

The contested values, promises and ethics of commercial cord blood banking in the UK

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Introduction

This paper offers some perspectives from my work in progress on the ‘banking’ of stem cells from umbilical cord blood, with the aim of contributing to the discussion of the ‘lived political economy’ that will take place at the conference. It takes as its subject one small element of the many activities that are concerned with researching, deploying and processing human cells and tissues for potential use in biomedicine and biotechnology. This is part of a wider project in which I aim to explore how the ethics of using parts of the human body are being negotiated in the UK, as the new value of human tissues for the biotechnologies is layered onto the older value of these tissues for biomedicine.ⁱ

Stem cells are the subject of intense scientific, commercial, clinical, patient, and consumer interest, and seen by some as holding the promise of future regenerative therapies. Amongst the various cells designated as ‘adult stem cells, are haematopoietic (blood forming) progenitor cells; these haematopoietic stem cells, which have established uses in transplant medicine. At the same time, these kinds of cells can be seen to have been enrolled into a future orientated of speculative capitalism or more specifically into an activity that so binds the biological together with the speculation of futures that it may be called ‘biocapital’ (Sunder Rajan, 2006).ⁱⁱ In this capacity, they become part of the ‘bioeconomy’ that is championed as a key part of economic growth by the UK government and by the European Union (EU) Commission.

Part of the interest for sociologists –and I hope, for anthropologists- in this field is that we can observe how developments in this field are being ‘co-produced’ through the interplay of ethical norms, regulatory regimes, technical and social possibilities and constraints. In other words, the shape that cord blood banking and cord blood cell therapies will take is still being negotiated, and constructions of ethics are prominent in these negotiations. Debates about this novel form of tissue banking are strongly influenced by a framework in which donated blood and tissues are seen as ‘gifted’, a framework that is deeply woven into the fabric of the post war settlement in Britain (Busby, 2006). Whilst in Britain this discourse on blood donation and altruism was most famously expressed by Richard Titmuss, it was interwoven with the discourse of the International Red Cross and of the many European countries that enacted legislation emphasising altruism and solidarity as the basis for blood banking in the post war years (Starr, 1998: 182-189).ⁱⁱⁱ

These ideals of altruism, solidarity, and of national self-sufficiency were subsequently taken up in European Union policy and legislation on blood and tissue banking^{iv}, and continue to be influential. Contemporary policy makers and ethical advisors on the biotechnologies are

caught between this recent history of humanitarian tissue banking and newer modes of venture science that require human tissues and cells.

This paper begins by outlining the promissory dynamic of cord blood stem cell banking, and then moves to consider the articulation of perspectives on the ethics of cord blood banking at several levels, from those of national and EU policy to interested individuals.

The promise of stem cells

Stem cells derived from bone marrow, have been in use in cancer medicine for many decades. More recently, stem cells were isolated from umbilical cord blood, and have been used in transplant medicine since the 1980s, and in addition became associated with such a range of anticipatory claims. Clinicians, scientists, parents and investors sought to preserve the potentially regenerative properties of this newly valued material through the development of a novel form of human tissue bank, the 'cord blood bank'.

Thus cord blood stem cells became incorporated into the growing enterprise of banking and exchanging of human cells and tissues for transplantation (Schulz-Baldes et al, 2007). A driver for the international exchange of such tissues is the need to find a donor tissue type that is sufficiently matched to the recipient's tissue to maximise the chances of a successful transplant treatment. This clinical need has led to the establishment of a number of registries and other bodies that facilitate the exchange of such tissues. Whereas tissue banks were traditionally based in particular hospitals, regions or national centres, there are now a number of organisations which procure and obtain income for human tissues and cells internationally. Of these, some are 'non profit' (where surplus income is reinvested in the facilities) and others are 'commercial' (where surplus income may go directly to company directors or investors). In 1992-1993 the first public cord blood banks were established in New York, Paris, Milan and Düsseldorf. A network of public cord banks now works in close cooperation with public health services, to register and store donated cord blood, extending the possibility of finding suitable stem cells for transplantation in children and adults where such treatment is indicated (Brunstein and Wagner, 2006).

Private companies have also been established that offer parents the opportunity to store their child's cord blood for possible future autologous and familial use. Whilst the use of cord blood stem cells to regenerate blood forming tissues is now established, many of the other hoped for future applications would entail the use of these cells in other physiological settings, for example for the regeneration of heart valves or of spinal tissues. The biological possibilities of using adult stem cells in this way are uncertain, but are the focus of much current research effort.^v

There is in a sense a double promise associated with cord blood stem cells. Firstly, they are associated with established and expanding applications in transplant medicine, and secondly with their future 'promise' in regenerative therapies. Activity in cord banking is often delineated into two sectors, 'public' and 'private'. Public banks are orientated to the need for allogeneic transplants, where the cells are donated by someone other than the patient, who is usually unrelated. In contrast, the private cord bank sector is primarily associated with future developments in cell therapies. Private banks appeal particularly to the possibility of autologous therapies, that is treatments based on the patient's own cells. However the distinction between the roles of public and private sectors is blurred in a number of respects. In particular, the banking of cord blood from one child for a sibling is something that both public and private sectors have a stake in, and engage in. Furthermore, the personnel, the research agenda, and the activities of the two sectors are interpenetrated.

Multiple expectations/contested ethics

Commercial cord blood banking in the European Union

‘Cord blood banks’, are but one of the more visible points of investment in the collection, transport, storage, and applications of human stem cells. Although they often function across national borders, their strategies and advertising are shaped by the possibilities of national and regional political health economies. The emergence of commercial cord blood banking poses significant challenges to regulators, which however are not the focus for this paper. Amongst these are the *promissory* element of cord blood banking, which, it can be argued, is a phenomenon characteristic of many of the developments in biotechnologies. In this case, the sense of promise and possibility is marketed directly to parents - rather than primarily to investors as is often the case in the biotech industry (Brown and Kraft, 2006).

Opposition to commercial cord banking has been raised by a range of influential groups in the European Union, including groups of clinicians, parliamentarians and public cord banks. In April 2001, a Dutch MEP questioned the legitimacy of commercial cord bank Cryo-Cell’s advertising direct to parents as well as the therapeutic claims it used to market its services. The MEP labelled it a ‘campaign [that] plays on the concern of prospective parents to prevent illness, and the fear of death’. ..and asked the EC to submit the matter to the its official bioethics advisory group, the European Group on Ethics and New Technologies (EGE). Whilst being highly critical of commercial cord blood banking, the EGE opinion on cord blood banking, issued in 2004, considered it ‘impossible, for ethical and other reasons’ to restrict the movements of consumers in this context as in others. Its eventual recommendations centred on the provision of information, the monitoring of advertising, the inspection of standards and processes of procurement and storage, and the provision of support to the public sector cord banking sector. The Opinion makes it explicit that the threat to the principles underlying tissue banking is of great concern to the group (European Group on Ethics in Science and New Technologies, 2004: 18). Nevertheless, the freedom of consumers and of enterprise were considered to be values that must also weigh in the balance when considering these issues. The EGE, whilst highly critical of the activities of such companies, advised that *prohibiting them would infringe upon the freedom of consumers and enterprises* in the EU (EGE, 2004).

Cord banking in the UK

The figure of the active consumer is one that has been prominent too in UK government policy, particularly so with respect to NHS policies (Clarke, 2004). Here, policy makers and practitioners inhabit both the older world of a national NHS that catered to patients based on professionals’ understanding of what is best for them and their community; and the newer vision of ‘patient choice’ that has driven NHS reforms over the past 20 years. (The historian Rudolf Klein describes this in terms of polarity between ‘church’ and ‘garage’ as underlying models in the recent history of the NHS (Klein, 2006: 252-265).

Private cord banks operating in the UK have faced consistent and vocal opposition from the key professionals in the field: that is, from obstetricians, midwives, and other NHS staff (RCOG, 2006; RCM, 2001; Edozien, 2006). Critical positions taken by professional and official groups reflect in substantial part a critical assessment of the technology and its future applications: private cord banking is seen to have zero utility, and so its attraction seems incomprehensible. However, the burden to the NHS if the practice of cord blood collection became widespread, and the physical hazards of collecting the blood in the delivery room

have been cited as key objections to private cord banking by obstetricians' and midwives' expert committees. Meanwhile the uncertainties about the eventual trajectory of technologies like this are unlikely to be resolved in the short term, and the possibilities for cord banking remain on the table.

Many NHS Trusts now having a policy that forbids personnel from assisting with cord blood collection for private storage. Parents sometimes report that their request to collect cord blood is met with objections that insurance cover does not allow midwives to assist, that they do not have time, or that it will inevitably be dangerous to do. Parents who are interested in private cord banking are criticised for being self-interested, and urged to donate 'for the public good'. However, there is little opportunity for them to donate these tissues for public use in medicine or research. (Although there is an NHS cord blood bank, it is a relatively small scale project that is only able to collect donations from five partner hospitals, in order to achieve the standards that maximises their quality of these cells for their application in transplant medicine.) Critics argue that the NHS is unresponsive and unwilling to innovate (The Lancet, 2007).

Modes of responsibility

Elsewhere in the landscape of government, meanwhile, meanwhile, there are concerted efforts to generate public interest in and engagement with stem cells science (UK Stem Cell Initiative, 2005). The strength of current commitments to research on 'public understanding' of new science and technology science is such that the more personal dimensions of moral reasoning and ethical reflection on science are sometimes overlooked. Charis Thompson's ethnographic work on the reproductive technologies used in infertility clinics signals the importance of 'private implication' in science and technology (Thompson, 2004). Taking account of this approach, it would be informative to reflect more thoroughly than space and time constraints allow for in this paper, on how the many aspects of the intensive process of 'becoming a parent' intersect with choices about cord banking. In the UK, the transition to parenthood is frequently constructed as a realm of making 'personal choices'-within limited domains. Shopping and consumption of goods and services are frequently promoted as formative process through which the identity of 'new parenthood' will be achieved. The promotion of a host of specialised goods and services to expectant and new parents is pursued energetically by a host of companies, and by the NHS itself through distribution by midwives of the 'Bounty packs' which reach 95% of NHS antenatal patients. (Bounty packs, which contain free samples from manufacturers of baby products and are distributed by the NHS, carried advertisements for commercial cord banks for several years. The inclusion of these advertisements in the antenatal Bounty packs was curtailed after the intervention of some of the midwifery groups. However they continued to appear in some of the subsequent mailings to parents on the database.)

What is striking about the advertisements for the private cord banks that now appear in the parenting magazines is not the difference, but rather the similarity with other adverts targeted at parents: they are on a continuum of advertising which appeals to the hope that technologies may protect children from risks that are as yet unknown or rather unspecified.^{vi} The information and marketing on the websites of commercial cord blood banks is interwoven with contemporary discourses of responsibility, choice and identity that are powerfully reinforced in the processes entailed in becoming a parent. Although some see these as distinctive features of the new landscape of 'biopolitics' (Rose, 2007), we may also find in them 'older' modes of responsibility, choice and identity.

In investigating this field so far, I have interviewed both parents who have banked cord blood cells privately, and those who, having investigated the possibility, decided not to.^{vii} I have found that the desire to make some use of this biological material, to ‘freecycle stem cells’ as one mother put it, is a desire that shapes many parents’ engagement and interest in private cord banking, just as it shapes their interest in public cord banking, or in the possibility of research using these cells. This trope of ‘freecycling’, these hopes that ingenious use can be made of parts of self no longer needed, that these alienable body parts could be being circulated without being fixed by ownership, are very difficult to accommodate in the formal world of science policy. Cord blood stem cells, like other human tissues and cells, are expensive to collect, store and process. Where applications using them are seen to be valuable, patents may be applied for and granted for these applications. Nevertheless, I find in these desires and ideals a challenge to have some debate about the banking and uses of stem cells that would even begin to address these aspirations.

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Notes

ⁱ See Waldby and Mitchell (2006) for an elaboration of the Waldby's notion of biovalue of cells and tissues, and for an exploration of tissue economies.

ⁱⁱ Rajan's work is based on an analysis of the modes of operating of several key biotech and pharma companies in the US and India. However, the analysis of how the biological and capital are fused together seems pertinent to developments in Europe.

ⁱⁱⁱ Eventually, this discourse ossified and became an orthodoxy that obviated a clear understanding and regulation of an international blood products industry.

^{iv} Hervey, T and McHale, J (2004) *Health law and the European Union* (343-347)

^v For a review of the scientific literature, see Institute of Medicine (2006).

^{vi} Koteyko Nelya and Busby, H (2008) *Vital promises and the website based advertising of novel 'health' products and services*. Paper forthcoming for British Sociological Association Conference.

^{vii} I will also be conducting interviews with parents who chose to donate umbilical cord blood to a charitable cord bank, and with parents who decline the invitation to do so. All interviews are in the UK.

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