners there may not ‘do’ cord. In this administrator’s view, the choice to do cord or not necessarily delimits the options available to patients receiving treatment at the centre. This produces, suggests the participant, a ‘postcode lottery’ in which some patients are referred to a centre that ‘does’ cord whilst other patients are not. This censure on particular options could, according to the same interviewee, have

quite remarkable material effects on the conclusion of your treatment. This is a point taken up in the 2010 inventory strategy report, where a graphical representation of the concentration of transplantations across the UK is mapped out for adult and paediatric recipients (UK Stem Cell Strategic Forum, 2010b: 73-74). These are reproduced immediately below.

Figure 14: (below) Adult transplant activity in the UK in 2009 reproduced from Stem Cell Strategic Forum report (2010b)



Figure 15: (below) Paediatric transplant activity in the UK in 2009 reproduced from Stem Cell Strategic Forum report (2010b)



A transplant centre's willingness to perform particular procedures could conceivably 'determine your outcome', as can be seen in these images that demonstrate how certain hospitals (equipped with the personnel and facilities to undertake transplants) appear to be less likely to undertake UCB transplantations than others. The same administrator described how a transplant centre's preference for one treatment could affect patients in other ways.

We should be careful how we message that to patients ... You want people to think, to be like, "this is an option!" ... I've had people say to me, [despondently] "yeah, they found me a cord" ... people are disappointed by it! Because the message that's out there from the transplant centres is a little bit negative about cord.
(Participant 2)

In the account above, the interviewee explains how the preference of the transplant centre clinicians filters into patients' views on their own treatment paths. Rather than an excitement that an option has been chosen and an HSC source secured, the interviewee has had contact with patients who 'are disappointed' by the fact that a cord has been found for them. They explicitly link this disappointment with the transplant centres being 'negative' about cord. This disappointment in having to resort to cord as a clinician and receive one as a patient speaks to the inherently affective dimensions of healthcare provision as well as healthcare receipt (see Mattingly, 2010) and is lamented by this registry administrator.

When, at the beginning of this thesis, I asked you to imagine you had been told you were about die, I did not ask you to consider what your emotional response might be when told that your chance at life was stem cells from umbilical cord blood rather than an adult donor. But if your clinician was disappointed, it is feasible that by way what feminist theorists have described as a kind of affective contagion (Gibbs, 2002; Gorton, 2007) you would have been disappointed too. Given the recognised need for archivists to encourage the use of their archival materials (Daines and Nimer, 2011; Harris, 2002), the challenge of doing so extends well beyond trying to encourage the movement of UCB up a selection algorithm. Encouragement might even include trying to influence the affective domain of the 'negative' and 'disappointed'

sentiments of clinicians who must somehow transition into ‘getting into’ and ‘liking’ cord.

As was explored in the introductory chapter, data from the first clinical intervention using UCB in 1988 were written up and published the next year (Gluckman *et al.*, 1989). The episode is used, as I am doing now, to preface most social scientific discussions of the use of UCB. This tends to done with little acknowledgement that the 1988 transplant was what might be called the thin end of the wedge. 27 years later and many practitioners who have the option of using UCB still do not. The 1988 transplant was *only one* clinical intervention. Though it is obvious, it is worth noting that just because *one* clinical team in *one* transplant centre was able to achieve a successful transplant in *their local context*, it did not then follow that every transplant centre in the world would immediately undertake UCB transplantation. The quotes below are from a scientist working in a public UCB bank in the UK and a patient activist working to explore gene therapy options for patients with a particular blood disorder. I had asked for their view on why some clinicians did not use UCB.

From the clinician point of view I think the risk was to try an alternative source of HSCs that was unknown, because bone marrow was the classic, the benchmark. (Participant 9)

Bone marrow transplant is still the preferred option because if you've got a sibling donor, it's a 90/95% success rate now. If it's unrelated donor, it's 80/90%. So at the moment that's far less risky than anything else. (Participant 14)

In the first quote, the scientist constructs UCB as an ‘unknown’, contrasting it against the ‘classic’ source of bone marrow. Given the existence of the ‘classic’, to step onto the *terra incognita* of a new technology would be a ‘risk’, a behaviour that one typically tries to avoid. The avoidance of risks, as we will later see, is magnified if the wager is one of life or death as it potentially could be in a clinical situation. In the second quote, we see a similar sentiment where ‘anything else’ that is not the ‘preferred option of’ bone marrow is ‘risky’. We might imagine, following on from this, that cord blood has emerged as – at best – an innovative and exciting new

technology in the blood malignancy treatment arsenal. At worst, though, cord blood stands to be viewed as an unnecessary risk given the prevalence and success rates of bone marrow technology. The accounts above demonstrate how the latter view has been prevalent.

This is not to say that cord will always be posited in this way. To demonstrate this it is useful to look back at the activist and the scientist's reflections above. Both of them use the term 'bone marrow'. Technically, this is a misnomer. As I touched upon in the introduction, adult stem cells are now considerably more frequently sourced not from bone marrow, but from peripheral blood. In 2009, out of the 812 stem cell donations sourced in the UK, only 13% were directly drawn from bone marrow, whilst 74% came from peripheral blood (UK Stem Cell Strategic Forum, 2010b: 15). Peripheral blood is often embedded in the term 'bone marrow', its own story of establishment black boxed in the process. The quote below comes from a policy maker with whom I had been discussing the willingness to invest state funds in a technology that might not be used.

The perfect example ... bone marrow kicked off in the seventies, then peripheral blood stem cells were available where the blood is collected from the donor's peripheral blood and that is the preferred option for clinicians who are looking for a stem cell source. So that transition happened. And then you've got cord blood, which is certainly not as established as either of those ... the same discussions were ongoing when peripheral blood stem cells started as well. Some clinicians wanted to stick with bone marrow, stick with a process they are familiar with and comfortable with.
(Participant 10)

The interviewee reflects on how there was a 'transition' from directly sourcing HSCs from an adult's bone marrow (a needle drawing tissue during a single procedure), to the use of peripheral blood where an extracorporeal aphaeresis machine removes stem cells from the adult donor's blood over a period of hours after the donor has taken a regimen of drugs understood to "draw out" stem cells from the bone marrow into regular circulation. Now, peripheral blood is the 'preferred option for clinicians'

according to this account (not ‘risky’, to use the term employed by the patient activist). However, as the participant points out, the ‘transition’ was marked by ‘discussions’. Try a new source (peripheral blood extraction)? Or continue to use a ‘familiar’ source they were ‘comfortable with’ (bone marrow extraction)? The interviewee suggests a similarity between that ‘discussion’ *then* and a cord blood/adult donor discussion *now*. Importantly, this policy maker states unequivocally that UCB is ‘certainly not as established’ as the adult donor sourcing techniques. The quote suggests that UCB, unlike peripheral blood, has not had its ‘transition’ yet, if ever it will.

There is something else important in this quote though that brings to life the importance of the various dimensions of clinical decision making that have been central to the chapter so far. This policy maker says that a clinician can be more ‘familiar’ or ‘comfortable’ with one technique over another. It is, they note, the ‘perfect example’ of what is happening currently with UCB technology. Clinicians want to ‘stick with’ a particularly technology (a term we might normally use for remaining faithful to a friend, or persevering with a carbohydrate-free diet), ‘stick with’ something they are ‘comfortable with’. Sticking to comfort, or – to use a different idiom – remaining in the comfort zone, is thus seen as an important element in the transition to a new technology and, more specifically, using the cord blood bank to engage with the technology. This obviously has implications for the use of the UCB collections in question here. Like a horse to water, you can ‘take the archives to the people’ (Harris, 2002: 148), but you cannot make the people use them. Tell every clinician in the UK that there is a well-stocked cord blood bank and, unless, they are comfortable with the technology, the bank will still not be used.

The affective repertoire enrolled in the above interview quote (the intimacy of familiarity and, in particular, the satisfaction of comfort) speaks to the ‘corporeal dimension of experience and sensation, response and reaction’ (Brown, 2015: 2) that has more recently come to the attention of those interested in the sociologies of affect and emotion. It is here, in this notion of comfort, that I suggest that we can really begin to understand use in the archival spaces in question here. There are different ways of understanding comfort. It is generally defined as a sense of physical ease. A person can be comfortable in *doing something* which also implies a lack of coercion.

That is, if you are comfortable with doing something, we can fairly assume your willingness to *engage in the activity*. Importantly, comfort can imply a preference too. One can be *more* comfortable doing *x* than *y*. There is also, perhaps, a moral dimension to comfort too. Is comfort something we are striving towards, attempt to preserve, or trying to move beyond?

Provided in a clinical setting, care is intended in part to bring comfort to a patient through the intimacy of the provider-patient interaction (Dowling, 2006). Indeed, much work has been done on the affective labour in such scenarios (Theodosius, 2008; Twigg, 2000). But in the context of the current study, it is interesting to explore how this affective register relates to engagement with, or *use of*, a clinical option. In the quote below, a scientist working in a public cord blood bank explained how UCB and bone marrow stem cells are used differently:

...people knew how to handle bone marrow. Clinically, it's a different way of handling. You need to train people in the clinical management of UCB transplantation. You cannot transfer the training immediately (Participant 9)

In this account, the scientist asserts that adult-derived HSCs and those from UCB both require 'a different way of handling,' highlighting the practitioner's manual labour in the process of transplantation. The practitioner must undertake a manual interaction with the cells, ensuring they are correctly managed before, during, and after entry into the patient. People 'knew' how to 'handle' bone marrow, but did not necessarily 'know' UCB in the same way. Knowledge would need to be acquired over time (it would, after all, be impossible to 'transfer the training immediately'). This scientist's reflections allude to the almost artisanal nature of cell transplantation. With this in mind, consider Harry Collins' discussion of the experiential vector of learning that is traditionally associated with craftsmanship but that is also important in the development of skills in scientific application:

The transfer of craft knowledge ... is a matter of acquiring skill. An apprenticeship, or at least a period of interpersonal interaction, is thought to be the necessary prelude to the transfer of skill-related

knowledge. This process rests on the enculturation model.’ (Collins, 2012: 323)

Enculturation is crucial to the transmission of scientific knowledge and complements codified, algorithmic transmissions like published guidelines. And yet it is not usually associated with scientific practice but with skilled craftsmanship. There is, then, some precedent to what I am laying out here about what Brown (2015: 2) calls the ‘corporeal dimension of experience’. This is the messy context of tacit knowledge and scientific application (Collins, 2012; Collins and Evans, 2007). Like the tinkering scientist (Knorr-Cetina, 1981), clinicians must develop knowledge (and, perhaps, comfort) through actual experience and practice, a point noted in the Sociology of Health and Illness literature, wherein the quotidian practice of clinical labour is inflected both by a technical component and the indeterminacy of clinical judgement (see Pope, 2002).

In this context, it makes sense that a practitioner might become more or less comfortable depending on the outcome of their use of the clinical option, and begin to use the technology more regularly. The adage *practice makes perfect* rings true here. Training with UCB means learning to *use* it, and use requires a patient. A transplant clinician might use UCB for the first time, and an unfavourable outcome (lethally acute graft-versus-host-disease, for instance) might put that clinician off using the treatment again. For instance, one interviewee connected poor outcomes with a clinician’s choice to adopt UCB technology.

It comes down to “well, I used cord before and we had difficulty. These are the difficulties that we had with it.” And that’s not based on experience of 50 cords. It’s experience of the one or two that they’ve used. And how can it not! They are people after all, whether we believe it or not. (Participant 2)

In this account, we see the participant make a clear case that ‘experience’ is what use ‘comes down to.’ If a clinician used a cord for the first time and ‘had difficulties’ (which we might read as an adverse effect for the patient) it makes sense to this participant that the clinician would be reluctant to take up the technology. How, the

participant asks, can that experience *not* have an influence? They make a point of the practitioners' personhood, as if to say that it makes sense for us all to be influenced by our experience. Karin Knorr-Cetina reminds us that social reality and sense making 'in no way stops short of the natural sciences' (1981: 434). Indeed, it is as much the internal, personal experience and material engagement with a technology as the professional standards that rank, order or otherwise classify it that will determine whether the practitioner will be comfortable enough to use it.

Conversely, a first positive experience might make the clinical option more appealing. For example, the quote below comes from an administrator involved in developing the SCSF recommendations in 2010, and refreshing them in 2014.

...subjective clinician preferences ... some [clinicians] are very, very happy to use cord blood and some that actually would never use cord blood... (Participant 18)

In this quote we see an explicit mention of 'subjective clinician preferences'. Practitioners, as subjects in a social world, have to learn from their personal experiences as we all do. Some will be 'happy' to use cord, like some of us might be 'happy' to drive a car. Others would 'never use cord blood' just like some of us would 'never' work in the hospitality sector. Just to demonstrate how important subjective experience is, we can turn to the archival lens. The clinical practitioners are informed by their own experience, just as the archivists are. In the archival profession, for instance, there is discussion about whether archivists themselves are led by a sort of archival intuition developed through working with archives and learning how to operate within them (Duff and Fox, 2006; Treffeisen, 2003). Cook calls this the necessarily 'culturally bound ... socially conditioned and subjective' practice of archiving, another physical practice not of learning how to handle stem cells but of learning how to select for storage, preserve and then retrieve (2011: 178).

What emerges is an understanding that a pivotal aspect of the growth of UCB technology's popularity rests with clinicians. Like us all, they have preferences that manifest in being more comfortable with certain options and less comfortable with others. We can think of this in terms of *clinical comfort*. An individual's level of

clinical comfort can be seen to have a recursive effect in the use of UCB and, thus, the collection that holds it. The account of a UCB scientist, below, speaks to this point.

Yes it's definitely the clinician view ... you can see where people are comfortable in using them, and they've got experience. They get better results. (Participant 7)

Asked about the uptake of cord in the UK, they equivocally cite 'the clinician view' as central to the use of UCB. The interviewee draws a relationship between experience and success. Those who use cord regularly 'get better results,' which echoes the sense that the skill is one of enculturation, or slow acquisition. Of course, if it requires sustained use to develop those results, it follows that this would render uptake of emerging technologies less appealing. This is because, according to this interviewee, one has to 'get comfortable' to get positive treatment outcomes (and negative treatment outcomes equate to patient death or remission). In the 2010 strategy report for the UK's stem cell inventory, a similar point is made about the complexity of what the authors call a 'centre effect' which is explained in the extract below:

'...a large portion of [2009 allogeneic transplant] activity was concentrated in a small number of transplant centres: 27% of allografts were performed by the four most active centres. ... There is increasing evidence that centres performing a higher number of complex transplants achieve superior outcomes when compared to centres with low levels of HSCT activity ... Recent data identifies this effect to be particularly marked in recipients of cord blood transplants ...' (UK Stem Cell Strategic Forum, 2010b: 70)

The data that they have suggest a relationship between frequency of using a particular technique in a centre, and the patient outcomes of that centre. This relation, they note, is 'particularly marked' in UCB transplantation. Interestingly, though, there seems to be less recognition of the individual clinician within the centre and their personal experience of using a particular stem cell source in treatment. A

different interviewee expanded on this dimension in a discussion about clinician preference that again takes up the notion of comfort in the clinic.

And that's down to clinician preference... what they think works for them best... A lot of it all boils down to expertise. What we do know [is] there are 32 transplant centres, of which I would say about ten use cord on a reasonably frequent basis. So what are the other 20-odd doing? They're not using cord, so they don't ever, ever have a problem finding an adult donor? It boils down to their clinicians aren't comfortable using cord, are not convinced about the case for cord ... A maturity of outcome data is going to be published this year ... once that gets published, we'll see greater infiltration of cord. (Participant 8)

In this account, the interviewee notes that out of 32 transplant centres in the UK, only ten 'use cord on a reasonably frequent basis.' They link this uptake of the technology, which they imply is quite low, with a singular causal factor. 'Clinicians,' they maintain, 'aren't comfortable using cord.' The implication of this is that with an *increase* in comfort, UCB might stand to grow in popularity as an HSC source and thus, the use of these UCB collections might increase. Importantly though, as this administrator points out, it is not the archivists themselves that will produce a 'greater infiltration' of UCB, a word that evokes a sense of very gradual percolation, but the release of data. Certainly archives might try to disseminate information about their own holdings to encourage use (Eastwood, 2006) but much more weight in this account is given to the comfort clinicians have (or, in this case, do *not* have) with UCB. 'It boils down to', we might say, a lack of clinical comfort.

6.4 The Archive Responds

Clinical comfort might develop through practical, personal experience with a clinical option, but it also engenders the recursive effect of the experiences of others, filtered through outcome data, that might bring confidence to a clinician taking her first step onto the unfamiliar terrain of UCB technology. Of course, until some are willing to take up the technology and produce these data, those who rely on the data to choose

new clinical options will not be swayed. If the archivists want their collection to be used (Kaplan, 2002), then learning how to influence clinical comfort is surely integral. One scientist who works in a public UCB bank described a situation in which they tried to convince a clinician simply to enter a search request:

I remember with [UK hospital] with [a transplant clinician], and I remember [they] mentioned [they] have a patient, “she needs an urgent transplant, I cannot find another donor.” “Look, [same clinician], I have 1000 cords waiting there for your patient. Probably one of them is there, why don’t you do a search when you have an urgent patient. And [they] did, [they] didn’t find a cord from us – OK, that’s fine. But since then [they’ve] started doing both searches. Adult and cord at the same time. And if [they find] a cord, [they do] a cord. (Participant 6)

In this account, the scientist describes an experience in which a practitioner was compelled to search for cords because of the lack of any other source. The scientist recounts their conversation, explaining how they encouraged the practitioner to search through available cords. They did, and ‘since then’, they have started considering the option. Now, the scientist recounts, ‘If they find a cord, they do a cord.’ This reflection illustrates how the practitioner’s clinical comfort with UCB increased such that they transitioned from never using UCB as an HSC source to making it a mainstay in their repertoire of treatment options. In this quote, though, is a sort of moral warrant to incorporate UCB and push, we might say, past the clinical comfort zone. In asking, ‘why don’t you do a search’ the participant essentially asks this clinician to take the risk of doing something they would not – given the existence of a more comfortable option – do.

Unnecessary risk-taking has connotations of foolhardiness, irresponsibility, and an inability to regulate the self (see Lupton, 1999). Often, though, risk beyond ‘the “comfort zone” and familiar territory’ can be read as an attempt at ‘movement and progression’ (Lupton and Tulloch, 2002: 117). Risk taking in the quote above is a chance to move beyond the boundaries of convention or standards, to potentially save the life of the patient who ‘needs an urgent transplant’ and who has no other

avenue. In the earlier quotes where any option that was not bone marrow was ‘risky’, this was a scenario where bone marrow was an available option. But what if it is not? What if there is only a choice between a UCB unit and nothing?

It is in posing the new option to a clinician that we can see a kind of *challenge* to the clinician to move beyond their comfort zone. Consequently, they are impelled either to try the new option, or make a kind of confessional admission that they are too comfortable to move, as if in a kind of techno-stasis. It is at this fork in the road where the risk is the choice that use stands to be made of the UK’s UCB collections. To refer back to the colourful diagram at the start of the chapter, it really does not much matter what the process of a UCB unit search is if the clinician never gets to the point where they make a ‘SEARCH REQUEST’. This is, perhaps, what Mbembe means when he writes that ‘however we define archives, they have no meaning outside the subjective experience of those individuals who, at a given moment, come to use them’ (2002: 23).

One might decide to use UCB, then, but which UCB unit should one use? Perhaps unsurprisingly, the same selectively that emerges in reference to picking a treatment option is still there when that treatment option has been selected. As I have suggested throughout this chapter, the use of its material is central to any archive. It is important, however, that the analysis of how the umbilical cord blood bank comes to be used is not cast simply as a normative indictment of clinicians to stretch themselves beyond their comfort zones. Archival theorist Kaplan argues that many working in archives view their work as part of ‘a service industry’ (2001: 3). Archivists, she argues, do their work so that others are enabled to use the material that the archivists have collected. Given the preceding sections of this chapter it is perhaps of little surprise that the same subjective preferences that lead up to a clinician choosing to use these collections is still at play once the clinician is selecting from them.

Accordingly, with the remainder of the chapter I want to explore how these archival spaces are managed in response to clinician preference. In the quote below, a scientist describes how TNC has itself become a kind of point of clinical preference.

...it's complicated because different centres privilege different units and have different practices, really. So some think HLA first and then TNC, for example, and for others this is a different order. They want a big unit! ... They have a very, very high cell count and a 4/6, [rather] than a 6/6 and a lower cell count. (Participant 3)

Here we see how some transplant centre clinicians 'privilege' different units because they 'have different practices'. Some prioritise the matching level of the unit/recipient over the size (or TNC) of the unit. Others, however, have 'a different order'. They 'want a big unit' and this takes precedence over the match of the unit/recipient who might match at as few as 4 out of 6 loci if the clinician can ensure the unit is large enough. The words 'privilege' and 'want' in this account speak to the sense of preference or taste even at the point of unit selection.

With this in mind, I want to focus specifically on how these collections are managed in response to the prevalence of preference as a caveat of archival use. To make this point I want to focus specifically on a single element of a UCB unit, its Total Nucleated Cell count (TNC) which is also referred to as its size or cell dose. By looking at the shifting importance of TNC in how the bank has been managed, we are able to see how those managing this collection – though reliant on the clinician to *try* a cord – must make important decisions to sustain the relevance of their collection for that clinician to keep returning to it. The below quote briefly sums up the connection between preference and use that I want to explore. It comes from a participant involved in the SCSF and the British Cord Blood Working Group.

...so how financially viable your bank is, is dependent on the quality of the units you store. So if you store tiny little units ... no one will buy them, because they'll buy big, better evaluated units. (Participant 5)

The bank's financial 'viability' – its very capacity to sustain itself – is thrown into question if all it stores is 'tiny little units' (i.e. units with a low TNC). According to this account, the uptake will be minimal because they will instead find a bank where they can get larger units. The point here then, is that a bank with larger units will be

better at sustaining itself. But this was not always the case. As might be suspected from Kaplan's (2001; 2002) argument that use is central to the archive, as TNC has become a more important factor in the mind of clinicians, TNC has equally had to become a central point in the practice of UCB banking. However, when scientists first began banking UCB in the UK in the mid-1990s, the factor of TNC had much less importance. The quote below comes from a scientist who works with the non-clinically viable units collected by one of the UK's public UCB banks.

I think at the beginning of cord blood banking, I think it was just a question of banking what you could ... everything was banked.
(Participant 7)

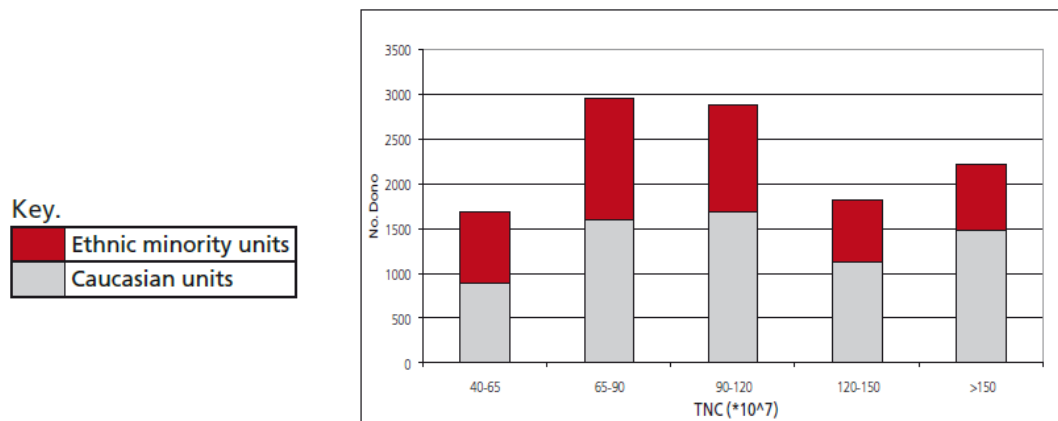
Whilst nascent banking practices ensured archivists were collecting indiscriminately by 'banking what you could' or banking 'everything', a much more defined kind of specific and selective practice of banking has since taken shape. As Featherstone (2006) notes, the archival gaze is a discriminating one, where the archivist's mandate is to find something of use to her users within the mass of matter. We have seen that usefulness is a central purpose of the archive. Likewise, the UCB collection exists to be of use to the practitioners trying to provide healthcare to patients. The archive acts as a bypass of sorts, to aid its user in retrieving relevant material more immediately. More specifically, when a practitioner does a tissue search and gets back the results, they see only what the bank workers made available to them. They are not privy to knowledge of which units were regarded as irrelevant, just as all users of archives are never privy to 'what archivists saw *before* the appraisal decisions were made to give researchers what they get' (Cook, 2001: 35, original italics).

In the Stem Cell Strategic Forum's 2010 report, the composition of one of the UK's banks⁶ as per its units' TNCs is laid out graphically (UK Stem Cell Strategic Forum,

⁶ In 2010, the UK's separate UCB collections were represented with individual data for the UK Stem Cell Strategic Forum report. The more recent collaborative alignment of these collections now means data is produced across the entire inventory. There are other

2010b: 34), then juxtaposed with another graph that demonstrates the pattern of TNC distribution across all *issued* units (i.e. those units that are *used*). These graphs are reproduced below.⁷

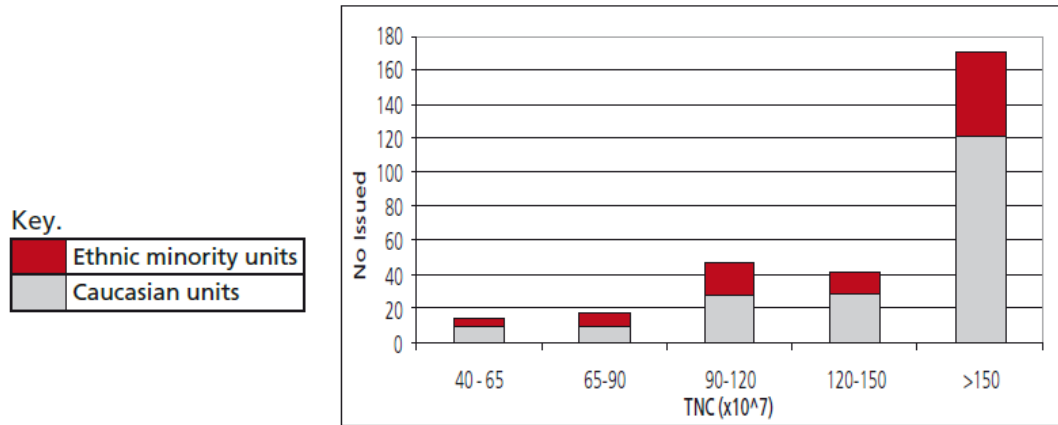
Figure 16: TNC of units in one UCB collection reproduced from Stem Cell Strategic Forum report (2010b)



institutionally beneficial reasons for this alignment which, though a digression here, I have explored elsewhere (Williams, 2015).

⁷ TNC is generally a large number and so is described in the scientific literature using integer powers. For example, $9 \times 10^8 = 900,000,000$. I note this because across different publications and documents, different scientists and policy makers use different integer powers. For example 90×10^7 , rather than 9×10^8 which are both the same value. For the sake of clarity here, I harmonise these different integers in any comparison, as in Table 4 below. However, it is interesting to note the move towards 10^8 in the documents considered here which might denote the industry's own attempt at numerical brevity given the coefficients being multiplied are getting larger as the threshold of TNC increases.

Figure 17: TNC of units issued from one UCB collection reproduced from Stem Cell Strategic Forum report (2010b)



As the second graph demonstrates, most units *issued from* the collection have a larger TNC count (greater or equal to 150×10^7 nucleated cells within the unit) whilst most of the units *in* the bank (to refer back to the first graph) fall below this threshold. Thus, the composition is not necessarily synchronous with the pattern of use. The report notes here that this pattern of use ('these data') should be used to transform how units are selected from bank inclusion:

'These data suggest that patients' needs are best met by banking only those units containing over 90×10^7 TNC. Additionally, all cord blood units containing over this threshold should be typed to high resolution for HLA-DR to assist transplant units in selecting the best unit for patients. Taken together, these changes should result in better overall utilization of cord blood units banked in the UK.' (UK Stem Cell Strategic Forum, 2010b: 34)

Because more use is made of larger units, those overseeing the collection should prioritise larger units. 'Only those units,' it is argued here, merit banking and being tissue typed at high quality so as to encourage clinicians to pick them and improve

the collection's 'overall utilization'. I suggest that what we see here is an example of the discriminating gaze at work. As in all archives, a decision must be made over what is worth archiving. This decision has various vectors, some of which were explored in the preceding empirical chapters around where and whom stem cells should be sourced from. In addition to this, there are yet more acts of selection that correspond more directly to the demands and preferences of clinicians. The discriminating gaze is apparent, for instance, in the maternity unit when collectors are deciding which, if any, collected cords should be sent on to the bank. This process is explained in some depth by a scientist who works with the research units that never qualified as 'clinical'.

There are steps before it arrives [at the processing laboratory]. Usually, we weigh the bag where umbilical cord blood has been collected because we know now that the weight is a good indication of whether or not that umbilical cord blood will qualify ... We always weigh it, because we know 120g is about the threshold where it's probably going to be clinical. So let's say it's 100g or 90g – it's definitely not going to be clinical. It's not possible, so those already, they're going to be diverted because ... they're going to be research units and not clinical units. (Participant 3)

The increasing importance of cell dose (or TNC) is clear in this person's account. Here, they describe how the physical weight of the collected unit is a first point of judgement that the matter must pass through on its way from the 'profane realm' (Groys, 2003: 179) into the selective realm of the collection. Weighing it is now something 'we always do' because 'we know now that the weight is a good indication' of the unit's perceived viability. One might see what Osborne calls the 'archival reason' (1999: 58) in this quote. Some matter is 'isolated out of the mass of detail and accorded significance' (Featherstone, 2006: 594) whilst the remainder is sent to the research scientist. The below quote comes from an interview with a collection co-ordinator who manages a group of cord blood collectors. I had asked if they recalled any change in the acceptable unit weight threshold since beginning their job in 2010.

Oh gosh, yes. Several times. When we first started, I have a feeling ... it was anything over 70 or 75g was considered to be clinical. Then it changed to anything over 90g was considered to be clinical. Or 100, I can't remember. Then it went up to 125. So, yes. Absolutely. ... It's always changing. (Participant 11)

In this account, the collection coordinator describes a scene in which collectors must be ready to transition their practice in accordance with collection criteria that are 'always changing' (read, always increasing). As the threshold for a UCB unit changes, collection practices must respond. There is an implication of increased selectivity in the account. They note that early on in the operation, 'it was anything'. The bank was far less discriminating. This is similar to the earlier account from the scientist who describes a scenario where 'everything was banked.' In what might be seen as a move away from an anything/everything mentality, archival practice demands that archivists quite literally *weigh up* their decisions. The threshold of weight, as the above account demonstrates, has changed so many times that it was a struggle for the interviewee to actually remember what the thresholds have previously been. Why, then, has the threshold of TNC risen so much? In the exchange below, I had been discussing the TNC threshold with a scientist working in a public UCB bank.

Participant 9: One of the things that is becoming clear is you need a really large TNC content....

RW: You've raised it to 140?

Participant 9: Yep.

RW: That decision, how was it made?

Participant 9: It was made on the basis of what people are actually selecting. Transplanters want large units.

As the quote suggests, the managers of the collection make their decision on what to incorporate (the criteria for admission in this archive, we might say) based on what clinicians ‘are actually selecting.’ As such, if the transplant clinicians want higher TNCs, it is incumbent on those managing the collection to provide that. They must build the collection around user requirement or their units will not be selected. The quote below comes from another scientist working with the non-clinical units sent to one of the public UCB banks.

*...now there is an incentive to go higher and higher. So for example ... the threshold was ... 120 ... then it changed for 150 ... because now we know that you've got a better chance with that cell number for the cord blood unit to be picked for transplant.
(Participant 3)*

The scientist’s reflection reveals their understanding not only that user requirement will change, but that it stands to become more fine-grained. The filter of selectivity will permit less and less entry, because the weight threshold is increasing. As such, those managing the collect of UCB are following practitioner preference (i.e. recognising what is more likely to be ‘picked’). In this account, the scientist shapes this in terms of an ‘incentive.’ This might be economic, for if a unit is ‘picked,’ the unit is also sold. But the notion of incentive speaks broadly to a compulsion to move forward, to spur on the project of collection. This resonates with archival theorist Kaplan’s assertion to the profession, ‘respond we must, or face irrelevance’ (2002: 218). Perhaps unsurprisingly, then, the increased centrality of TNC as a point of utilisation can be noted in the comparison of the initial Stem cell Strategic Forum report (2010b) and its refresh in the 2015 Stem Cell Oversight Committee report (2015)

In the 2015 ‘refresh’ of the UK inventory’s strategy, units in the inventory are ‘graded’ in terms of their cell dose. These grades, *A*, *B*, *C* and *R&D* (research and development), denote the borders of the quality of a unit as laid out below. The act of grading perhaps represents a solidification of the importance of TNC (recall in 2010 that units were not ‘graded’ but simply grouped by their dose).

- Grade A donations: post-processing cell dose $>19 \times 10^8$ TNC
 - Grade B donations: post-processing cell dose $14-19 \times 10^8$ TNC
 - Grade C donations: post-processing cell dose $9-14 \times 10^8$ TNC
 - R&D donations: post-processing cell dose $<9 \times 10^8$ TNC
- (UK Stem Cell Oversight Committee, 2015: 46)

Quite explicitly, as in the table below, these ‘grades’ are linked to their ‘annual utilisation’ (2015: 25). This is not dissimilar to the 2010 report shown earlier in this section, where a relationship between unit use and unit size was clearly expressed.

Figure 18: Utilisation of the UK’s UCB according to TNC and ‘grade’ reproduced from Stem Cell Oversight Committee report (2015)

Inventory segment	Post-processing dose ($\times 10^8$ TNC)	Donations banked	% annual utilisation	Use
Grade A	> 19	1,288	3%	Clinical inventory
Grade B	14 – 19	3,446	1%	
Grade C	9 – 14	8,907	0.2%	
R&D	4 – 9	9,038	0.01%	Research inventory

Notes:

1. Shows inventory composition and utilisation rates as at January 2014.
2. Banking of donations containing less than 9×10^8 TNC (pre-processing) ceased 2011.
3. Banking of donations containing less than 14×10^8 TNC (pre-processing) ceased 2013.

Here we can see how more use is made of Grade A (3% of this section is used) as compared to Grade B or C (1% and 0.2% respectively). The table notes too that particular potential units (those below certain TNCs) ‘ceased’ being collected between 2010 and 2013, which serves to exemplify how the discriminatory gaze of collection practices has transformed since 2010. Notice too that there are more of the less desirable units (R&D and Grade C), and fewer of the more desirable ones (Grade B and Grade A). As the qualifications of quality increase, a unit is less likely to meet them. It is particularly interesting, in this respect, to compare the TNC boundaries between the two reports, compiled in a table below.

Table 4: A comparison of the 2010 and 2015 brackets of TNC grading

Stem Cell Strategic Forum report (2010a, 2010b)	Stem Cell Oversight Committee report (2015)
>15 x10 ⁸ TNC	>19 x 10 ⁸ TNC
12-15 x10 ⁸ TNC	14-19 x 10 ⁸ TNC
9-12 x10 ⁸ TNC	9-14 x 10 ⁸ TNC
6.5-9 x10 ⁸ TNC	<9 x 10 ⁸ TNC
4-6.5x10 ⁸ TNC	

These classificatory borders (Beer, 2013) of TNC have shifted considerably since 2010. The two extremes here are particularly telling. The *top* selection of cords must now meet or exceed the threshold of 19, whilst in 2010 this included anything from 15 and over. The *lowest* grade in 2015 would not include any units equalling or below 9. Excluded here are many of the units that *would* have made the cut in 2010 (4-6.5, and 6.5-9). The comparison of these documents thus demonstrates the shift in archival inclusion to accommodate ‘utilisation’ by the constituency of clinicians that make up the user group.

6.5 Conclusion

Use in these archival spaces, as I have argued in this chapter, cannot be reduced to a simple flow chart of forward-moving interactions. Indeed, one of the key things I have attempted to point out here is the contingency of the UCB collections in question here being used at all. So much goes into the decision of whether a tissue search request is issued for a UCB unit, and both clinical standards and personal clinical preferences are seen to have their role to play. We saw how standards are produced to rationalise clinical use of HSC sources, providing a consensus from which all clinicians can move forward. These standards, though, are malleable as the people producing them acknowledge that there will always be the need to change standards in line with new clinical developments. I suggested that this raises important questions for these archives, in that if clinical decision making standards are always potentially changing, these collections’ contents are likely to have to

change too. This is an issue I take up more fully in the next and final empirical chapter.

Importantly, though, whilst these standards exist, the parasite of locale-specific decision making (Berg and Timmermans, 2000) thrives, and different hospitals and the clinicians in them stand to circumvent standards. The discussion here centred on how the corporeal dimension of clinical application – ‘getting into’ or getting ‘better’ at ‘doing’ cord – could lead to a sense of ‘comfort’ with the technology. The other side of the coin, as we saw, was that many clinicians are *not* clinically comfortable with using cord, have never trained in the manual application of the cells, and see it as an unnecessary risk when more established sources are available. These affective and rational registers of decision making are key in how these collections come to be used. I offered the example of Total Nucleated Cell (TNC) counts to bring this point into relief. The archivists have moved towards larger units expressly because those are the archived matter being used more often. The UCB archive, like Mbembe (2002) notes of all archives, thus operates (and therefore can only really be defined in reference to) the demands, preferences and subjective experiences of those who come to use it.

Critically, though user expectations (Conway, 2010) inform the composition of any archive, the complexity of the collections under examination here perhaps exemplify a difficulty encountered in maintaining a collection that is to be scientifically useful. These transitions in TNC are the by-product of the movement of scientific theory (inflected, as we have seen, with clinical comfort). These transitions, inevitable in their nature, are inherently problematic for collections managers. Bowker reminds us, ‘the measurements that are made now are necessarily constrained by current theory’ (2005: 177). Theory changes (in our case, the issue of TNC) and a whole array of practices must be adapted, meanwhile a whole array of archived matter is jettisoned into uselessness because of its meagre hopes of ‘utilisation’.

Chapter Seven: Risk and the Archive

7.1 Introduction

In this final empirical chapter, I want to move beyond chapters four and five where we considered how the UK's public UCB collections are ordered and exclusionary, and beyond chapter six, the previous chapter, where we considered how use comes to be made of them. Building on the discussion of the last three chapters, I want to focus on how these archival spaces, in a way, are protected from the risks that face them. Those risks take different forms, but highlight the importance of the temporal dimension of all archives and, indeed, of technologies more generally. The starting point of this discussion is the risk of obsolescence. That is, that the archival content is at risk of becoming irrelevant as the criteria of value – a unit's clinical viability – change around it.

Tying in the reflections of STS scholars around the notion of path dependency and path creation (Garud and Karnøe, 2001; Kemp *et al.*, 2001) this discussion endeavours to highlight the way in which those working with these UCB banks actually conceive of the space and attendant practices as generational. What, I explore, is the difference between a first- and a second-generation umbilical cord blood bank? Furthermore, what does this conceptualisation tell us about the recognition of a need to respond to the changing external demands of archive users? It is out of this exploration of the very temporal risk – change in user requirements – that is inbuilt to any selective collection of material, a risk that also speaks to the concern that a technology can potentially become 'locked in' (Garud and Karnøe, 2001) or 'irrational' (Rip, 1995) that the chapter moves forward.

Risk in these archival spaces takes on many forms, not all as potentially abstracted as 'obsolescence'. Other more obviously material risks are faced by those working to protect its relevance as it moves forwards, inevitably, into the future. Building upon Derrida's description of the archive writ large as a domicile for the selected matter, guarded by those in charge against the physical risk of destruction, I think more explicitly about how these UCB banks might become spaces of guardianship. How are these collections managed to ensure they are protected from, say, a flood? What

mechanisms are in place to ensure the archive's continued resilience? It is important to explore this because it highlights the eternal concern held by those working across archives about being able to respond to that which is yet to come. As such, the chapter ends by demonstrating how the future is central to the archive in the way archivists plan strategically through regular review and constant oversight of the broader field in which they and their collections exist. We are left, at the end of the chapter, with a clear sense that these archival spaces – as selective collections of matter deposited and retained in the past and present – are, as Derrida (1996) notes more generally of archives, irreducibly experiences of the future.

7.2 The Risk of Obsolescence

We have seen so far that the dominant model of understanding UCB transplantation technology has undergone regular and significant transformation. As Arie Rip reminds us, the development of technology is not a process of continuous, linear accumulation of functionality. He contends that it is more akin to a patchwork quilt. 'The eventual shape of a technology ... can be very different after 5, 10 or more years than it looked at the beginning' (1995: 418). How the developers of technologies facilitate development, and how they escape 'lock-in', to use Garud and Karnøe's (2001: 31) provocative term, is important here, and is brought into sharp relief in the context of umbilical cord blood banking. Relevant factors emerge, and preferences and comfort coalesce and then transform in response. The regularity of change (but not its direction) can be seen as inbuilt into the standards and practices of the field, as we have seen in accounts so far. I want now to consider more explicitly what the implications of this might be in terms of the archival practices of collection management. The quote below is taken from an interview with an administrator working in a public UCB bank in the UK.

...it seems like every six months something new comes along which almost makes you almost redefine your strategy on how you're going to proceed forwards. And because it's quite a rapidly changing landscape it requires you to be on your toes... and a lot of assumptions that maybe we had just five years ago have been a little bit blown out of the water. (Participant 8)

In the participant's reflection, the field of UCB technology is described as a 'rapidly changing landscape', not unlike accounts in the last chapter that described it as an 'intrinsically dynamic scenario'. Findings can, in the words of the interviewee, blow assumptions 'out of the water,' suggesting not small changes, but potentially seismic recalibrations in the way things have to be done. Indeed, in the account, these new discoveries force those overseeing the banks to 'almost redefine' their strategy, as they move into the future. There is, as Borup *et al.* note, no 'neat slope of enlightenment' over time (2006: 291). Given the likelihood that change will come rapidly, workers in these archives must remain 'on their toes', remaining alert and ready to spring up and move at any point. This is particularly telling in the environment described here. The archival workers must always be vigilant to change. There can be no prescribed path for a technology, as this would not capture the unpredictability of users' and developers' expectations. What is asked of those working in these collections is that they make their collection ever relevant to the present, a reflection that Bowker makes more generally of contemporary collations of data: 'What is being demanded of the dataset is precisely something which over twenty years of science studies have shown cannot be asked of the scientific paper - to stand outside of time' (Bowker 2005:177). The requirement of heavy maintenance is like a regular rewriting of an old journal article to keep it up-to-date.

This point is echoed when considering the issue of incorporating a new HLA allele into the processing of newly collected UCB units. In the account set out below from an interview with a scientist working in one of the UK's public UCB banks, they describe the need to incorporate the typing of HLA-C into the measurements taken on all new units.

But every two years cord blood banking is changing, because cord blood transplant is changing ... [Senior staff] who are not science people ... I told [them] we need to do this ... Why? Because it's changing and we need to change. We need to move with how things are going on. ... I remember, in 2009 ... I heard [leading UCB scientist] from the NMDP [the American 'National Marrow Donor Program'] talking about HLC-C and still we don't have consensus about doing it. And in her last talk, 4 years after, she's still saying

HLA-C is important ... and still there are banks that aren't doing it. (Participant 6)

In this reflection, the scientist overtly says bank workers 'need to move' – that some 'still' are not transitioning their practices in accordance with the early signs of a shift in transplantation practice. Two things in this quote combine to demonstrate an interesting point here: firstly, the interviewee had to convince their senior management about the value of this anticipatory act of moving ahead of the curve. Secondly, many other bank workers have 'still' not made their own move. There is evidence here of a consonance with Bowker's findings regarding updating biodiversity databases. He argues that the more information about data one provides in order to make it useful, the more work is required. And yet, as he notes, 'people will not see it as a good use of their time to preserve information about their data beyond what is necessary to guarantee its immediate usefulness' (Bowker 2005: 116).

This interviewee's reference to a compulsion to move is telling though. Because the technology is changing, those working with the collection 'need to change'. Some within the industry (this interviewee included) see these steps for future usefulness as a necessary act in the present or, in Rip's parlance (1995), a currently irrational act that will be at some point become rational. The scientist's account paints a lack of movement as anathema. Simultaneously, what Garud and Karnøe might call path creation (as opposed to 'dependency') becomes the standard. In such configurations, those involved in working with the technology over an indefinite period of time may 'intentionally deviate from existing artifacts and relevance structures'. Though inefficiencies may be the immediate product in the present, such deviations are 'required to create new futures' (Garud and Karnøe, 2001: 6). As we saw in the last chapter, standards around the clinical selection of UCB are designed in the knowledge that they may need to be 'refreshed', or changed in reaction to new data and practices. This 'reflexive' practice (Timmermans, 2015) can also be located in archival practice itself. What we see in the above quotes are descriptions of literally reflexive practice, the reflex of being on one's toes, or needing to 'move with how things are going on'.

One might argue, then, that there are resonances here with Bowker's (2000) argument that the notion of a perfect archival system is itself chimeric if only because, as he explains elsewhere, 'the measurements that are made now are necessarily constrained by current theory' (2005: 177). The technology behind this archive's existence is prone to change, and archival workers sense the need to redefine, or change their archival practice in response to that. What is evident in these two quotes is how much the two participants seem to *anticipate* the requirement of change, as though it were written into their job descriptions. The latitude to absorb change, rather than be somehow *perfect*, seems to be the aim here. Capturing system perfection is unrealistic, indeed nonsensical given that change is an accepted and central feature of the practice. This is most apparent in the collection managers' requirement to move away from previous iterations of their collection practices. For example, the quote below comes from an interview with a scientist who played a role in setting up Anthony Nolan's bank in 2006.

[Anthony Nolan's UCB bank] started in 2006 ... the NHSBT cord blood bank was already in existence. Barcelona cord blood bank was also in existence. It was the bank I created in 1995. We said second-generation because at that time, all the learning curves of the first banks were already there. We knew at that time that the cell dose was more important than at the beginning we thought.
(Participant 16)

The participant's description of a 'learning curve' speaks to themes that appeared in previous chapters where UCB is cast as an emergent technology about which much is still to be learned. The notion that a UCB bank could be 'second generation,' suggests that the practices of collection management today were essentially born of the discoveries made in the course of managing the collections in the past. In establishing their second-generation bank, those managing the collection were equipped with the knowledge that had emerged since 'the beginning'. This resonates with the point that began to open up at the end of the last chapter. That is, the practices of managing the UCB collection must respond to the TNC preferences of the practitioners who might use the collection. To be a second-generation bank obviously infers that there would have been a first-generation of banks preceding it.

RW: OK, so what would a first generation cord blood bank be?

Participant 6: They were doing very low units with very low number of TNCs from their units. They were not testing all the virology panel diseases that they need to do as we are doing.

In this exchange, the scientist describes how the practices of first-generation banks were incomplete. The manner in which this participant places first-generation practices in the past ('they were not'), as compared to the second generation being placed in the present ('we are doing'), speaks to the idea that practices in the field are indeed changeable. The term is also used by another scientist who currently works in the bank.

We are what you would call a second-generation cord blood bank. We have learned how to process, how to test the samples, and have high quality units. ... In the past, they were doing it at 6 and now they have realized that HLA-C has an impact on transplant.... We have always been doing this for clinical grade... Because we've started as a second generation cord blood bank, knowing what they were doing wrong in the past and learning the lesson and thinking ok, "if we do this, if we do that..." (Participant 6)

In this account the notion of 'learning', present in the other scientist's account above, reappears. The scientist's choice of words is telling of their view that there is a need to enrol, and build upon, the knowledge of the past. The scientist explains that 'we have learned how to process' units, as compared to 'in the past.' Similarly, the scientist suggests that second generation bank workers are 'learning the lesson' from what has been done 'wrong' in the past. Waterton describes archives as epistemic time machines, not because the matter derived at one point is suspended from the ravages of time, but in the sense that archival spaces are 'built on some kind of guesswork, some faith, that we are doing this right, that we are entrusting and laying things and meanings that will be interpretable and meaningful in times to come' (2010: 649).

Waterton's point comes into relief in the account above. For instance, the scientist implies that 'if we do this, if we do that' then these collections can almost stave off making the errors of the past – of avoiding 'lock-in' (Garud and Karnøe, 2001). This speaks more broadly to Garud and Karnøe's point about the criteria which establish a technological artefact's value. In this case, the quality criteria of UCB 'do not lie in a marker that is an overall arbiter of what is good and bad, but instead, become endogenized as a pattern of stabilized relationships within an emerging technological field' (2001: 8). Relevance, put simply, is produced *alongside* the technology.

In the context of relevance's contingency, there are implications for archival practice. Even if the seemingly correct decisions are made in the present about what the collection should preserve, no archival content has guaranteed permanence. The relevance of material, along with its worth and its importance, are contingent. As Featherstone puts it, archival matter 'travels backwards and forwards between ... rubbish, junk and sacred' (2006: 593). Matter considered of worth at one point might transition into worthlessness at another. The salience of this point is not lost in collections of UCB. We have seen that collection workers conceptually divide temporal shifts of banking practices into different iterations, or 'generations' of bank. The generation of a UCB bank is, as we shall see, seen to have a direct connection to the relevance of the material stored in it. The quote below comes from an interview with a scientist involved in setting up one of the UK's public UCB banks.

Participant 16: At that time, the international standards of cord blood banking including donation and processing were edited ... This means that the first generation banks have a lot of units that are not useful for transplantation any more.

RW: But might they become useful again?

Participant 16: Maybe not, because the regulation also changed ... For instance now, we consider mandatory ... an integrally attached segment to the back in order to verify the identity. There are many units at the beginning that don't have this attached segment, so this means that this unit may not be any more useful

for clinical transplantation. Just as an example... the Japanese cord blood bank has erased 20,000 units of their inventory because they don't fulfil the licensing criteria ... approved [by] their Department of Health.

In the above exchange, the scientist explains that many units saved by first generation banks are no longer 'useful for transplantation'. The reason the participant gives for this is because standards were 'edited.' Because of this change, units can be seen to 'travel' (using Featherstone's terminology) from useful to useless. The participant offers an example from Japan. Some twenty thousand individual units have been 'erased' because they no longer 'fulfil' particular criteria that have since been put in place. This obviously raises interesting questions, explored elsewhere by Tupasela and Stephens (2013) about what happens to material in tissue banks when the institutional arrangements around it break down or change. Though a worthy digression, it is more pertinent to the current discussion to ask what situations such as the Japanese cord blood bank can teach us about the practice of UCB banking. One of the most crucial elements of this discussion is that it is the *criteria* rather than the UCB units themselves that change. This is an important point, which speaks directly to the archival countenance of the umbilical cord blood bank. Archival content is not meaningful simply because it is in the archive. It is meaningful in reference to the externality that the archive intends to serve. Another scientist working in a public cord blood bank refers to a different bank as another example.

*So for instance, in Barcelona. I think they have 17,000 cord blood units, but they are working with four- or five thousand, because the others are so old that they are totally obsolete. And if someone requests ... these obsolete units, they're going to need to re-do tests on everything because they don't meet the current standing.
(Participant 6)*

In the quote above, the scientist offers an example from Barcelona rather than from Japan, but the issue is similar. Less than a third of the bank's inventory (this bank, it is worth point out, is referred to by a participant in an earlier quote as a first generation bank) is being 'worked with'. The remainder is 'totally obsolete'. Again,

the units are ‘so old’ that they can no longer be used. But their age is not an intrinsically unattractive element. Rather it is the data that had been initially collected about them that will not suffice. The bank would be required to ‘re-do’ tests, because though they may once have met a previous version of viability, they do not meet the ‘current’ one. The temporal dimension (the ‘old’ versus the ‘current’) is central to the usability of all archives. Brouwer and Mulder argue that value is determined in how archival material can be utilised in the present, ‘in its operationality’ (2003: 5). What has been operational once may not always be. In Rip’s words, ‘what were rational decisions in the context of the time may become historically irrational’ (1995: 419) and the continuing relevance of a technology can hinge on its developers’ capacity to move past these temporally contingent irrationalities (that is, to avoid irrational path dependence).

Japan and Barcelona serve as demonstrations of how archival practice must be responsive. Even by ensuring the transition of practice, there is no guarantee that matter saved in a given archive will move with the practice of the archivists. In the case of the Japanese units, it is too late and the units must be ‘erased’. In the Barcelona bank, they will have to ‘re-do’ tests on two thirds of the units should they ever be called upon. In the quote below, the scientist was expanding on the reality that some public banks have had to remove portions of their inventory because the units have, for one reason or another, become unusable.

...the established cord blood banks have a responsibility to monitor the quality of their units and also to do a clearance of their units that don't fulfil the criteria of safety and potency.
(Participant 16)

For those creating the paths of technology, there are no benchmarks that ‘flag the outcomes of an exploratory act as mistakes’ (Garud and Karnøe, 2001: 8). The participant in the previous chapter who described how ‘everything was banked’ when banking was a nascent practice did not know then what was known now. In the account above there is a suggestion here that bank workers have a ‘responsibility to monitor’. This is a charge or a burden of their position. Monitoring (and the management, guardianship and reflexivity embedded in that sentiment) is the *raison*

d'être of the bank workers. An attempt to monitor the rationality or operationality of the collection. As the chapter has already considered, this monitoring can take the form of 'erasing' sections of an inventory as in Japan. The quote below comes from a participant involved in the APPG. They reflect on this issue in the UK context.

...a lot of the cords that were banked in the early days of cord blood banking ... are not really suitable now... we've already got quite a big inventory in the ... cord blood bank but the proportion of that inventory that is really suitable for transplantation is much smaller ... what we're doing now is we're doing a very careful housekeeping exercise of looking at the units... we've started off with the units which are red cell-replete. They were processed in a different style a long time ago and those units are now commonly, have been, associated with some serious adverse events in transplantation. Cardiac arrests et cetera. So we're starting out looking at those. (Participant 8)

In this extract, some units are again seen to travel from useful to useless: those 'banked in the early days... are not really suitable now'. As we saw earlier in the chapter in the example of Barcelona, there is again a description of a 'proportion' of the banked units being 'suitable for transplantation'. What was once rational (collecting smaller units) is no longer considered to be so. The rest, they explain, requires some kind of 'housekeeping', which speaks to the idea that the archival space is one of domiciliation – a 'house arrest', as Derrida (1996) puts it – in which the archival workers are essentially managing a space, running a household (i.e., allowing it to move forward). The red cell-replete units are the first point of consideration in the housekeeping exercise in which they essentially appraise the inventory. The issue behind these units, which have gone through a different kind of cell reduction during initial processing and thus have a high dose of red blood cells came to a head in 2011 (two years before the above interview took place), when two leading UCB scientists published a response to an emerging controversy around this particular feature which is exhibited in many early UCB units. In their published response, the authors note a statistically significant incidence in a study of patients who had received a graft with a unit that was red blood cell-replete.

‘recipients in whom one unit of a double-unit graft was RBC-replete exhibited infusional toxicity that was of clinical concern. Subsequently, multiple severe or life-threatening infusion-related adverse events occurring at other centers using unwashed RBC-replete units have been reported to the National Marrow Donor Program (NMDP). As patient safety is of paramount importance, this prompted a detailed analysis by and subsequent alert from the NMDP in 2009 recommending the wash of RBC-replete CB products as a prudent safety measure while the investigation of these events was conducted.’ (Barker and Scaradavou, 2011: 480)

Appraisal, as Cook notes, ‘is the theory and methodology for determining the value of archives – which records should be kept and which ones should be destroyed’ (Cook, 2005: 102) or which units should be left in the freezer and which should be ‘erased’ as an earlier participant termed it. We can, then, think of housekeeping as a form of archival appraisal that aims for the reduction of redundancy through the disposal of ‘uninteresting records’ (Bearman, 2002: 328), the records that clinicians would have no interest in because they are red blood cell-replete, and thus would be thought to cause adverse effects. These kinds of housekeeping or appraisal ensure these collections run efficiently. Archival matter might be ‘weeded, reconstructed, or even destroyed’ (Cook, 2001: 26) as a direct result of the fact that things once perceived to have a potential use value are no longer deemed to. Archives are populated in response to users’ ‘information needs’ (Schwartz and Cook, 2002: 3), which I explored in the first and second empirical chapters. These needs are heavily contingent. If a given archive pivots around them, those in charge of it must be ready for change. This means that the whole archival experience is one of flux. The fear of obsolescence, of outdatedness or irrelevance is, as we have seen, a key element in the rhythm of these collections.

Appraisal is the articulation of archivists’ power. In appraisal it is decided ‘what will be reflected in archives, and, as starkly, and with finality, which will not’ (Cook, 2005: 103). Discarding is definitive – particularly the UCB unit which cannot be put back into the freezer. It must be maintained at that temperature or lose its potency and, with that, its regenerative capacity. As such, one must be *sure* that there is no

potential use in the unit. In Japan, they did not fulfil safety legislation and as such could not be accepted for transplant because this would be an infraction of the law. The red cell-replete units above need to be *considered*. Workers are ‘looking at’ those units, as if to seek out a reason to keep them. In Terry Cook’s analysis of appraisal in the archives of the Government of Canada, he notes the view of the leading archivist towards appraisal. Archivists ‘must attempt to anticipate needs ... must find means to pass judgement on the probable value of source material’ (Lamb, cited in Cook, 2005: 111). The general rule underwriting this practice, as Cook argues, is that one must be sure that discarding is the only option: ‘If in doubt,’ he writes, ‘keep it!’. The exchange below follows on from the quote earlier in this section in which the participant explained that they were undertaking a housekeeping exercise in which they were ‘looking at’ the red blood cell-replete units.

RW: Will the cord units with lower TNCs [lower stem cell doses] be discarded in this housekeeping exercise?

Participant 8: They wouldn’t be discarded. We wouldn’t discard them because they’ve got HLA characterization and occasionally they do get issued ... and saying “those units which are under a certain cell dose we’ll discard or issue for research” then we’ll start looking at other ones where we’ve got a lot of the same but a low cell dosage in terms of HLA type if we’ve got a common HLA type... We don’t want to get rid of fairly unique HLA types or uncommon HLA types and dump those even if the units are fairly small because, paediatric transplant, you know.

In the quote above, the administrator describes a fairly ambivalent relationship between these collections and their low-dose units. Units that have a smaller dose of stem cells are, as we have seen, less likely to be chosen. But that *decrease* in chance of selection does not mean that definitively they would not be selected. When they come to doing this appraisal (‘we’ll start looking’ – it hadn’t begun at the time of interview) the judgement about whether to discard these units will partly rely on the rarity of the HLA type. This speaks to themes that emerged in the second empirical chapter around what Groys (2003) calls the ‘formal dissimilarity’ of archives where

rarity is valuable. Importantly, they would not ‘dump those’ units because of the possibility of paediatric transplants that do not require the same large doses as adult patients who generally have larger body masses.

As we have seen, archival theorists have claimed that there is an intuitive sense called for in the act of appraisal. Archival theorist Booms (1987) calls this *fingerspitzengefühl* - a ‘fingertips feeling’. This notion captures the idea that archivists are in general knowledgeable enough about their users’ current requirements and, to an extent, future users’ capacities that they can judge the potential worth in the archived matter. This echoes the last chapter’s consideration of the discriminating gaze (Featherstone, 2006) around making choices in relation to current clinical selection criteria for UCB units. This is evocatively summed up by Bowker who notes that contemporary archives

‘require an act of imagination on the part of the record keeper to place him- or herself in the position of any possible reader.... In essence, the record keeper is being asked to abstract the record set out of the historical flow or time – to provide enough information so that an limnologist from Mars... can come along and, from the data set and a sufficient command of English, interpret the data’ (Bowker 2005: 177)

Bowker is speaking directly here to the temporal dimension of judgement, of trying to make decisions *now* that will have relevance *in time to come* – to a limnologist from Mars, or (more likely) a clinician who possibly has not even been born yet. The archive’s contents wait for a ‘constituency or public whose limits are of necessity unknown’ (Osborne, 1999: 55). The constituency’s technological limits may expand significantly beyond the imagining of the archivist who lodges the matter in the archive. Old state intelligence documents produced in one political milieu might be read through a thoroughly different lens in another (Lynch, 1999). Biological matter saved with a particular purpose in mind might be the object of different research interventions at some future point. In the quote below, I had asked a participant about the future of lower dose units in the UK’s public stem cell inventory:

...there's a point to be made around future technologies allowing for stem cell expansion which are quite expensive at the moment, but no doubt over time they will become – they will develop them – so that they are more affordable. That does bring in to play, then, the lower dose units as well. (Participant 10)

In this interview extract, the policy maker explains that ‘future technologies’ which will ‘become’ economically feasible technical options for the low dose units that are currently unattractive to clinicians. This technology which currently exists, but which is ‘quite expensive’ will become ‘more affordable’ and ‘bring in to play’ the units with small TNCs. This point is echoed in the latest strategy report:

‘It has been predicted that a 4 fold expansion of stem cells in cord blood donations would allow the majority of banked donations worldwide to be used for adult patient transplantation ... candidate technologies for ex vivo graft manipulation are emerging. The potential to utilise low dose cord blood donations to improve patient outcome is significant...’ (UK Stem Cell Oversight Committee, 2015: 39-40)

The kinds of words used here in 2015, ‘predicted’, ‘emerging’, ‘potential’, suggest that this technology is, though anticipated, still some way off. But it might be suggested that what we see here in the interview extract and the policy documentation is a recognition, however implicit, of the *possibility* that there is a window of usefulness that stands to be (re)opened for these smaller units that stand to travel back out of obsolescence when technology finally permits such a return to usefulness.

Interestingly, this is not only a problem for the UCB bank. The continual risk of obsolescence informs the practices of adult donor registries as well. Old archival content has to contend with revised standards of practice, new techniques, and emergent methodologies. As Cook puts it, the ‘history of the record is a never-ending, dynamic process ... always being reborn, reimagined, reinvented’ (2001: 35). Take, for example, the idea that units stored in the 1990s might have to have

tests re-done if ever they are called upon. Adult donor registries have existed for a much longer time, and face a similar risk of obsolescence. The quote below was taken from an interview with an administrator at one of the UK's public adult donor registries.

For a lot of people on our register, the data is quite old. They would've joined twenty years ago. And obviously tissue typing capabilities are better now than they were twenty years ago. They're a lot better now they were five years ago! Or even two years ago! ... They get better all the time, and we're always trying to improve the tissue typing that we're getting from people.
(Participant 2)

This administrator describes a similar scenario to the ones set out in the quotes above. Like old units, old adult donor data have been collected and managed according to the capabilities of the time when they were stored. Those donating twenty years ago were tissue typed according to the typing technologies of that era. As the administrator says, contemporary tissue typing techniques have changed. That is, the quality and specificity of the typing that can be done on a stem cell. 'They get better all the time.' In response to this perpetual technical advancement, the registry workers must also adapt their practice in perpetuity. They are 'always trying to improve the tissue typing'. There is also an equivalent to 're-doing' tests on old UCB units in the adult donor archive.

...there's a judgement call as to whether you ... go back and re-type older donors ... It's which ones you go back to. You might want to do the rarer ones, or the ones maybe you've got in contact with to make sure they're still engaged with the process and would want to go. (Participant 10)

This quote describes how registry workers can 'go back and re-type.' This retrospective typing could mean that the volunteer donor is called in to have further tests as a means of updating their data. Once donor samples have been re-typed, they are no longer outdated. Of course, as we have seen, it need not take long for a unit or

a donor to pass back into obsolescence, travelling ‘between the known and the unknown’ (Featherstone, 2006: 593) as techniques further improve. Re-typing essentially brings meaning, or context, to older data which otherwise would, to use Bowker’s phrase, ‘rot away in some “information silo” for want of providing enough context’ (2000: 646). Without this interaction, the data remain unusable ‘legacy data’ (*ibid.*: 662) that speak only to outmoded criteria. Navigating this conundrum in which a ‘judgement call’ has to be made about *who* to re-type is necessary because it is expensive to type somebody. The registry workers cannot, with their limited resources, re-type everybody. Even if resources were *unlimited*, it would be a Sisyphean task to do so anyway, as typing capacity is in a constant state of change, swiftly rendering data outdated.

The registry workers can exercise judgement about who it might make the most sense to re-type. As the policy maker suggests, it might make more sense to approach ‘rarer’ donors. From this, we might infer minority ethnicity adult donors. Or perhaps it would be better to approach those who have already re-asserted their continuing desire to remain on the registry after volunteering potentially years ago. Again, this speaks not simply to a discriminating gaze in these archival spaces, but to the importance of temporality and the drive to avoid lock-in that marks these elements of archival judgement. Without these judgements, the adult registry archive could slip into obsolescence quickly. It resonates with the discussion of the UCB bank above, wherein the managers of these collections of matter and of data must be ready to absorb the changes of the technology they are involved in. Derrida’s (1996) point that archives are never finished, but always in becoming rings true here. Adult volunteer donor registries and umbilical cord blood banks are collections that require anticipatory management. Without this constant consideration, their archival relevance stands to diminish.

7.3 Physical Risk

Protection from the lock-in of obsolescence has been central to our discussion so far. Derrida (1996) notes that the etymological underpinnings of the archive refer directly to the guardianship of space. Those in charge of the *arkheion* warded against risk to the collection of public records, policing entrance of users as much as the material

itself. The role of being a guardian of the archive means protecting the space from risk. So far in this chapter we have seen this concern with risk unfold in the umbilical cord blood banks in question, where risk might be enfolded into temporality itself. Technologies might advance, and matter and data in a given collection might become obsolete in reference to that. But the archive faces more material, physical risks too. Pickering perhaps did not mean what follows quite as literally as I present it below, but consider this quote from his book in which he explains how we must understand technology – like all things in the world – as part of a material environment.

‘Think of the weather. Winds, storms, droughts, floods, heat and cold ... One could not survive for any length of time without responding in a very direct way to such material agency ... My suggestion is that we should see science (and, of course, technology) as a continuation and extension of the business of coping with material agency.’ (Pickering, 2010: 6-7)

Pickering’s suggestion that we think about how technologies and their developers engaged in ‘the business of coping’ is a good foundation on which to reflect on my fieldwork. Between 2012 and 2014, I had cause to visit three different sites where UCB is stored. One was a space where UCB units were processed after collection before being sent to the bank for storage. The others were cord blood banks proper, where clinically viable units are stored until a practitioner calls upon them or until, as we have seen, those units ‘travel’ *out of viability*. As Lynch notes, the archive is a guarded space (1999: 79). In my experience, this was literal. In one instance, a tall welded mesh fence stood between the building’s car park and me. On the first visit, the security guard telephoned the internal building to check that I was expected. On the second, I was recognised and permitted entrance through the gate (I was lucky, it was incredibly cold outside on that day). At one of the banks, I stood in the rain waiting for somebody to answer the intercom that got me to the foyer. Then I had to be escorted into a reception area. Suffice to say I received more interrogation at the door of the processing buildings than I faced on the several occasions I visited the police-guarded Palace of Westminster to meet parliamentarians.

I describe these scenes to emphasise the point made by Achille Mbembe. He reminds us that we cannot define the archive without acknowledging the building itself as well as the documents stored there (2002: 19). The use made of physical spaces is indeed key to understanding the way in which creators, workers and users interact with archives and the matter inside them (see Losh, 2004). As Derrida notes, ‘the very gesture which consists in keeping safe... is always... threatened by the possibility of destruction’ (Derrida 2002: 42). Put differently, the very existence of the UCB banks looked at here (and, indeed, those across the world) is because the units housed in them need to be suspended in particularly freezing temperatures without any risk of disruption to their regenerative capacity. Thus, their position in the freezer of the bank is always threatened by the possibility of their removal for some reason other than use.

Physical space, then, means everything in the material work of UCB collection management. The quote below is demonstrative of this, and comes from an interview with an APPG contributor. I had asked them why Anthony Nolan and NHSBT kept their banks separate from one another. This question was borne of my interest early on in fieldwork about the institutional interests that lay behind the Stem Cell Strategic Forum policy documents (UK Stem Cell Strategic Forum, 2010a, 2010b)

There’s an advantage in not having all your cords in one basket ... [a public UCB bank] had a flood. If we’d lost all of our cryo-storage vats – which we didn’t – that would be the UK’s stock of cord blood down the Swanee. (Participant 8)

To an extent, I had anticipated the participant to answer that the institutions had a financial interest in keeping their operations and resources separate. But in the account, the ‘advantage’ of having the cord blood banks in separate spaces is not financial. Here, the phrase having all one’s eggs ‘in one basket’ might suggest a risky cash investment but it is used here much more literally. The phrase infers that the delicate egg shells could all be destroyed with a single drop. The alternative, sharing the eggs (or ‘cords’, as this participant is suggesting) out between ‘baskets’ or banks, essentially shares that risk. They draw on the example of a flood that took place in 2012. One of the UK’s public cord blood banks exists in a larger blood processing

facility that ‘had a flood’. In the reflection, the participant ponders the conditional risk. ‘If we’d lost’ the cryopreservation facilities, ‘that would be’ the entire national stock of UCB ‘down the Swanee,’ a nightmare scenario. The flood prompted the institution to write a report about the incident. In it, the authors described the incident as a ‘potentially catastrophic event’ (Rackham and Lawson, 2013: 4). Reproduced below is an extract from the document.

‘...all power, data and telephony to the building was lost, resulting in the loss of refrigeration, monitoring, air handling and building management systems. The building had become unable to function as a blood processing centre.’ (*ibid.*: 5)

As the document explained, the flood occurred due to maintenance of nearby land rather than because it had been built on a flood plain. The document focused on ways that the organisation could ‘learn lessons ... which will serve to improve and enhance resilience,’ (*ibid.*: 4) with recommendations around chains of command in emergencies, and the clarification of outdated and vague protocols. The event, along with a similar incident in Australia, would form the basis of a case study article on ‘business continuity in blood services’ in the international journal *Vox Sanguinis* (Morgan *et al.*, 2015). That this event occurred demonstrates the logic behind the existence of the World Marrow Donor Association’s *Crisis Response, Business Continuity, and Disaster Recovery Guidelines* (Pingel *et al.*, 2012), published in the international journal *Biology of Blood and Marrow Transplantation*. The guidelines advise on the intricacies of the immediate response that its international member registries and banks should undertake in the wake of a crisis.

‘Here we provide general guidelines to WMDA members for the development of a generic emergency response plan to natural, human-caused, and technical-caused events that threaten the timely delivery of HSC products and essential related operations, as well as to raise awareness of the problem in general. These guidelines for the development of an organizational resiliency program should be viewed as a basic approach intended to assist registries wishing to

establish a new organizational resiliency program.’ (Pingel *et al.*, 2012: 1785)

‘Resiliency’ is integral in the management of HSC products. This must be resiliency to events of various kinds. Flooding cannot necessarily be predicted, but these collections must be prepared for it. Spreading out risk in the form of different banks can be seen, as the participant above suggested, as a form of resilience. The spatial context of banking becomes crucial. Not building near a river, but near enough to transport links to issue cells, whilst central enough that collection points can send matter in a reasonable time period.

In Derrida’s terms, choosing where to build the *archons* will have an impact on whether the *house arrest* of material can be effective. But risk can never be completely avoided. After all, once the unit leaves the UCB collection’s confines, it must face the same risks as any moving matter. In the quote below with a practitioner active in the APPG, we had been discussing the merits of a domestic supply of units. Though they suggested that there was an economic case for this, they argued there was also a ‘scientific’ case.

It would be very nice to have our own bank for our own patients. Scientifically, that would make life a lot easier as well because you’ve got easier access. Volcanoes erupt. You’ve got cords stuck in wherever they are... and you can’t ship it out. It takes too long. (Participant 1)

The 2010 Icelandic volcano eruption meant the plane supposed to transport that unit was grounded and the cord got ‘stuck’. The other courier option – shipping the unit – was unacceptable because ‘it takes too long’. As such, the proximity of the bank to the transplant centre becomes a vital aspect. Importantly, this quote demonstrates that whilst the ‘guardians of the register’ can care for the data, and whilst the workers in the UCB bank ensure the cryogenic freezers retain their temperatures in a flood, they can do very little once the HSCs have left the house arrest of their guarded, maintained archival spaces. The extent to which collection management can mitigate risk is inevitably limited by the unpredictable events that none of us can foresee.

Importantly, though, the *willingness* to foresee is central to the practice of collection management. We see this prominently in the discussion so far, but no more so than in the underpinning strategy that laid out the political mandate for what is a government-funded enterprise.

7.4 The Stem Cell ‘Refresh’

Star asks the question, ‘when is an infrastructure finished?’ (1999: 379). The archival infrastructure these chapters have considered is open to judgement, re-evaluation and determinations of outdatedness, irrelevance or insufficiency. As Bowker (2005) reminds us, the goal instead is an ability to anticipate change as much as can be possible. As the introduction and the first empirical chapter touched on, the composition of the UK’s cord blood collections has been developed in reference to the Stem Cell Strategic Forum’s 2010 report. In that report, it was recommended that the UK’s inventory of UCB across its public banks should comprise 50,000 units (2010a). As a scientist working with research units collected by one of the public banks explains below, the figure was based on an analysis of ...

...how big your cord blood bank needs to be to substantially increase the probability to find a cord blood unit ... for a patient.... It saw that there comes a point where – from zero to 15,000 – it really increased exponentially so there is a real benefit in increasing the number ... when you come from fifteen thousand to fifty thousand ... you still have a benefit of doing that. But then you need to increase so much the number of cord blood units to really make an impact on the patient, that it’s hardly viable at all... So that number is when it starts to plateau... There comes a point when it almost doesn’t matter how big the bank is. (Participant 3)

The study producing the figure demonstrated how a particular number of figures would ‘increase the probability’ of finding a matching unit. The improvement ‘starts to plateau’ after the 50,000 mark, and eventually the size of the bank ‘almost doesn’t matter’ because there is no longer a ‘real benefit’ – a phrase the participant uses twice here. The figure pivots around the notion of benefit. This benefit can be ‘for a

patient' but the figure must be 'viable'. If it is not, it is not practicable within the limitations of the technology. Those limitations might be technical, but they may also be economic. The participant below was involved in the initial study that recommended that the UK should have 50,000 units.

...using the matching criteria at that time in 2009, we observed that 50,000 donors were needed to offer a proper or a highly qualified donor to 80% of the population and that enlarging the inventory further has ... not returned sufficient new numbers of new match to make this project cost-benefit. (Participant 16)

The study demonstrated that an increase of the inventory to 50,000 donors would offer '80% of the population' an adequate match. Further increase would not return 'sufficient' match numbers to justify the project in terms of its 'cost-benefit'. The economic notion of cost benefit casts the judgement less in terms of direct benefits to patients, but within the resource limitations touched upon in the second empirical chapter. Importantly, though, as the quote above highlights, the study was based on the selection criteria 'at that time in 2009'. As the third empirical chapter explored, these criteria are heavily contingent. Regular changes in criteria have rendered the 2009 selection criteria out of date. An example of how changes in criteria have altered the relevance of the study's findings is the issue of level of match (i.e., how many HLA loci a unit and a recipient should be matched at). The quote below comes from a public UCB bank administrator who was explaining the limitations of the original study:

It was only considering 6-out-of-6 and 5-out-of-6 matching. We know from experience now ... that 4-out-of-6 does play a big part in this. When you look at the 4-out-of-6 profile, already the provision we've got in the UK, most of the population almost regardless of ethnicity will find a match, some sort of level of match. (Participant 8)

In this quote, the administrator explains that the initial study used recommendations that UCB units should be matched to at least five of the six HLA loci. Those units

that would have provided a 4/6, now regarded by many as suitable, were not included. Because 4/6 units are now considered to ‘play a part’ in meeting the UK’s stem cell supply goals, the many people in the UK population considered unmatched until the 50,000 unit figure was reached might have actually found a match before this goal had been met. As such, the entire basis of the 50,000 figure is now called into question. A scientist involved in this original study highlighted other areas where the study’s findings are now outdated.

The criteria basically has changed ... this was a study based only in HLA matching, not in cell dose. And the criteria is that ... matching on high resolution provides more chances of better outcomes. So this means that probably, this may affect the size [of the inventory], but still we have not been able to test that in a scientific study. (Participant 16)

Along with the level of match referred in the administrator’s quote, the scientist above notes that the resolution of HLA typing has changed. They assert that ‘high resolution provides more chances of better outcomes,’ a view that has emerged since 2009, along with the importance of cell dose or TNC (an issue explored in the previous empirical chapter). At one time, it was the point around which the UK’s public UCB banks were developed. Now, the strategy needs to be refreshed. As such, the whole archival strategy is one of flux, of repercussive and anticipatory movements. This is perhaps what Derrida means when he argues that all archives ‘take place’ (1996: 2). Archives can be thought of not simply as buildings but as spaces of anticipation. This might be anticipating abstract risks of obsolescence, material risks such as flooding, or the risk of moving forward with a strategy that has lost relevance with respect to professional and technological trends (Cook, 2001: 29).

How this change is directed has emerged as a contentious point of discussion that reveals the diverse political interests of the different people involved. Take as an example the quote from an interview with a scientist who works in one of the public UCB banks. Below, they describe the purpose of the section of the SCSF that deals with the UK’s stem cell supply.

We were discussing ... the operational cord blood stock that we want to have... if we need to recalculate this famous figure that we have of 50,000 cord blood units in the UK because it's not sustainable for a cord blood bank to have so many units because you need to collect so much to get this figure. Our clinical conversion rate is around 25-27% so per 100 units that we collect 25 are clinical so we'd need to collect loads of them to get this 50,000. (Participant 6)

The 'famous figure,' one that has found its ways into press releases, parliamentary debate and news items, is not considered 'sustainable' for a cord blood bank. The reason for this, they explain, is because of the amount of units the UK's public banks would need to collect to meet this goal. They describe how only around a quarter of collect units 'are clinical,' which is to say 75% of units collected could never qualify to be considered in amongst the ranks of the 50,000. As such the banks would 'need to collect loads' to meet this goal, using up the various resources they have to do so. The same scientist explained that a smaller figure would be more realistic, but noted that others (particularly clinicians) may not agree.

...we think that probably with 30,000 we will be enough ... Clinicians, always they are saying that still we need to collect too many, but this is from the clinical point of view. But from the cord blood business point of view – if we are funded by the government. Well it's really difficult because to sustain a facility like this with so many cords, it's not sustainable. (Participant 6)

Rather than 50,000 units, 30,000 'will be enough,' because any more would make a bank hard 'to sustain.' This viewpoint, the participant notes, is the 'cord blood business point of view.' By making reference to the source of funding, the participant's implication here is that sustainability refers specifically to economic sustainability. The participant notes that there is another point of view held by clinicians who 'are saying that we still need to collect too many.' The clinical point of view is effectively divorced from a business point of view via this participant's juxtaposition of the perspectives. The accounts below from practitioners involved in

the APPG and SCSF described their view on the size of the public UCB inventory. Their views mirror the ‘clinical point of view,’ which the scientist above is referring to.

Because we’re going to advise more stringent matching, that potentially would mean we need more. And so I think those figures are being re-looked at... 50,000 units may not be enough so we definitely shouldn’t say we need less than that. (Participant 5)

I think it would be much better if we have much larger public collection. Because actually we’re only using a very few percent of the cords anyway.... The safest thing to do would just be to have a big public bank. (Participant 1)

The first quote comes from a practitioner who contributes to the APPG and the SCSF. According to the first account, the recommendation of higher resolution matching at more HLA loci translates to the selection of units for clinical work becoming more fine-grained with ‘more stringent matching.’ From their view point, fewer existing units will qualify to this standard. Thus, they assert that 50,000 ‘may not be enough’ and that more would need to be collected to increase the chances of clinicians finding a match for a patient. The second quote, from a different practitioner, suggests that ‘much larger’ scope of UCB collecting is required to combat the fact that so few cords are clinically viable.

Ideally, having ‘a big public bank’ (notice, no figures here) would be ‘safest,’ presumably ensuring that more matches could be made. This is the perspective of somebody who does not work *within* the limitations of these UCB collections, but whose knowledge is clearest regarding the issue of trying to find matches for patients in an external capacity as an archival user. This last quote, which highlights the same issue as the banker (that most cords are discarded) takes the argument in a very different direction from the scientist. The scientist’s solution is to say that collecting more to try and combat this trend in which most units are clinically unviable is unsustainable because of the amount one would need to collect. This is informed by their familiarity with the practicalities of banking.

These different logics bespeak similar professional divisions we have seen elsewhere in the thesis – the bankers facing the limitations of their technology versus the clinicians whose interests revolve around their work with patients. This division between the bank and the clinic, as we saw in the previous chapter, reflects the different practicalities that the two professions face in their working lives. In the bank, collecting 50,000 cords – which was once a conceivable notion - now seems anathema given the criteria clinicians are using now that were not being used then. Meanwhile, there is a sense in the data that clinicians are invested in the idea of collecting as many cords as possible. More HSCs simply means more chances for matches for patients. Ultimately, these archive workers must stay a step ahead of their users and their current needs. As we saw in the previous chapter, this might be in terms of tissue typing the HLA-C loci that clinicians currently have no interest in, but may soon have. This can also be in terms of a broader strategy. Clinicians might disagree with the workers who manage these collections. However, these workers must be ready to serve tomorrow’s clinical need as well as today’s, all whilst labouring within the confines of their resource limitations.

The collection management strategy, which guides the workers’ goals and actions must itself be open to change lest it fall into obsolescence like a UCB unit collected in the 1990s and then left in a freezer for two decades, untouched and under-typed. In this sense, the strategy must essentially be future-proof. This is not to say that it must be so perfect that any future that befalls it would be manageable. Rather, it is to say that the strategy must have an inherent latitude to absorb the changes the future might bring. Future is unknowable, and so to an extent the strategy’s purpose is also unknowable, because purpose and use are *in the future*. It must be speculative. The exchange below comes from an interview with a participant involved in the World Marrow Donor Association. I had asked them about the shifting nature of strategies in stem cell donation and banking.

RW: Is there any way you could –

Participant 17: have an eternal strategy?

RW: Impossible?

Participant 17: I would say so! If you had an eternal strategy then you would know how the illness actually works. And basically then you would be in the position to say this is not the right treatment, or this is the correct treatment... [research] advances every year... and as a consequence you have to readapt your strategy.

A strategy that determined a route worth taking has to be ‘readapted’, an evocative word that speaks to the idea that archival strategies have to be malleable with the upcoming changes to the circumstances of their existence. The archive, then, is defined by the temporal dimensions that sustain it. As ‘an irreducible experience of the future’ (Derrida, 1996: 68), the archive is a selective collection of matter that is itself ‘in an eternal process of becoming’ (Waterton, 2010: 654). The participant above speaks to the eternality of becoming by explaining the impossibility of ‘an eternal strategy’. Indeed, this recognition is present the account reproduced below, where a policy maker describes the necessity of reviewing the SCSF strategy.

...we’ve asked for a kind of review, a refresh really, of that annex that deals with the 50,000 figure, the cord blood figure. Because obviously this work’s been ongoing for the last three, four years. We need to see what’s changed, because there has been a move globally to increase the quality of the cord blood samples that are collected. Increasing the cell threshold may mean you don’t need a bank as big as that ... The oversight committee is basically what the stem cell strategic forum became ... we’ve asked them to look at the data around that work to see what an up-to-date figure should be and what targets we should be looking at, and that will inform any funding decisions that we make going forward post-2015. So that’s pretty much under review, I suppose, at the moment. (Participant 10)

The policy maker in the quote above explains that the policy document that explicates the 50,000 unit figure is undergoing a ‘review’, or a ‘refresh’. They explain that the reasoning behind this is ‘to see what’s changed’ in UCB technology. Stasis is not on the table in this account, which resonates with a point made by Selin

that ‘technology can only be understood as becoming, as neither solely constructed, nor determined, but amid the conceptual territory of the two perspectives’ (2006: 125). The technology itself cannot be statically defined, as its very purpose and form stands to change. The policy maker above notes that the Stem Cell Strategic Forum has itself had a change of name. From the forum that produced an initial strategy, it is now an ‘Oversight Committee,’ which bespeaks a change in task to the continual monitoring of the strategy and the ability to come together and change that strategy. As such, in 2014 the Oversight Committee gathered to reconsider the initial strategy. The quote below comes from an interview with a senior person involved in the refresh after it had been completed, but before the conclusions been clarified in a single document (UK Stem Cell Oversight Committee, 2015). In the quote, they make reference to haplo-identical transplant where an HSC donation comes from a mismatched family donor (effectively, the donor is half a match, and the non-matched side is ‘deactivated’). The technique, they say, has attracted...

...a lot of interest but it's still a very niche procedure. About 3% of transplants, I think, are currently haplo-identical with really no long-term outcome data. And that which is starting to emerge is actually quite worrying. A lot of relapses four to five years out ... what we've said in 2014 is that we're going to seek continuity of central funding to expand the inventory to 30,000 units and then we're going to pause and review. And if haplo-identical transplantation is at this point proving safe and effective, it is quite likely that the demand for cord blood will diminish significantly and we wouldn't plan to push on to 50,000. If on the other hand a different scenario emerges in 2018 and haplo looks a less desirable option, then we would use the sales income derived from selling UCB predominantly overseas to drive the inventory up to 50,000. (Participant 18)

In this reflection, the participant positions haplo-identical transplantation as a technology that, if it gains popularity, could shift focus away from UCB technology altogether. However, because haplo-identical transplant has ‘no long-term outcome data’ and emergent data are ‘quite worrying,’ the de-seating of UCB is by no means

certain. Interestingly, then, the archival strategy is open to its own closure. If it loses relevance in a clinical context and they see ‘demand ... diminish significantly,’ the collection managers are willing to step aside. A similar point is noted in the 2015 strategy report, where it is mentioned that the committee

‘...has paid close attention to developments in the field of haploidentical stem cell transplantation. These donations, derived from partially-matched family donors, have the potential to reduce the requirement for stem cells from unrelated donors’ (UK Stem Cell Oversight Committee, 2015: 32)

The awareness of the potential reduction in user requirement for this archive is balanced out by a scoping out of different avenues for making the collection useful in new ways. For example, in the report, the authors lay out potential new regenerative medicine therapies that may eventually be made available to patients. Induced pluripotent stem cell therapies taken from adult cells, somatic cell therapies, and tissue engineered products were all recognised in the latest strategy report as therapies that might require adult stem cells and UCB (of which there is, as we have seen in this thesis, a ready supply) in the course of their production (UK Stem Cell Oversight Committee, 2015: 37). There is an implied scope here for the future of these current registers and collections. But even in its reflection on these future additions to the available regenerative medicine repertoire in the UK, the report plotted out the continued usefulness of the existing banks and registers in their own right:

‘In some ways the new generation of cellular therapies are likely to be the ultimate in stratified medicines in that, like [haematopoietic stem cell transplant] HSCT, a degree of immunological matching and tailoring of the clinical therapeutic to the condition of the patient will be required. It is important therefore that we continue to build on the panels of potential voluntary stem donors and cord blood donations in order to leverage the widest possible breadth of compatible regenerative medicine products for individual patients.’ (UK Stem Cell Oversight Committee, 2015: 37)

Here we see that, given the specificity required of these new therapies as ‘the ultimate in stratified medicines’, the current collections of HSCs through adult donor registration and UCB donations would need to continue alongside them to ensure that patients have access to at least one of this diverse array of regenerative medicine therapies that stands to expand in the future.

Derrida argues that ‘the archive is never closed,’ but rather ‘opens out into the future’ (1996: 68). The continued existence of these collections through the ‘continuity of central funding’, but also more generally in its attractiveness to current and future clinical users, relies on the collection managers’ willingness to reflect on its current state. These archives’ continuation also relies on archivists’ capacities to posit different possibilities in which their collections becomes more and less useful, anticipate what Deuten and Rip term the ‘contingencies of the innovation journey’ (2000: 70). If it is conceivable that the workers can adapt their practices to ensure their collection’s continued usefulness, then the practices will be pulled in that direction. For instance, electing to type particular loci, adopting new TNC thresholds, and removing old units collected when they were ‘rational’ (Rip, 1995) but now held in abeyance to make space for new ones. If it is *not* conceivable then those overseeing the collection must be able to admit this.

7.5 Conclusion

It seems fair to conclude, in the light of these discussions, that any archive’s continuation is at least partially reliant on its archivists’ capacities to mitigate risk in the various forms it takes. One of the big risks that the collections in question here face is that the technology they rests upon is – as all technologies are – in a constant process of becoming (Selin, 2006). One cannot know what an umbilical cord blood bank will be used for in ten years’ time. We see here how a rational decision in the past can become *irrational* in the present (Rip, 1995). It is, then, this dimension of temporality that comes to define these archives. Along with a temporal risk that can manifest materially (17,000 cord blood units, for example, that have travelled out of value and lost their status as archive-able matter), this archive faces other risks of a more immediately physical nature. The concern with resilience demonstrates the

guarded nature of these collections, these frosty domiciles for those valuable tissues whose preservation relies on the capacity of their archivists to keep them safe.

These points can be seen as a broader effort on the part of those managing these collections to absorb inevitable and largely unpredictable change (changes in the examples here were floods, new HLA alleles, or emerging regenerative therapies). This is a recognised need for an inbuilt capacity to create paths, lest the technology become dependent upon one path, and lose its archival relevance (Cook and Schwartz, 2002) or become locked in (Garud and Karnøe, 2001). This resonates with a point made by Bowker that, whilst ‘it is easy enough to develop a potential revolutionary technology... it is extremely hard to implement it – and even harder to maintain it’ (2005: 115), especially given the speed at which change is felt to occur in the accounts of those quoted in this chapter. In the face of the ‘interminable turbulences’ (Derrida, 1996: 18) of the scientific context in which these collections exist, cord blood may one day no longer serve a purpose, or may have to exist alongside a cadre of newly emerging regenerative medicine options

Risk, then, is not so much an unusual experience, or something negative to be avoided. Rather, risk constitutes the normal state of affairs for collections like these. It can take many forms, cannot ever be fully predicted, but can be anticipated and therefore be prepared for to an extent. Crucially, I would argue that what we see here in the UK example of cord blood is an example of the effective strategic management of risk. A publically funded initiative as it is, with a mandate to be available *to* that same public, it might be argued that there is a particular imperative for regular strategic consideration. Irrespective, perhaps, of this impetus, the case in point demonstrates the extreme importance of being aware of and prepared for (as much as anybody can ever be) the variegated changes faced by any collection that exists in a physical world for use by an unknowable future scientific constituency.

Chapter Eight: Conclusion

8.1 Introduction

Having engaged heavily in thinking about the future, and stressing its importance in how we understand the UK's UCB collections, it feels strange to now draw together the key points into an 'ending'. The context in which the research for this thesis began was dominated by the notion that collections of umbilical cord blood should be described as *banks*. This research has not focused on whether calling these spaces 'banks' is, in and of itself, problematic. Rather, I have suggested that it is useful to ask what we might be missing as analysts by using the term 'banks' when we come to analyse such spaces. More explicitly, I have argued that we would do well to steer clear of thinking of these spaces as though they engender some kind of inertia. By this, I mean that UCB collections are not simply a gathering of matter that does not change, save for the indiscriminate entry of new donations every time a person wants to put their UCB unit into the public bank. Yes, matter *is* aggregated. But its initial inclusion is highly mediated. It is variously informed by molecular understandings of what features of stem cells make them valuable to keep, or by whether stem cells are viable in the context of prevailing clinical preferences. By the same measure, matter is also removed when it no longer matches the transient status of viability, no longer merits the status, as Achille Mbembe calls it (2002), of the archive.

There are, then, two dominant points that I have tried to communicate through this thesis. One of these is the offering of a kind of inversion of the umbilical cord blood collection by highlighting a number of important elements within the UK's collections that have, in other accounts of public UCB initiatives, gone relatively untouched. The second point was to offer an in-depth use of the archival paradigm and demonstrate how worthwhile a tool it can be for those of us interested in a broad array of material and data collections. Below I offer a kind of synthesis of these key points, drawing out key critical threads from the preceding empirical chapters, highlighting their importance and contextualizing them as contributions to existing literature in the fields of Science and Technology Studies and other related areas such as the sociologies of health and illness, and of race and ethnicity. In an effort to bring coherence to a set of interrelated themes, what follows is ordered much like the

thesis – into four sections responding to the four empirical chapters. This exercise explicitly unpacks the *so what* of this thesis. What, I explore here, are the implications of what I have laid out in the preceding chapters?

I move on to reflect on the experiences of the last three years. In this period, I have become acutely aware of the contingency of social research. Issues of limited access to parliamentary meetings that I could only explore via luckily comprehensive minutes, the fortuity of having willing participants give so generously of their own time to talk to me when they operate in a field so politically, professionally and intellectually demanding of their energies. For this reason, it seems remiss not to reflect on *what if*, the various different directions this thesis might have taken and how the eventual turns I *did* take have limited the findings I can provide here. Finally, I am also interested in exploring the new issues brought into view and the different questions prompted by the preceding chapters. As such, I am interested in thinking about *what's next* and laying out explicitly what I view as important avenues for further enquiry that have emerged out of the substantive discussions of this thesis.

8.2 A Bank by Any Other Name?

In drawing heavily on the archival anatomy I proposed in chapter two, this thesis constitutes a shift from existing accounts of public UCB collection as defined in beneficent opposition to the private model of collection (Dickenson, 2007; Martin *et al.*, 2008). I attempted instead to think purely about the complexity of interests, knowledge and practices that comprise the black boxing of the ‘public’ UCB bank. I am not so interested here in telling everybody to stop using the word ‘bank’. This was not the intention of, or conclusion drawn from, using this anatomy. The worth of the anatomy and this analysis has been to use that lens to look for features of these collections that happen regardless of whether or not we call them banks. It would be superficial here to suggest my contribution is an attempt to popularise the term “umbilical cord blood archive”. Rather, what I hope to have done is generate a number of critical insights *via* that lens, which I want to unpack here.

What I offer here is an exposition of both what I have argued, and why I have argued it. A number of the insights hinge on binary tensions. For example, chapter four explored the relationship between the molar and the molecular characterisations of the individual self (Anderson and MacKay, 2014; Rose, 2007). What does this tension mean for the contemporary practice of UCB collection management, but also for its future? In its most racialised moment this molar/molecular distinction intersects with another binary that came into sharp relief in chapter five, that of archival inclusion/exclusion. As I explained in that chapter, these ‘public’ collections limit people’s access to donation through selective positioning of collection sites in areas chosen by funding delimitation and/or national ethnicity data, and extensive eligibility criteria on the part of individual women. I argued in that chapter that this challenged, at a very basic level, the communitarian ideal of public donation. In light of this, is it time to reconfigure our binary construction of the public/private division of stem cell donation?

Chapter six offered an account of how the UCB collection comes to be used. As well as the more rational register of recommendations and published consensus, a layer of what I described as ‘clinical comfort’ was also at play. This formed, I argued, an affective register of decision making. In the chapter, I argued that we needed to recognise that the collection’s usefulness can be managed in reference to how distant its matter is from this clinical requirement informed by that binary of the rational/affective. What implications, though, might this have for how we view clinical decision making more generally? In chapter seven, I described a number of issues at play in managing the UK’s UCB collections. These issues, which I argued could be viewed as *risks*, were various. The risk of destruction, the risk of obsolescence and the need for strategy to manage both these as the collection moves into the future. These vectors of risk and resilience are crucial, I argued, in understanding the contemporary UCB collection (and, indeed, collections of tissue more generally). As I explore here, this observation offers fertile ground for thinking about the focus and direction of future work in this area.

8.3 The Molar and the Molecular

The first empirical chapter, chapter four, focused on the establishment or construction of the UK's umbilical cord blood collections. It considered how they were aggregated and ordered, and uncovered an apparent tension between the binary division of the bodily, or *molar*, self, and the immunitary, or *molecular*, self. The findings here echo Nikolas Rose's (2007) argument that contemporary life is marked by an unstable ambivalence between our molar and molecular selves. We sit at a juncture where, with sufficient tissue samples from our blood or saliva, and some intensive computer-based calculations, you and I could feasibly determine whether our tissues constitute "a match". What this does for our sense of individuality and identity remains to be seen, but we can assume that the potential to know ourselves molecularly will only increase as the technologies that allow it transform. Might, then, one's awareness of her molecular individuality produce a kind of 'data double' or 'data self' (Lupton, 2012) that recursively inflects on her self-identity and behaviour?

I am prompted here to imagine two worlds. One is *molecular*, one is *molar*. In our *molecular* world, a next-door neighbour's stem cells might kill you, but a person living in a town you have never even heard of might offer the cellular similarity that makes your bodies compatible. Does one's molecular persona stand to obviate their other markers of differentiation? In our *molar* world, compatibility takes on a different guise. The bodies that can come together at a social level have been, and continue to be, policed by our genders, by our skin colour, or even our nationality. The occasional union of these different molar and molecular registers might be quite jarring. For example, Stefan Beck writes an account of the Greek-Cypriot child who received a stem cell donation from a Turkish-Cypriot man. Beck reveals here that the two parties live on either side of Cyprus' demilitarized zone. Their 'invisible "sameness"' (2011: 95) was made intelligible by HLA typing, and the two were then seen to share a kinship that penetrated and confounded the physical buffer zone between their respective political administrations.

Not every example of stem cell donation is quite so poetic in its transgression of the molar/molecular divide. But each occasion of an unrelated "match" demonstrates the

disjointedness between the molar and molecular registers as they exist today. And yet, the disjuncture is made messier still. As we saw in the introduction to this thesis, the immunological imaginary that bore the HLA complex and the articulation of molecular individuality, was enacted by scientists influenced by race as a molar way of knowing bodies. Thus, the development of the nomenclature of HLA happened in parallel with scientists' efforts to bring molar sense to this molecular style of thought (Rose, 2007). World maps, isolated indigenous communities, and migratory patterns were all brought to bear on how scientists would understand how HLA individuality worked in practice.

The outcome of that has been that the selective collections made possible by immunological knowledge are, confusingly, *constructed* by a molar register, but *used* by a molecular one. To the extent that ethnicity and immunological profile take on what I have described elsewhere as a metonymic quality of interchangeability (Williams, 2015), these different registers sit ambivalently as tools of order in the UK's UCB collections. Whilst such racialised classifications are seen only as an approximation of genetic diversity, they are still seen to be 'potentially useful' (Kittles and Weiss, cited in Rose, 2007: 159) for helping to order a social world in a scientifically salient way. To the extent that ethnicity is useful in the sense of encouraging donation amongst certain bodies, it is described as a luxurious, *secondary* datum next to the more specific and scientifically meaningful HLA type of the anonymous donor at the point of a tissue request. "Ethnicity data is nice to have", said one participant in chapter four, whilst noting that it is not really something they *need*.

Racial classification is frequently acknowledged in various archival practices. Why? Perhaps because archives are spaces that demand a certain amount of order, as Brothman (1991) contends. Archivists will tend to enrol familiar metrics for organising things. As Claire Waterton notes, archives seem to 'build upon deeply held, spatially segregated, cultural understandings of knowledge whereby certain forms of "raw data" are gathered "in the field," through experience of life and of the world' (2010: 648). Artifacts can be measured in centimetres, weighed in grams. Ethnicity is one such familiar ordering mechanism in these UCB banks. A good diversity of HLA types (which is the normative point of representativeness in this

context) is best achieved, in the view of those managing these archives, by enrolling donors of minority ethnicity. Ethnicity, the ‘racial register’, as David Theo Goldberg has called it (2014: 170), represents an intelligible point of reference for encouraging donation. As Goldberg reflects:

‘How easy is it to characterize someone as white or black, describing to a person you have never met whom they will be waiting for, what look to expect to find each other. The frontier of the skin becomes a default reference.’ (Goldberg, 2014: 174)

It is easy, as Goldberg argues, to characterise someone racially. It should, then, be little surprise that such distinctions are enrolled for a selective collection wherein some kind of order is required. But there is an issue here that I have not given space to in the thesis. The use of race here (at face value, at least) is to combat a supposed dearth of stem cells, to *ameliorate seeming inequality*. But should we not give pause to ask why it is that pre-UCB, adult stem cell registers have since the 1970s systematically failed to penetrate the communities they are now so intent on accessing? How did the practices and understanding that produced those collections of data compel the current demand for minority ethnicity tissue? I will return to this point, but think it is useful here to posit the possibility of a postracial archive.

How would collections managers organise stem cells differently if they stopped using race and ethnicity as cornerstones of accumulation and order? How would a collection’s composition be portrayed in a pie chart, for example, if the most salient datum were not a donor’s ethnicity? What if collecting the data were impossible (as in the case of France, where it is, as a participant in chapter four notes, illegal), or if all people’s HLA types were already known in advance (if, for instance, all people were all typed at birth, or if it were an obligation to place one’s data on a register). If ethnicity is but a luxurious datum when these collections come to be used, can we expect its grip on their ordering practices to loosen? Can we expect the capacity for molecular analysis to move the primary distinction of bodies away from racialised molarity? It remains vital to follow what continuing work ‘race’ and ‘ethnicity’, the obdurate lines of human differentiation, are being put to as these technologies transform.

8.4 Privation within the ‘Public’

The exclusionary dynamic of the UK’s UCB collections was the focus of chapter five. In this chapter, I outlined the different ways in which the titularly public bank is highly exclusive, allowing donations from only a fraction of the many women who give birth in the UK. STS scholarship, as I explained in the first chapter of this thesis, tends towards a binary characterisation of UCB collections as one of two “models”. They tend to be thought of as *public* banks (the kind of collections that this thesis has focused on) or *private* banks. The former, in most conceptualisations, is thought of as the more communitarian “model”. Women *donate* their cords *altruistically*, receiving no payment with the donated tissue being placed on a register that might be accessed *universally* by clinicians across the world. Literature interested in this iteration of banking focuses on the complexities of international exchange of UCB tissues, and in its position as the emancipatory opposition to the atomistic private model (Brown and Williams, 2015; Dickenson, 2007; Waldby, 2006).

In the private model, individual companies provide storage of UCB tissues on behalf of the *customer* who will then pay the company for *exclusive* future use of the tissue should it be required by a family member. As I mentioned earlier, the focus of this thesis has been in many ways an opening of the black box of the public UCB bank. The argument of this chapter is a challenge to the very notion of the ‘public’ collection. Indeed, on reflection I am perhaps more inclined to take issue with the word “public” than I am with the word “bank” because calling the collection a bank does not confer the same moral weight on the initiative as calling it public. The usefulness of the archival lens in this instance is in understanding that archives cannot hold everything, and within a mandate to represent (Jimerson, 2009), can only ever retain that deemed most relevant in the given archive. We see these points in operation in the UK’s UCB collections, which cannot take tissue donations from everybody. Though ostensibly public, the system operates, as I argued in the chapter, on a *privation* of access. This matters for a number of reasons, not least because the moral injunction to donate what would otherwise be wasted is a mobilised rhetoric of the public UCB collection initiative.

As a ‘selective collection’ of things (Stoler, 2009: 45), not everything can go into an archive. This is what Bowker calls the jussive force of the archive. They operate, as he asserts, ‘through being invisibly exclusionary’ (2005: 14). I plotted out some the practices of UCB collection in the UK that could be seen as exclusionary (in the sense that they literally exclude certain donors from giving their stem cells). These practices were necessitated primarily by resource limitations. Resources stretch only so far, and data suggested that it made more sense for those involved to concentrate resources on ensuring collection at fewer sites 24 hours a day, rather than open more collection sites in more maternity units to offer collection for only a portion of the day. The kind of funding available also made a difference to where collection sites could be placed, with sites outside of London being selected in part by whether they qualified to receive the kind of regionally-specific funding the government had awarded the initiative.

One of the most intriguing things to emerge from this chapter was the relevance of ethnicity as an exclusionary criterion as well as an ordering one. Ethnicity in the UK is recorded by the government census which those planning collections sites used to guide which areas would be chosen. As participant 8, a bank administrator explained, a good collection site has “preferably a high birth rate of diverse ethnic mothers and that’s what we’re focused on”. The encouragement of particular people who are racialised as minority bodies (who thereby produce ‘rare’ tissue) to donate takes focus away other bodies racialised as white (who thereby produce ‘common’ tissues) raises very interesting questions here about the *value* of particular kinds of bodies. Compare the archival demand for high-value minority tissues in the collection, with the political struggle to raise awareness of the seemingly *low* value placed on black lives in the public sphere manifest in contemporary political movements like #BlackLivesMatter (Day, 2015).

This inversion, which prompts me again to highlight the disparity between our molar and molecular existences, is not simply intriguing, but has a potentially emancipatory core in which the molecularisation of race stands to produce equity (Rose 2007), but might as equally reify molar difference (Kierans and Cooper, 2011). This archival aperture, so intent in its focus on black and brown bodies, might appeal to a racialised communitarianism that for the racialised individual to fall short of is

tantamount to a kind of ‘civic defection’ (Benjamin, 2013: 44). As Titmuss (1970) explored in relation to blood donation, there can be a powerful tenor of shamefulness involved in *not* giving of one’s self to the rest of the community. This can potentially invert the communitarian spirit that underwrites the systems of donation that concern us here. In what spirit, with which discursive tone of encouragement, are certain people asked to donate? How does that shape one’s relationship to the act of donation, and how could this efface the communitarian heart of the “public” collection model? Does the conferral of archival status reify racial differentiation or is there beneficence in race’s invocation here?

Whilst I have explored the private sector in more theoretical depth elsewhere (Brown and Williams, 2015), I feel there is scope here to consider in more depth the possible limitations of critical accounts of private banking based on the promissory dimension of the product and the attendant implication of capitalistic avarice (Martin *et al.*, 2008; Waldby, 2006). I argued in chapter five that the private bank might offer an outlet for tissue storage for those individuals precluded from donation by the public model. With no avenue for universal donation, could self-pay alternatives begin to partially reopen that option even if in another limited way given not everybody is in a position to pay for such a service? The important distinction here that limits such an argument is that the private bank does not offer universal access to stem cells for treatment. The public bank stands to be very public in the sense that it *does* offer universal access. The *munus* of community (Esposito, 2011) remains unfulfilled through private banking, though still only partially fulfilled in the public model.

What I suggest here, then, is that the dualism of private/public cannot be settled easily. The motivations of tissue providers/donors are of course revealing (Brown, 2013) and the management of the collections into which they donate are complex, and confound simplistic titular distinction. As Healy notes, to think of these systems of donation instead as systems of *procurement* is helpful. By bringing focus to procurement the motivations of donation have less weight as a way of defining and understanding such systems. In a more sociological language, the agency of a donor means little without an in-depth knowledge of the structure that permits (or excludes) the donation.

8.5 How an Archive Comes to Be Used

The focus on imminent/latent future use of data and matter is integral to the theoretical invocation of the “archive” and was central in the discussion of chapter six. When I first started thinking with the archive, the weight of the future and its performative attributes (Waterton, 2010) made very little sense. The archives I had been using were full of artifacts from some time long past. The point, though, was that I was *using* them. They were established and maintained because the people in charge of such decisions felt their collections might be useful. In chapter six, I suggested that to be able to understand the centrality of use in a given archive, one had to have a grasp of how that archive comes to be used. I explored how these UCB collections come to be used, arguing that there were different elements at play in how clinicians come to use these public UCB collections. The argument this built into was that those working in the archival spaces in question here must be responsive to these elements to ensure their collections’ continued usefulness.

I considered professional guidelines, produced by the consensus of senior scientists and practitioners, which are published for the consideration of practitioners working with the technology of HSC transplantation. In what Harry Collins might call the ‘algorithmic’ style of knowledge transmission, these guidelines represent a rationalising tool (Berg and Timmermans, 2000) designed to bring consistency to clinical practice. In the local space of a given transplant centre, though, experience with particular technologies inflects the decision to use UCB over different sources of HSCs. The subjective experience of the individual practitioner, the data demonstrate, has a large impact on whether they will use UCB and, therefore, the collection. Through using the technology and developing a manual capacity for UCB, clinicians stand to become more comfortable with the source, echoing Collins’ notion of ‘enculturation’ as a means of knowledge transmission.

These findings resonate with discussions had in the Sociology of Health and Illness literature on clinical technical preferences, where the issue of practitioners’ discretion and their clinical autonomy has been seen to sit uneasily with imposed guidance on the specificities of clinical practice, particularly the prescription of drugs (Armstrong and Ogden, 2006; Prosser *et al.*, 2003). The broader adoption of new

clinical approaches within general practice, for example, has been of interest for some time, with findings highlighting that implementation is a fluid and complex process, where no single factor could be given causal precedence in whether an approach is adopted. As Armstrong and Ogden note in their review of the literature, accumulation or a gradual building up of knowledge is perhaps the best way of understanding uptake of a new clinical intervention. The importance of practitioners' personal preference, argues Pope, works in tandem with 'past experiences, sensory responses and abilities' (2002: 379) to determine the path most likely taken in a particular clinical intervention.

In chapter six, I argued that a clinician's subjective view of (or their 'clinical comfort' with) a clinical option plays a key role in its uptake at a local level even if disseminated professional guidelines exist. This argument came out of data from those involved at a senior level who, for the most part, have never been practitioners using UCB in a clinical setting. This thesis is not, and was never intended to be, a study of practitioners who use HSC transplant technology. To be able to see the decision-making at work through other means (for example, ethnography or direct observation) would, of course, have added a different vector to these reflections, but equally would have removed focus from the broader concern about the organisation of these collections and how they might promote use rather than focusing on the use itself. This notwithstanding, the consensus-led guideline as well as user preference or users' 'clinical comfort' both made a bid in the data for being integral to how these collections come to be used. I would agree with the sociological consensus that there is a complex interrelation between external guidance and individual clinical preference in the uptake of an option. The ensuring of archival use is an important element unique to the context of interest in this thesis that perhaps heightens the importance of recognising this interrelation.

These different registers are at play *within* clinical settings where choices about treatment are made. Though I did not spend any time in such settings, it is very telling that there was an acknowledgement of these registers *beyond* the clinic in discussion with a diverse array of people involved in the initiative of public UCB collection (who had, for the most part, never actually worked in a clinical environment making such decisions). I would suggest that there is such a heightened

awareness of this because of the importance in ensuring that the collections come to be used. These different registers play on the minds of those involved in collection management. Regarding the rational register of clinical consensus algorithms, one administrator in chapter three noted that because cord is moving “up the algorithm ... we’re making progress”. Another administrator who lamented a clinician’s preference – the affective register – being based on only a few experiences, said “they are people after all, whether we believe it or not”. There was a clear resignation to the importance of these two elements that work together to bring users to these collections and, therefore, make them useful.

But these are also recursively folded into collection management practices in this instance. How do those managing a collection know what is useful (i.e., what matter and data to retain)? The answer here, I would suggest, is in learning from the patterns of use. Recall the scientist who explained the decision to raise the threshold for the total nucleated cell (TNC) count of a unit. How was the decision made? “It was made,” they explained “on the basis of what people are actually selecting”. This responsiveness is an integral element in understanding the practices that lay behind UCB collection in the UK, as it highlights the driving force of users in how an archive is constituted. It is important, then, to think about what this means for how public UCB collections might be studied in the future. I would argue that a future port of call for the research that emerges out of this chapter is for a more in-depth consideration of how those managing collections such as these actually get to know their users, and what mechanisms are in place to maintain those relationships.

In light of this, we can see how UCB collections are managed and monitored with care. They are intended to exist in synchrony with the potential constituency of users whose choices are wrapped up in subjective experience as much as standardised recommendations of professional consensus. This argument goes to the heart of challenging the simplistic imagining of public banks as large accumulations of matter retained prudentially for some future time. The amount of mediation and management, and the required awareness of user requirement, means these collections are no less than highly contingent. The units within in them will not stay relevant forever, and their continued archival status is certainly not guaranteed.

8.6 Risk and Resilience

Chapter seven focused in on some of the risks faced by the UK's UCB collections, but also how those risks are managed. Some risks, like the formless risk of obsolescence, are something that all archives are faced with. Such a risk cannot be seen, per se, but its presence holds significant purchase in how the UCB collection is managed. Obsolescence, as I talk about it in this chapter, suggests the possibility that the archived content within any collection might become, at some point, irrelevant to those users who in the near or distant future may come to use it. This comes to life in the UCB collections as we considered, in chapter seven, what has been seen to happen to material collected earlier on in the project of UCB banking which, though still preserved in a freezer, no longer retains its relevance in reference to the contemporary expectations and standards of users. We can, perhaps, think of the desire for a synchrony between collection and user (as I explored in chapter six) as a means of mitigating obsolescence in the sense that awareness of the distance between archival provision and user need is best kept in check by knowledge of the constituency's requirements.

User requirements, then, have a powerful influence over what those managing these collections put into them, and what they retain of what is already in them. The sustainability of a collection has a great deal to do with how user requirement is monitored and responded to. Sustainability as a notion, however, tends to refer to *economic* sustainability when discussed in relation to the management of collections of human tissue. For example, in the literature on the management of *research* biobanks, there is a sense that, as Vaught *et al.* (2011) put it, 'market need' must be met with 'a high-quality portfolio'. This is clearly the language of economics (or 'biobankonomics', as the authors call it). I am not in a position to disagree with these authors whose interests here are in the research-based biobank. Data from this thesis relate to the clinical bank – a collection established and aggregated with a very different purpose. Accordingly, I suggest that in the clinical context, if not the research context, we could afford to think outside of this remit of economic sustainability.

‘Market need’, for example, may be understood in our context of interest as ‘user requirement’, a ‘portfolio’ as a ‘collection’. Quality is *maintained over time* rather than taken for granted and constant. It relates, as I have demonstrated, not to some essential characteristic *within* a UCB unit, in the distance between that unit (stored on a given day in reference to the standards in play on that day) and the requirements of the practitioner at the time she comes to look for it to use in treating a patient. Quality relates, in short to the maintenance of this important link between archive and user. The distance between these UCB units and the user’s requirements constitutes an ever-present risk in the UK’s UCB collections. By understanding them as archives (not as investment portfolios which sits a little awkwardly with the practice of the public collection), the risk comes into sharp relief as an inevitable by-product of establishing and maintaining a clinically useful collection of stem cells. Whilst we can have, to use Bowker’s term, ‘empire over the present’ (2005: 227), we cannot ever hope to sustain it without conscious and consistent maintenance.

I am not arguing here that economic factors are irrelevant, but my conviction is that just because the stem cells – like other human-derived tissues - are ‘bought’ does not mean they are commodities, or the basis of a market (see Hoeyer, 2009). The profit motive may play a role in the more research-based biobank but, as I have pointed out elsewhere it has relatively little to do with the management of a bank of tissue used for public health purposes. Here, collectors’ institutional interests and state funder pressures may have their role to play (Williams, 2015) but the ethos of the market is hard to locate (Brown and Williams, 2015). A collection may indeed face closure, the end of a finite funding stream for example (Tupasela and Stephens, 2013). But to focus purely on its economic sustainability risks obscuring those practices that allow the units to be saleable in the first place.

Returning to the focus of chapter seven, I also argued that risk takes on another more familiar guise. The risk of physical destruction, decay and deterioration informs the spatiality of all archives. This is what Derrida (1996) might call the archontic principle that makes archives *protective* spaces. Resilience becomes a central tenet of the management of UCB collections. The loss of electricity to a cryogenic freezer is likely to be as harmful as the more abstract slippage of a UCB unit into obsolescence. The spatiality of the all archives is crucial. ‘There cannot,’ wrote

Mbembe, 'be a definition of 'archives' that does not encompass both the building itself and the documents stored there' (2002: 19). The archival space, which came into relief in the data, is ideally sealed off (*autos*), protected from the other (*állos*) of the flood, the fault, the spectre of failure produced out of the need for material existence of the collection.

A broader issue that overarches these themes is what emerged at the end of chapter seven as acute awareness of the need for strategic direction in how the collection is managed as it moves forward through time. One of the major points here is that (unlike this thesis) there can, by definition, be no end to any useful archive, because a useful archive must be transformed alongside changes within its user constituency. As we saw in the introduction, these collections are imagined (in this instance, over several decades) then they might be constructed. Archival matter might be exchanged, developed, or taken out of an archive for some other reason. An archive itself might be flooded or it might be moved. The people who manage them, though, do not want their collections to 'end', but to continue on indefinitely and usefully into a future that they are unable to see, for a consistency of users 'whose limits are of necessity unknown' (Osborne, 1999: 55).

There is, in these findings, a sense that it is important to discern, in the increasingly common practice of archiving matter and data for a number of different pursuits (one in the suite of regenerative medicines being our pursuit of interest here), how risks are constituted and managed. The destructive core of all archives was recognised by Derrida, when he suggested that archives are always 'a location... You need the exteriority of the place in order to get something archived'. He goes on to explain that it is 'because of this exteriority [that] what is kept in the archive can be erased, can be lost'. What constitutes exteriority may change. A freezer and the risk that the electricity may be lost and the archived matter a long with it, or a datum which risks becoming useless, lost in an information silo 'for want of providing enough context' (Bowker, 2000: 646) in a style appropriate to the mode of thought of the user at the time.

8.7 Limitations of the Study

It is apposite in the context of this discussion to reflect on what I have not done in this study that I might otherwise have. Here, then, I want to take the opportunity to think about the other methodological approaches I might have undertaken. I am also keen to think about my focus on the *practice* rather than *economics* of the UCB collection enterprise, as well as my concentration on one national context. These are, I suggest, things that were lost to the periphery through my focused use of an archival sensibility that I consider here. Finally, I consider the issue of the study's timing to suggest that this limitation reveals much about the responsive pace of collection practices. These reflections give a foundation to a final consideration of how these limitations can be addressed through further, future explorations.

In the earliest stages of this thesis, I could have selected to undertake a hospital-based ethnography of the specific practices of UCB collection or a lab-based ethnography of UCB processing. These different approaches would have taken the project in significantly different directions, and the conceptual position and empirical findings would doubtless have been very different. The thesis as it exists here, though, offers an important starting point as a piece concerned more broadly with how the UK's publically available UCB collections operate from the perspective of those involved at a senior level in the production of the strategy and policy that steers those collections through a wider and shifting landscape of regenerative medicine and related technologies. I would argue that on the basis of what I have laid out in this thesis, focused studies on particular areas of collection and process within the broader field of practice stand to benefit from the archival sensibility I have proposed here.

Another *what if*: an element that I have necessarily focused less on in this thesis, though have taken up elsewhere (Williams, 2015) are the issues of cost, money saving, public funding, and unit pricing. The focus of my data collection did not explicitly touch on these themes that I felt, at the time (and still feel, in retrospect), risked taking focus from the other rationales that underpin the broader field of practice I have been interested in here. However, as the effects of increasing clinical commissioning devolution proceed, it will be important to trace how a patient's

geography delimits their clinical treatment choices. This is a slightly different focus from the one I have taken in this thesis which has in the main been removed from patient experience, excepting the reflections that emerged around how personal clinical preferences in a given hospital (rather than local commissioning constraints) can have an influence on a particular patient's experience to the extent that one participant asked me, as I outline in chapter six, 'if I were to get leukaemia, where would I want to go?'

To that extent, it is important to reflect on what the findings of this UK-based study might tell us about situations in other countries. One of the biggest differences between the UK context and elsewhere is not only that patients receive treatment through a National Health Service but also that the collections I am interested in here are publically funded through centralised funding from the UK government, and also (as I explained in chapter five) through competitively awarded public money in the form of the UK's Regional Growth Fund. I would suggest, however, that since more than 40% of UCB units released globally for clinical treatment travel across state borders (Welte *et al.*, 2010), the practices of collection management and the archival response to risk are key issues internationally. Indeed, it is telling that examples of the management of obsolescence in chapter seven reached across international borders into Europe and Asia.

The notion of an archival anatomy, which I plotted out in chapter two, has been a directing force in how this thesis has taken shape. I am cautiously convinced of the usefulness of the protean archive, having seen it put to work successfully elsewhere. Whilst I think it has given me a lot, it would be remiss of me not to offer some reflection on what it might have taken away. What if I had not used an archival lens? I did not think to immerse myself in STS writing on data management in the field of biodiversity during the first months of the research project. Nor did I happen upon Derrida's *Archive Fever* until sometime later, in the midst of data collection when particular themes around classification, exclusion and so forth started to emerge (as I explain towards the end of chapter three). The data probably *would* have been different if I had been more explicitly looking for archival practice from the start, but I would argue that the fact that the paths of data collection and theorising converged *during the process* speaks to their consonance. Put in a different way, it was not so

much me being invested in an archival lens so much as practices that might be described as *archival* being integral within the context I have been interested in here.

The analysis would also have been different if I had not used the archive. I could go through the entire thesis and remove all references to ‘archive’, ‘archival’, ‘archiving’ and so forth (an act that would itself rely on the word processing software to offer an archival function of a kind). Where would we be then? The themes would all be there: the generational thinking, the exclusion, the selection, the classifying, and the order. They would not, however, *cohere* as a set of practices that make sense. As a lens, the archive not only helps to bring these practices into relief but also imbues them with a kind of teleology. There is purpose behind the decision not to put a collection site here and not there, a logic for the choice to make the TNC thresholds what they are, a reason for the racialisation. That is to say, they only make sense because the collections managers, like all archivists, are trying to protect their collection from risk, make it representative, and ensure its usefulness for a future constituency.

There is, though, an important limitation to what I have produced here. The archive as a concept in 2015 is different from what it may look like in a century in response to shifts in how knowledge, data and matter are retained, measured, ordered, and accessed in different ways. This project has lasted for *three* years, has focused on the practices of those involved with producing the policy and strategy behind *two* interacting UCB collections, in relation to the policy regarding *one* country’s provision of HSCs. Had there been four or five years, three or four collections, two or three countries, the findings might have been different, though I do wonder *how* different. In terms of the practices of collection maintenance, of trying to keep ahead of clinical practice and demand, I find it hard to imagine that different countries would fair very differently from the context of concern here. The more pertinent factor that stands to be considered here is not one of the *scale* of the project, but its *timing*.

As chapter seven demonstrated, practices of the current generation of UCB collections, is very different to how they have been undertaken in the past (that is, practices in the mid-nineties when UCB collections were first being established). Remember the brilliant reflection from a participant I quoted in that chapter, that

assumptions from then have since been ‘a little bit blown out of the water’. Looking forward, then, how might this project have differed if it had been undertaken in ten years’ time? We cannot say for sure, but judging by the last chapter, the landscape of regenerative medicine might have changed so much (different demands borne of different technical capacities; new technologies vying for the attention of clinicians) that UCB collections might be unrecognisable. Remember Derrida’s assertion:

‘the technical structure of the archiving archive also determines the structure of the archivable content even in its very coming into existence and in its relationship to the future. The archivization produces as much as it records the event.’ (1996: 16-17)

It stands to reason, then, that just as Freudian psychoanalysis would have been a different thing if the Austrian neurologist and his contemporaries had all be communicating by email (Derrida, 1996), the practice of UCB collection will be different in ten years’ time, when new techniques of procurement, new metrics of quality, new clinical options, new demands from users, completely transform the practice of UCB collection or indeed, as chapter seven pointed out, negate the practice altogether. This is, to borrow from Beer on talking about digital archives like Facebook and YouTube, a problem of keeping up. ‘Once something that is so changeable is written about then we might wonder what use or value is in the text’ (Beer, 2013: 5). Does the non-transferability of the context, its very historicity, count against it? HLA types may mean nothing in twenty years’ time, for instance. Cord blood could be a thing of the past altogether in thirty! I would argue that the historicity of this thesis is key. In many ways, I think one of its enduring resonances is the very transience of usefulness (of classifications, or data, or matter) in the contemporary technoscientific moment.

8.8 Archival Definitions and Future Directions

This thesis, then, stands as a contribution to the important scholarship of writers such as Geoffrey Bowker whose engagement with the database as a “memory practice” in the disciplines of ecology and biology represents perhaps the first example of the significance of the archival paradigm for understanding practices of ordering data

and matter in the natural sciences. Those who have expanded on Bowker's work, primarily Waterton *et al.*'s writing on the complexity of constructing meaningful, useable databases for biodiversity preservation (2013). I took inspiration from these and other scholars whose work directed me to think in particular ways, to keep my ears pricked for particular themes. It is important, though, that I am able to give something back to this archival lens, to offer a few reflections on what the archive has been useful for here, and what its wider potentialities might be for STS scholarship.

As I argued in chapter two, the archive in a conceptual context is not the same as the archive as many of us might think of it. The theoretical archive, writes Stoler, 'leads elsewhere' (2002: 94). Over this thesis, the archive has led us to a particular formulation of what an umbilical cord blood collection is, how it is managed, and what it can possibly come to be. Archival thinking has fortified analyses of all kinds of selective collections of data: the social network Facebook (Beer, 2013), a DNA-barcoding biodiversity database (Waterton *et al.*, 2013). Here I have applied its elasticity (Osborne, 1999) to an ostensibly material collection with attendant data. Using the archive as a heuristic has been key to producing the initial lines of enquiry, as much as informing the enquiries themselves that formulate the four empirical chapters you have just read. Its use lies, as we have seen here, in its ability to sharpen focus on the practices of collection, maintenance and use, and the understandings that underwrite them.

Would it make sense, then, to think about producing some useful definition of an archive? I am wary on this count, given that because (i) we cannot know what is to come, and (ii) the archive is itself an experience of anticipated future, we cannot really define any archive. This is a point that Derrida makes when he writes that the archive is 'only a *notion*'. He goes on:

'We only have an impression, an insistent impression through the unstable feeling of a shifting figure, of a schema, or of an in-finite or indefinite process ... I consider it to be the possibility and the very future of the concept, to be the very concept of the future, if there is such a thing and if, as I believe, the idea of the archive depends on

it... a concept in the process of being formed always remains inadequate relative to what it ought to be.' (1996: 29)

Keeping this in mind, it makes sense here to think about the future of this research. What questions now need to be asked? Something that becomes acutely important here is that there is a clear need to keep asking what work the classification(s) of ethnicity are being put to in the contemporary biotechnologies. We saw in this thesis a difficult relationship. Ethnicity was a means of focusing the collection of stem cells, but had little use in the actual task of stem cell transplantation. As the molecular takes on more precedence over molar categories, it remains important to watch what happens with ethnicity because of its potentiality as a powerful tool of producing health equity, but also of reifying difference. Tracing race in this way to see where it is used and why, stands to be a productive way of exploring the social implications of biotechnologies, and contribute further to the growing body of literature being produced at the nexus of race/ethnicity and Science and Technology Studies (Benjamin, 2013; Bliss, 2011).

It is also, I have suggested here, important to question what we mean in our differentiation of public and private models of umbilical cord blood collection. This is another trajectory for the future. My main issue here has been with the notion of “public”. What discourses are being put to use in encouraging women to donate their stem cells? Whilst avoiding normative suggestions of what discourses of encouragement *should* look like, another thread of future investigation is to think about more effective ways of positing the act of donation or the gift (Titmuss, 1970) elicited for systems of procurement (Healy, 2006) like UCB, organ and blood donation. These systems exist not because of the practice of universal giving, but of a fraction of the population donating because of very specific criteria necessitated by limited resources and exacting requirement. As a contribution to the emergent sociology of donation, this critique stands expansion across systems of procurement, perhaps comparing stem cell donation against other ‘public’ systems such as organ donation, a practice that has very recently dropped in popularity in the UK (Knapton, 2015).

In a different vein, I would suggest that there is scope for focused exploration of the notion of resilience, a term that reveals an awareness of and preparation for the variety of risks that face UCB collections. I would suggest that clinical requirement and attendant possibilities of obsolescence are more likely in relatively nascent technologies like adult donation and UCB. However, there is potential to think more broadly across the different collections of tissue about the need for resilience against and (vigilance about) risks of disease, flood, time, (lack of) demand. This might be in thinking about the guardianship of collections – the importance of spatiality and environment. Perhaps the archival lens would again be useful for exploring questions about how resilience is ‘built in’ to the physical environment in contemporary collection practices. It seems logical to ask how, more generally, risks are constituted across collections as well as considering what practices are being enacted in order to efface them.

8.9 Conclusion

This thesis has explored the UK context of public umbilical cord blood banking. My argument, reduced from eight chapters to a sentence, would be to insert inverted commas around the words ‘public’ and – in particular – ‘bank’. I have problematised them, arguing that these terms fail to capture the complexity of the intentions behind them. I have argued that a stronger grasp of UCB banking is achieved by thinking archivally. I have suggested that we must recognise the complexity of these aggregations of matter from which lifesaving matter is drawn for clinical use but also removed because it has travelled out of clinical usefulness. I have proposed here that the enrolment of ethnicity as a tool of aggregation must be questioned given its limited use beyond this. So too have I argued that we fail to fully comprehend the complexity of the public system of UCB banking without understanding that it relies not on public donation, but on systematic exclusion for a number of reasons. I have also put forward the suggestion that clinical use of UCB stem cells rests on more than standards, but a complex nexus of recommendations and personal preference that collection managers respond to in their own collection practices. Finally, I have argued that we need to think of anticipation and response to variegated risk as central to the project of UCB collections.

The thesis has therefore demonstrated that an archival lens offers the heuristic richness that ‘bank’ thinking cannot provide to highlight these various important aspects of establishing, operating and planning the future of a collection of biological material. It thus constitutes a novel contribution to the STS literature on regenerative medicine and tissue banking (Brown, 2013; Brown *et al.*, 2011; Dickenson, 2007; Martin *et al.*, 2008; Waldby, 2006; Waldby and Mitchell, 2006) as well as the growing interdisciplinary corpus on the usefulness of the archive in understanding the complex aggregations of matter and data facilitated by contemporary technologies (Beer, 2013; Bowker, 2000, 2005, 2010; Featherstone, 2000, 2006; Waterton, 2010; Waterton *et al.*, 2013). To take the position that we have reached some definitional closure in understanding stem cell collection would be untenable, not least because it would be out of step with the archival sensibility I have promoted in this thesis. As time marches forward *around* these collections forcing those in charge of them to change direction any number of times, our critical analyses will doubtless have to change direction too. I am of course in no position to postulate what the future of the UK’s UCB banks will be. However, we can be assured that those working inside them will be doing just that. They will, as I have demonstrated here, be trying to anticipate *a future* of users and requirements, and respond in the present with the hope that the work they do today will one day be useful.

Appendices

Appendix A: Information Sheet

Understanding Emerging Forms of Governance in public Cord Blood Stem Cell biobanking in the UK.

Information Sheet

You are being invited to take part in an interview for a research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. Talk to others about the study if you wish. Take time to decide whether or not you wish to take part.

Purpose of the research

This doctoral research project has two main aims:

- To develop a better understanding of the emerging governance structure of umbilical cord blood banking in the United Kingdom
- To explore the views of clinical experts, policy makers and other stakeholders, and how these feed into (1) the production of a policy to expand umbilical cord blood banking (2) the novel forms of governance that are facilitating this expansion

The project is using research interviews with those involved in the public umbilical cord blood industry in the UK to address these aims.

Umbilical cord blood banking has enjoyed a growth in popularity among parents, and resultant stem cell stocks have become more accessible to clinicians delivering therapeutic treatments to their patients. In response, clinical experts, third-sector charities and policy makers have sought to develop an infrastructure to increase the collection of immunologically diverse domestic stem cells.

The importance of developing an adequate framework of stem cell treatment provision in the United Kingdom is clear, and this research looks to develop a more intricate social scientific understanding of how an efficient system of public biobanking can be developed and sustained. In doing so, it seeks to explore the growing importance of experts in the development of policies that aim to expand umbilical cord blood banking in England and Wales and investigate the role of third-sector charities and patient advocacy groups in the production and rolling out of policy.

I would like to invite you to take part in this research because I feel that your expertise in the wider area of stem cell transplantation as either a clinician, policy maker other stakeholder, will contribute to an understanding and knowledge of the changes which have and will take place.

What would taking part involve?

This research will involve your participation in a short interview that will take about thirty minutes to one hour.

Your participation in this research is entirely voluntary. You will not be asked to share personal beliefs and you do not have to share any knowledge that you are not comfortable sharing. You can end the interview at any time without giving a reason. If, after the interview you change your mind about taking part then you can contact me to withdraw from the study and I will destroy any data that you have provided. You will have three months to change your mind about participation, as beyond this point in the time the data will have been analysed and it will not be possible to remove your data from the study

The interview involves questions relating to: your professional background, what the purpose of the developments in transplant science and policy are and how their success is measured, what the barriers to development are, what the problems that development aims to address are, how scientific understanding and concerns translate into policy, how existing communities of expertise are consulted, and how effective these collaborations between experts, third-sector parties and policy makers are.

The interview will be audio-recorded with your permission. A professional typist who has signed a confidentiality agreement will then transcribe the recording. The recording will be kept securely and your name will never be used in the analysis of the data or in any output from the research. After transcription, the audio recording of the interview will be destroyed

Confidentiality

Your participation is confidential and any information that you provide will be stored securely. Your name will never be used in connection with this study or its published findings. When the findings of the research are published, short excerpts from your interview may be used to support the arguments being made. However, these excerpts will be given a pseudonym to protect your identity.

While every effort will be made to ensure that your identity remains anonymous, this research will identify organisations by name. While you personally will not be named, you may be referred to as, for example, “an employee of Anthony Nolan Trust” or “a senior immunologist in the field”. This means that there is a risk that

others may be able to identify you if there are only a small number of people with the same role within your particular organisation. However, it is important to reiterate that no names will be used or any other details of your profession, which would allow for specific identification.

Benefits

Whilst there is no direct benefit to you, your participation will help provide important information about policy-making from the point of view of the stakeholders involved. This will help to produce a more intricate social scientific understanding of how an efficient system of public biobanking can be developed and sustained in the United Kingdom. The research will produce recommendations that will have relevance both in the UK and abroad.

Duration

The research is taking place over two years: The project end-date is October 2015.

Sharing the results

Following the completion of the study, a summary of the results will be made available to all participants. The research findings will also be written up in the form of a doctoral thesis, disseminated in academic journals, at academic conferences and in reports to relevant stakeholder organisations.

Who to contact

If you have any questions then you can contact the researcher at the following: Ros Williams, 07814406789 or rgw511@york.ac.uk.

The ethical aspects of this research have been reviewed and approved by the appropriate University of York ethics committee whose task it is to make sure that research participants are protected from harm. If you wish to find about more about this please contact: elmps-ethics-group@york.ac.uk.

If you wish to get in contact with the researcher's supervisor, Professor Nik Brown, at nik.brown@york.ac.uk.

Appendix B: Consent Form

**Understanding Emerging Forms of Governance in public Cord Blood Stem Cell
biobanking in the UK.**

Consent Form

Please initial

1. I confirm that I have read and understand the Information Sheet for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary: I am free to withdraw at any time. I do not have to give a reason. Also, I am free to refuse to answer any question.

3. I agree that the interview can be audio-recorded and I understand that direct quotations from the interview may be used in the publication of findings.

4. I agree to take part in the above study.

Name of Participant

Date

Signature

Name of Researcher

Date

Signature

Appendix C: Documents Included in Data Analysis

Year	Institution	Title
2009	Technopolis	Cord Blood Banking in the UK: An International Comparison of Policy and Practice
2010	UK Stem Cell Strategic Forum	The Future of Unrelated Donor Stem Cell Transplantation in the UK: A Report from the UK Stem Cell Strategic Forum. Part 1: Findings and Recommendations
2010	UK Stem Cell Strategic Forum	The Future of Unrelated Donor Stem Cell Transplantation in the UK: A Report from the UK Stem Cell Strategic Forum. Part 2: Annexes
2011	World Marrow Donor Association	Race Codes
2012	World Marrow Donor Association	International Emergency Task Force: Operating Guidelines
2012	World Marrow Donor Association	Crisis Response, Business Continuity, and Disaster Recovery Guidelines
2012	Anthony Nolan	Search Algorithm for a Basic Cord Blood Unit Selection
2012	Anthony Nolan	Operations User Guide
2012	NHS Blood and Transplant	Report on the Flooding Incident at Filton in September 2012

2012	All-Party Parliamentary Group on Stem Cell Transplantation	Cord Blood Transplantation: Meeting the Unmet Demand
2014	Anthony Nolan	Stem Cell Registry Review 2014
2015	UK Stem Cell Oversight Committee	Unrelated Donor Stem Cell Transplantation in the UK: Effective, Affordable, Sustainable

Appendix D: Indicative Themes and Questions for Semi-Structured Interviews

Involvement in APPG/SCSF/WMDA

How did you get involved in the organisation?

Why was it that you were invited to participate?

How did you come to contribute to a particular event organised by this institution?

The role of APPG/SCSF/WMDA

Can you reflect on the purpose behind the establishment of this group?

How do discussions at one organisation feed into the other?

What differentiates the particular organisations you're involved in?

Cell count thresholds

Can you describe the relevance of cell count to the practice of UCB collection?

What is the current TNC threshold, since when and why?

When did it last change, and how did you become aware?

HLA typing resolution

What is the current consensus on HLA allele typing?

Has the HLA typing consensus changed since you first became involved?

Can you describe the production of the consensus in *x* article you co-authored?

Establishment of participant charities

Why/how was your charity established?

How did you find yourself involved with the APPG?

Is the charity involved in any ongoing projects that might be relevant?

UCB and adult donation

Are the technologies of adult and UCB HSC different?

What are the benefits, if any, of UCB over adult donation?

Can you imagine UCB becoming a more popular HSC source?

Uptake of UCB

Why has UCB become more popular between the 2010 and 2015 reports?

Why are some parts of the UK more likely to undertake UCB transplants?

When and why did the WMDA set up a UCB working group?

UCB collection sites

How was the decision made to open up a collection site in a particular city?

Did ethnicity data play a large part in the decision to select a particular city?

Individual's knowledge of UCB

When/how did you first hear about UCB technology?

How did you get involved in one of the first UCB banking operations?

Why has your charity become interested in UCB?

SCSF recommendations

How was it decided to have a 50,000 unit target?

What do you perceive to be the main purposes of an aligned stem cell registry?

Why has the 50,000 target decreased to 30,000?

Ethnicity data

Are ethnicity data useful for your purposes?

Is there international consensus on how ethnicity data should be collected?

How were you involved in designing this ethnicity classification framework?

HLA and ethnicity

Why is there such concern about the ethnicity composition of the UK adult register?

Can you explain what you mean that ethnicity determines HLA?

Do you provide clinicians with ethnicity data as well as HLA data?

Private banks

What was the purpose of inviting private banks to comment on the SCSF strategy?

Are private banks currently involved in meeting the SCSF targets?

Do you anticipate that private banks will be involved in achieving 50,000 units?

Economics of UCB

Is there economic motivation behind encouraging domestic UCB utilisation?

How much does it cost your charity to collect, process and store one unit?
Is it more expensive to have two separate storage facilities instead of one?

Individual documents

Do you recall your involvement in producing this document?

How did the TNC count recommended in this document get decided?

Why did you produce this particular document?

Appendix E: The WMDA ethnicity code framework

Broad Race/ Ethnicity	Code	Geographical Region	Code
African	AF	North Africa	AFNA
		Sub-Saharan Africa	AFSS
Asian	AS	Southwest Asia: Middle East, Turkey	ASSW
		Southern Asia: India, Pakistan, Bangladesh, Sri Lanka, Bhutan, Nepal	ASSO
		Central Asia: Kazakhstan, Uzbekistan, Kyrgyzstan, Tajikistan	ASCE
		Southeast Asia: China, Mongolia, Burma, Laos, Cambodia, Thailand, Vietnam, Taiwan	ASSE
		Northeast Asia: Japan, North Korea, South Korea	ASNE
		Oceania: Pacific islands, excluding Japan, Australia, Taiwan, Sakhalin, Aleutian Islands	ASOC
Caucasian	CA	Europe: Mainland Europe, Greenland, Iceland, Western Russia	CAEU
		Eastern Russia	CAER
		North America: U.S., Canada, Mexico	CANA
		Australia: Australia, New Zealand	CAAU
Hispanic	HI	Central America & Caribbean	HICA
		South America	HISA
Multiple/ Mixed	MX		
Other	OT	Ex. Australian Aborigine	
Unknown	UK		

Glossary

AIDS Acquired Immune Deficiency Syndrome
AN Anthony Nolan
APPG All-Party Parliamentary Group
BAME Black and Minority Ethnicity
BSBMT British Society of Blood and Marrow Transplantation
BSE Bovine Spongiform Encephalopathy
CCNE Committee Consultatif National d’Ethique (France)
CJD Creutzfeldt-Jakob Disease
DNA Deoxyribonucleic Acid
DoH Department of Health (UK)
GIAS Graft Identification Advisory Service
GVHD Graft-Versus-Host Disease
HIV Human Immune Virus
HLA Human Leukocyte Antigen
HSC Haematopoietic Stem Cell
HSCT Haematopoietic Stem Cell Transplantation
IVF In-vitro Fertilisation
MFD Matched Family Donor
NHS National Health Service (UK)
NHSBT National Health Service Blood and Transplant (UK)
NMDP National Marrow Donor Program (US)
R&D Research and Development
RBC Red Blood Cell
RGF Regional Growth Fund (UK)
SCSF Stem Cell Strategic Forum
STS Science and Technology Studies
TC Transplant Centre
TNC Total Nucleated Cell
TRM Tissue-Resident Memory
UCB Umbilical Cord Blood
vCJD Variant Creutzfeldt-Jakob Disease
WMDA World Marrow Donor Association

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