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## Public umbilical cord blood banking and charitable trusts

Cameron Stewart, Lorena Aparicio, Wendy Lipworth and Ian Kerridge (2014)

### Introduction

Umbilical cord blood (UCB) is the blood from foetal and maternal circulation in the placenta and umbilical cord. This blood is rich in haematopoietic stem cells. These cells have the capacity for self-renewal, proliferation and differentiation—developing into all of the mature blood cells and maintaining bone marrow function throughout life.<sup>1</sup>

Since the late 1980s, haematopoietic stem cells collected from UCB have been successfully used in haematopoietic stem cell transplantation (HSCT) to treat leukaemia or bone marrow failure syndromes, as an alternative source of stem cells to those obtained from bone marrow or peripheral blood<sup>1</sup>. As a result, many societies have heavily invested in public banking of cord blood units to provide them as a resource for treatment and research.

The chapter examines the nature of public cord blood banking (with a particular focus on the Australian experience) and the notions of ‘stewardship’ and ‘custodianship’ that have been a feature of other accounts of biobanking.<sup>2</sup> Since 2009 a number of common law decisions have recognised the possibility that the *res nullius* rule (which prevents unprocessed human tissue from being considered an object of property) may be relaxed. Some scholars have begun to examine how notions of stewardship and custodianship might work within a property law framework.<sup>3</sup> Following

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<sup>1</sup> KK Ballen, E Gluckman and HE Broxmeyer, ‘Umbilical cord blood transplantation: the first 25 years and beyond’ (2013) 122 *Blood* 491; JE Wagner and E Gluckman, ‘Umbilical cord blood transplantation: the first 20 years’ (2010) 47 *Seminars in Hematology* 3; E Gluckman, ‘Umbilical cord blood transplant in human’ (1996) *Hematology and Cell Therapy* 38.

<sup>2</sup> B R Jeffers, ‘Human Biological Materials in Research: Ethical Issues and the Role of Stewardship in Minimizing Research Risks’ (2001) 24 *Advances in Nursing Science* 32; PH Williams, K Schepp, B McGrath, P Mitchell, ‘The Stewardship Model Current Viability for Genetic Biobank Practice Development’ (2010) 33 *Advances in Nursing Science* E41;

<sup>3</sup> The traditional rule prevented tissue from being the subject of property rights, unless it had been transformed by work and skill: *Doodeward v Spence* (1908) 6 CLR 406; *Dobson v North Tyneside Health Authority* [1997] 1 WLR 596 *R v Kelly and Lindsay* [1999] QB 621. Recent cases have opened up the possibility of having property rights in tissue which are not based on the work and skill exception: *Yearworth v North Bristol NHS Trust* [2010] QB 1; *Bazley v Wesley Monash IVF Pty Ltd* (2011) 2 Qd R 207; *Re Edwards* (2011) 81 NSWLR 198; *Re*

the work of Winickoff and Winickoff, this chapter will argue that donations of UCB (and tissue more generally) are best regarded as charitable gifts and that public UCB banks might be re-imagined as charitable trusts.<sup>4</sup>

The chapter begins by reviewing the history of UCB banking (with a focus on the Australian experience) and the concepts of tissue stewardship and custodianship that are a feature of public biobanking. The chapter then reviews the law of charity and sets out its basic elements. The final part of the chapter applies charity law to public UCB banks, arguing that charity law provides a legal framework for understanding the nature of the steward/custodian relationship in the context of UCB donation.

### **UCB and emergence of public banking in Australia and internationally**

Since the late 1980s, haematopoietic stem cells collected from umbilical cord blood (UCB) have been successfully used in haematopoietic stem cell transplantation (HSCT) for leukaemia or bone marrow failure syndromes, as an alternative source of stem cells to those obtained from bone marrow or peripheral blood.<sup>5</sup> There are a number of advantages of using UCB for HSCT. The first is that the collection of UCB, which occurs at the time of delivery, does not require a surgical procedure (as is needed for bone marrow collection) or administration of drugs (which is needed for collecting stem cells from peripheral blood). The second advantage of UCB is that, because of the relative 'immaturity' of the neonatal immune system, there is less necessity for complete immunological (HLA) matching between the donor and recipient. Third, because UCB is taken from a newborn, the donor blood is less likely to carry infection risks to the recipient. UCB also has the advantage of being immediately available because it is stored in umbilical cord banks.

Outcomes following UCB transplantation in adults and children are generally equivalent to outcomes of bone marrow or peripheral blood stem cell transplants. There are some limitations with using UCB for transplantation, particularly those related to the lower quantity of cells and prolonged time for engraftment (the length of time from transplantation before mature cells are seen in the recipient's blood). Questions are emerging about potential risks to the 'donor' related to early cord clamping and possible effects on haemoglobin and iron stores, but overall UCB transplantation is considered highly efficacious.<sup>6</sup>

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*H (No 2)* [2012] SASC 177; *Re Section 22 of the Human Tissue and Transplant Act 1982; Ex parte C* [2013] WASC 3.

<sup>4</sup> DE Winickoff and RN Winickoff, 'The Charitable Trust as a Model for Genomic Biobanks' (2003) 349 *New England Journal of Medicine* 1180.

<sup>5</sup> United States National Marrow Donor Program, *Disease-Specific HCT Indications and Outcomes Data*. (<https://bethematchclinical.org/transplant-indications-and-outcomes/disease-specific-indications-and-outcomes/>) (accessed 25 November 2013). Bone marrow transplant is an established treatment modality for many patients with acute or chronic leukaemias, lymphomas, or bone marrow failure syndromes. Haematopoietic progenitor (or stem) cells for transplantation may be sourced from umbilical cord blood or from adult donors. In adults, there are two types of haematopoietic progenitor cell donation: bone marrow and peripheral blood stem cell. Bone marrow donation involves a surgical procedure in which liquid marrow is extracted from the back of the pelvic bone. Peripheral blood stem cell donation is a non-surgical procedure in which haematopoietic progenitor cells are removed from the blood using a procedure similar to donating plasma. In each case, the cells are infused into bone marrow recipients following the administration of high doses of chemo/radiotherapy

<sup>6</sup> SJ McDonald, P Middleton, T Dowswell, PS Morris 'Effect of timing of umbilical cord clamping of term infants on maternal and neonatal outcomes (Review)' (2013) 7 *Cochrane Database of Systematic Reviews* CD0047074.

As the advantages of cord blood transplantation have come to be recognised, and the number of cord blood transplants performed (particularly in children) has increased, an international network of 54 public cord blood banks have been established to support transplantation. Cord blood stored in publicly funded banks is generally available to anyone in the world for whom the blood is an immunological 'match', meaning that cord blood collected in one country might be used elsewhere. In the last 20 years an estimated 600,000 UCB units have been banked worldwide, and 20,000 have been used in the treatment of adults and children with life-threatening malignant and non-malignant diseases.<sup>7</sup>

In Australia, the first public cord blood bank opened in New South Wales in 1995, followed by Victoria in 1996, Queensland in 1998 and Western Australia in 2011. There are now a number of public cord blood banks, which are all affiliated with the Australian Bone Marrow Donor Registry (ABMDR). These include the Sydney Cord Blood Bank, Melbourne's BMDI Cord Blood Bank, the Queensland Cord Blood Bank in Brisbane and Cord Blood Bank at Perth's King Edward Memorial Hospital. The Australian National Cord Blood Collection Network (Auscord) provides national co-ordination of these banks. The Network includes 11 collection centres, the majority located at public hospitals in large metropolitan areas. There are participating hospitals in Sydney, Melbourne, Brisbane and Darwin (Darwin accepts donations from indigenous Australians only). Auscord stores approximately 25,000 cord blood units, and around 100 of those are released for transplant each year.<sup>8</sup>

While the focus of UCB banking has traditionally been to provide UCB for transplant, UCB units have also become a useful resource for research.<sup>9</sup> This research explores the biological properties and potential therapeutic uses of haematopoietic stem cells, other stem cells present in cord blood (particularly mesenchymal stem cells), and the cord tissue. Animal and human pre-clinical and clinical studies are investigating the use of UCB in a range of diseases where the capacity for cellular regeneration and immunomodulation may be beneficial, including diabetes, arthritis, brain and spinal cord injury, and cerebral palsy.<sup>10</sup>

In Australia, the dual possibilities of therapeutic use and research use for UCB are acknowledged in the consent process. The Auscord consent form states:

After quality control testing requirements are met, the banked cord blood will be available anonymously to patients needing treatment for blood disorders such as leukaemias and some types of cancer. If the cord blood is not suitable for banking, it may be disposed of appropriately, or used for quality control purposes or for research into stem cells or treatment of relevant diseases using protocols approved by an appropriate Human Research Ethics Committee.<sup>11</sup>

The use of UCB for therapy and research is an excellent example of the way in which advances in technology can transform our perception of human tissue as waste material into recognition of it as something highly valuable in both clinical and monetary terms. As Waldby observes, 'for hospitals and clinics that have the right of disposal, waste tissue has considerable commercial and

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<sup>7</sup> Wagner and Gluckman, n 1.

<sup>8</sup> Australian Bone Marrow Donor Registry, *Frequently asked questions* ([http://www.abmdr.org.au/dynamic\\_menus.php?id=4&menuid=87&mainid=4](http://www.abmdr.org.au/dynamic_menus.php?id=4&menuid=87&mainid=4)) (accessed 25 November 2013)

<sup>9</sup> W Fodor, 'Tissue engineering and cell based therapies, from the bench to the clinic: The potential to replace, repair and regenerate' (2003) 1 *Reproductive Biology and Endocrinology* 102.

<sup>10</sup> H Zhou, S Chang, M Rao, 'Human cord blood applications in cell therapy: looking back and look ahead' (2012) 12 *Expert Opinion on Biological Therapy* 1059.

<sup>11</sup> Auscord, *Cord Blood Donation to Public Cord Blood Bank Informed Consent Form*.

epistemological value'.<sup>12</sup> This change of status has been viewed sociologically as 'a critical site for social change', modifying associations, relationships and institutions.<sup>13</sup> But this means that UCB is now a commodity over which particular groups vie for control. As a consequence, cord blood stem cells have become a focus of public, medical and scientific debate, and issues of ownership and control arise frequently.

There are many ways in which this contest becomes evident. The most obvious is the threat that private banking poses to the very viability of public cord blood banks, as UCB transplantation relies upon having sufficient numbers of cord blood units donated by people of diverse immuno-genetic heritage. The more cords that go to the private banks, the fewer cords there are available for the public banks. Controversy also arises when people want access to their child's publicly banked UCB for use in experimental therapies, either for the child or for another family member. Controversy also surrounds the use of both publicly privately stored UCB units for research that precludes their subsequent therapeutic use. Disputes of this kind mean that greater clarity is needed about the legal nature of stored UCB and the responsibilities of public banks in using these resources.

### **Concepts of stewardship and custodianship**

One way that commentators have tried to negotiate competing claims to banked human tissue is via the concept of stewardship. Stewardship is characterised by:

...the responsible use of resources, accountability for the well-being of another, and service to others. The steward acts to benefit others with an awareness that what is stewarded is something of value (footnote omitted).<sup>14</sup>

According to Jeffers, in the tissue banking context:

Using a model of stewardship to guide the ethical conduct of research using human biological materials obligates the researcher to conserve the donor's values, traditions, and culture in ethical decision-making. Stewardship recognizes the importance of not only preserving the human dignity of individual research participants, but also changing what is stewarded to benefit the community of the participant. The change that occurs within a stewardship model increases the value of what is stewarded in order to achieve the outcomes of preservation of human dignity and benefit for the common good. It does not rule out possible benefits to the individual donating the material or the steward; however, the primary obligation of the steward is to improve what is given for the common good. The emphasis is protection of entrusted resources to serve common humanity (footnotes omitted).<sup>15</sup>

Importantly, as the practice of biobanking grows from single purpose and isolated repositories to multinational networks of biobanked tissue, the concept of stewardship must also change. Fullerton et al, make the point that:

In most first generation biorepository research, the burden of stewardship fell to the originating investigator or institution and was achieved by faithfulness to the terms of

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<sup>12</sup> C Waldby and R Mitchell, *Tissue Economies: Blood, Organs and Cell Lines in Late Capitalism* (Durham, Duke University Press 2006), 115.

<sup>13</sup> P Santoro, 'Liminal Biopolitics: Towards a Political Anthropology of the Umbilical Cord and the Placenta' (2011) 17 *Body & Society* 73-93, 76.

<sup>14</sup> Jeffers, n 2, 40.

<sup>15</sup> Jeffers, n 2, 40.

informed consent and the adoption of data protections like anonymization. However, with the retention of identifying information, an expectation of ongoing oversight coordinated across independent institutions, and the need to maintain communication with participants in light of the opened nature of the research commitment, next-generation biorepository research entails far greater demands for stewardship and researcher accountability. These responsibilities may include taking due care with the analysis and sharing of confidential genetic and linked health information, the adoption of research goals consistent with the intentions of participants, and the avoidance of forms of dissemination (publications and similar) that promote harmful or derogatory conclusions about certain populations or groups.<sup>16</sup>

Some authors alternatively characterise this way of holding tissue as ‘custodianship.’ Concepts of custodianship also emphasise the duty of the tissue bank to protect and preserve the tissue, to protect the privacy of the donors and promote observance of and compliance with the donor’s consent.<sup>17</sup> The Office of Biorepositories and Biospecimen Research, US Department of Health and Human Services, National Institutes of Health and the National Cancer Institute have said, in a joint statement:

Custodianship is the caretaking responsibility for biospecimens that extends from collection through research use. Responsible custodianship requires careful planning and transparent policies to ensure the long-term physical quality of the biospecimens, the privacy of human research participants, the confidentiality of associated data, and the appropriate use of biospecimens and data. In the interest of transparency, biospecimen resource policies should be made available to the public either electronically or for onsite inspection.<sup>18</sup>

As the discussion above indicated, the practice of public UCB banking is made difficult by the competing claims of therapeutic uses and research needs of society. Incorporating concepts of stewardship and custodianship into the regulatory frameworks of UCB biobanking would help to provide a framework which both reflects how public UCB banks see themselves and a framework to mediate disputes over access to these tissues. The challenge from a legal perspective is to choose a regulatory mechanism which both respects the power of the public bank to control the resource of the biobanked tissue but in such a way that the bank both fully adopts, and is regulated by, concepts of custodianship and stewardship.

One method might be to employ the doctrine of informed consent, which would focus on the act of donation and require that banks fully inform the donor of how the tissue is going to be taken, stored and used.<sup>19</sup> In ethics, informed consent is concerned with respecting patients’ autonomy over their bodies and preventing bodily interference which has not been agreed to. When applied to tissue

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<sup>16</sup> SM Fullerton, NR Anderson, G Guzaukas, D Freeman, K Fryer-Edwards, ‘Meeting the Governance Challenges of Next-Generation Biorepository Research’ (2010) 2 *Science Translational Medicine* 1.

<sup>17</sup> K Melham, G Marsden, J Wiles, Divija Jatavallabhula, ‘Enacting regulation: tissue in practice’ (2013) 19 *Diagnostic Histopathology* 9; B Godard, J Schmidtke, JJ Cassiman, S Ayme, (2003) ‘Data storage and DNA banking for biomedical research: Informed consent, confidentiality, quality issues, ownership, return of benefits. A professional perspective’ (2003) 11 (suppl 2) *European Journal of Human Genetics* S88; G Hallmans and JB Vaught, ‘Best Practices for Establishing a Biobank’ in J Dillner (ed) *Methods in Biobanking* (New York, Springer, 2010).

<sup>18</sup> Office of Biorepositories and Biospecimen Research, US Department of Health and Human Services, National Institutes of Health and the National Cancer Institute, *NCI Best Practices for Biospecimen Resources 2011*, (<http://biospecimens.cancer.gov/bestpractices>).

<sup>19</sup> EW Clayton, et al, ‘Informed Consent for Genetic Research on Stored Tissue Samples’ (1995) 22 *JAMA* 1786; L Trommelmans, J Selling, K Dierickx, ‘The importance of the values attached to cells for a good informed consent procedure in cell donation for tissue engineering purposes’ (2009) 10 *Cell and Tissue Banking* 293.

donation there is an assumption that this concept of bodily integrity can be extended to tissues which have been excised from the body. Applied in this way, the patient should be informed not only about the process of extracting the tissue but also future processes to which the excised tissue will be subjected.

In law, the doctrine of informed consent is a doctrine of negligence which is concerned with the duty to inform patients about the risks of medical treatment.<sup>20</sup> Ordinarily those risks are risks which may impact on the person's health, but in tissue donation the risks would relate to how the tissue would be used in research or treatment.

The main problem with informed consent in the tissue banking context is that it is impossible to gain informed consent when a person is donating tissue for future unspecified uses. The whole benefit of tissue banking lies its potential to provide resources for unknown research and yet to be discovered treatments.<sup>21</sup> Using the informed consent doctrine in tissue banking requires researchers to either 're-approach donors for informed consent to every new study or they have to apply a concept of "broad" consent at the time of collection which is so far removed from the informed consent doctrine that it becomes fictional'.<sup>22</sup>

Another option would be to employ contract law as a mechanism for regulating tissue use in UCB banking. While the primary mechanism in donation is the gifting of tissue it is possible to envisage the UCB bank providing promises to the donor about how the tissue will be used. The exchange of tissue for promises about future behaviour would, arguably, be valuable consideration that would support a legally binding contract. This would enable the donor to enforce the promises concerning future use, whether through specific performance or damages.

However, contract law suffers from a major shortcoming. The contract is only enforceable between the parties due to the doctrine of privity of contract. If the tissue passes out of the hands of the original bank and into the hands of other members of a biobank network, for example, contract law can no longer apply and the donor no longer has any direct control over the use of the tissue.

A third alternative is to apply a property-based approach. Unlike contract, where the rights exist only between the parties (*in personam*), property rights create rights that are enforceable against the world (*in rem*).<sup>23</sup> Those rights flow with the property and can control how third parties can have access to and use the property. Rights in rem have the potential to avoid the limitations of both the informed consent doctrine and contract law because of their ability to control behaviours of people

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<sup>20</sup> In some jurisdictions, (for example, England and Wales) the medical profession can determine what types of risks should be communicated to patients (a doctor-based standard): *Sidaway v Governors of Bethlem Royal Hospital* [1985] AC 871. In other jurisdictions (such as Australia) a patient's own subjective desire for information may set the standard for information (a patient-based standard): *Rogers v Whitaker* (1992) 175 CLR 479.

<sup>21</sup> T Caulfield, R Brown, E Meslin, 'Challenging a well established consent norm? One time consent for biobank research' (2007) 4 *Journal of International Biotechnology Law* 69; T Caulfield, 'Biobanks and blanket consent: The proper place of the public good and public perception rationales' (2007) 18 *Kings Law Journal* 209. But for a defence of broad consent see M Otlowski, 'Developing an appropriate consent model for biobanks: in defence of 'broad' consent' in J Kaye and M Stranger (eds), *Principles and Practice of Biobank Governance* (Ashgate, Aldershot 2009) and NHMRC, *Biobanks Information Paper* (2010), pp 23-25.

<sup>22</sup> C Stewart, J Fleming, I Kerridge, 'The law of gifts, conditional donation and biobanking' (2013) 21 *Journal of Law and Medicine* 351, 353. See also B Hoffmann, "Broadening consent – and diluting ethics?" (2013) 35 *Journal of Medical Ethics* 125; LA Siminoff and HM Traino, 'Consenting to donation: an examination of current practices in informed consent for tissue donation in the US' (2013) 14 *Cell and Tissue Banking* 85.

<sup>23</sup> For a discussion of the costs and benefits of property rights see S Douglas 'The argument for property rights in body parts: scarcity of resources' (2014) 40 *Journal of Medical Ethics* 23; J Wall, 'The Legal Status of Body Parts: A Framework' (2013) 31 *Oxford Journal of Legal Studies* 783.

accessing and using the property into the future. However, if a property approach were adopted it would need to be one which balanced out the interests of UCB banks as the holder of property and which also protected and enforced concepts of stewardship and custodianship. In our view, the best legal relationship for that purpose is the charitable trust.

### The law of charitable trusts

Trusts are property relationships that originated in the equitable jurisdiction of Chancery during the Middle Ages. They remain incredibly useful and popular today. In an ordinary express trust, a person (the *trustee*) ordinarily holds the legal title to property on behalf of a third party (the *beneficiary*). The trustee is the legal owner but the beneficiaries have an equitable interest in the property. The trustee is a fiduciary, meaning that the trustee is obliged to refrain from acting in ways which cause conflict between his or her own interests and that of the beneficiaries. Trustees must also comply with the instructions contained in the trust instrument and comply with the intention of the creator of the trust (the *settlor*).

Charitable trusts are a species of express trust, but they are distinct because they exist for a purpose rather than for identifiable beneficiaries.<sup>24</sup> In a charitable trust, the legal title to property is transferred to the trustee with instructions on how the property may be employed towards the charitable purpose that serves the public interest. The charitable trust therefore employs private property rights but in such a way that they must be used in accordance both with the instructions of the settlor and in the service of the public interest.

There are two main requirements for a charitable trust to be valid. First, the trust must be created for a charitable purpose. Secondly, the trust must benefit the public.

What types of purpose are considered charitable? There is no exhaustive definition of the term 'charitable purpose.' Instead, the courts have traditionally begun with the *Statute of Charitable Uses 1601*,<sup>25</sup> which is sometimes referred to as the *Statute of Elizabeth*. The Preamble to this statute contained a statement as to the types of charitable purpose that would be recognised at law. They included, in rough translation, the relief of poverty; the care of aged persons and the sick; the care of soldiers and mariners; the advancement of education through building universities and schools; the repair of bridges, havens, ports, churches and highways; the care of orphans; the maintenance of prisons; the marriage of poor maids; support for young tradesmen and persons decayed; the relief or redemption of prisoners or captives; and relief for poor persons concerning the payment of taxes.

In the 19<sup>th</sup> century in *Commissioner for Special Purposes of Income Tax v Pemsel*,<sup>26</sup> Lord Macnaughten simplified the process further by dividing up the purposes in the Preamble into four main groupings, namely, trusts for the relief of poverty; trusts for the advancement of education; trusts for the advancement of religion; and trusts for other purposes beneficial to the community, not falling under the preceding heads.<sup>27</sup>

Up until recently, the Preamble was still employed by judges as a tool for determining whether a purpose was charitable.<sup>28</sup> The judges began with the Preamble and would then test whether the

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<sup>24</sup> *Attorney-General (NSW) v Perpetual Trustee Co Ltd* (1940) 63 CLR 209 at 222.

<sup>25</sup> 43 Eliz I c 4.

<sup>26</sup> [1891] AC 531.

<sup>27</sup> at 583.

<sup>28</sup> *Royal National Agricultural and Industrial Association v Chester* (1974) 3 ALR 486 at 487. In some jurisdictions the use of the Preamble is recognised in legislation even though the Act has been repealed: *Trustee Act 1925* (ACT) s 104, Sch 1; *Imperial Acts Application Act 1969* (NSW) s 9(2); *Trusts Act 1973* (Qld) s 103(1).

proposed usage of trust property falls within one of the traditional categories or whether it is analogous to the traditional categories. Traditionally, this test was framed as whether the purpose was 'within its spirit and intendment' of the Preamble.<sup>29</sup> Lord Reid discussed this process in *Scottish Burial Reform and Cremation Society v Glasgow Corp* and said that the courts should look for an analogy between the intended purpose and one that is either in the preamble or one that has already been recognised as charitable by the courts.<sup>30</sup>

Over the last ten years, the United Kingdom, New Zealand and Australia have all adopted statutory tests for charitable purpose which have essentially preserved and codified the existing law, while trimming away some of the infelicities. In the United Kingdom the Preamble has been replaced by a lengthy definition.<sup>31</sup> In New Zealand the statutory definition is based on the four *Pemsel* categories (meaning that the older Preamble-style approach survives).<sup>32</sup> In Australia the codification is similar to the United Kingdom definition but this definition only applies at a Federal level.<sup>33</sup> The Australian States are still bound by the older definitions and the test for whether the proposed purpose meets the spirit and intendment of the Preamble.

As stated above, charitable trusts are often referred to as 'public' trusts because of the requirement that they confer a benefit on the general public.<sup>34</sup> The benefit must be for the entire public or for a significant proportion of it.<sup>35</sup> In

Equity adopted a rebuttable presumption that trusts for the relief of poverty, trusts for education and trusts for the advancement of religion would be for the benefit of the public. In contrast, trusts in the fourth *Pemsel* category would have to be proven to be beneficial.<sup>36</sup> This is also reflected in the Australian legislation.<sup>37</sup>

The public nature of charitable trusts also means that Crown has power to supervise their operation.<sup>38</sup> The Crown, usually acting through an Attorney-General or through courts of superior

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<sup>29</sup> *Gilmour v Coates* [1949] AC 426 at 442–3.

<sup>30</sup> [1968] AC 138 at 147.

<sup>31</sup> *Charities Act 2011* (UK), s 3.

<sup>32</sup> *Charity Act 2006* (NZ), s 5. See *YMCA New Zealand Soldiers Great War Memorial Trust* [2013] NZHC 2516; *Greenpeace of New Zealand Incorporated* [2012] NZCA 533 (leave to appeal granted in *Re Greenpeace of New Zealand Inc* [2013] NZSC 12).

<sup>33</sup> *Charities Act 2013* (Cth), s 12(1).

<sup>34</sup> G E Dal Pont. *Equity and Trusts in Australia* (5th ed, Sydney, Lawbook Co, 2011) 841.

<sup>35</sup> *National Anti-Vivisection Society v Inland Revenue Commissioners* [1948] AC 31; *Gilmour v Coats* [1949] AC 426; *Re Compton* [1945] Ch 123; *Oppenheim v Tobacco Securities Co Ltd* [1951] AC 297

<sup>36</sup> *National Anti-Vivisection Society v Inland Revenue Commissioners* [1948] AC 31 at 42. But see *Helena Partnerships Ltd v Commissioner for Her Majesty's Revenue and Customs* [2012] EWCA Civ 569, where this approach was doubted.

<sup>37</sup> *Charities Act 2013* (Cth), s 7. Section 7 stipulates that there is a rebuttable presumption that the requirement of public benefit set out in s 6(1) if the entity's purpose is any of the following:

- (a) the purpose of preventing and relieving sickness, disease or human suffering;
- (a) the purpose of advancing education;
- (b) the purpose of relieving the poverty, distress or disadvantage of individuals or families;
- (c) the purpose of caring for and supporting:
  - (i) the aged; or
  - (ii) individuals with disabilities;
- (d) the purpose of advancing religion.

Special provisions also apply to trusts for indigenous Australians: s 9.

<sup>38</sup> *Num-Hoi, Pon Yu, Soon-Duc Society Inc v Num Pon Soon Inc* (2001) 4 VR 527; *Tomasevic v Jovetic* [2011] VSC 131.



jurisdiction, is the only competent authority to protect and enforce charitable trusts.<sup>39</sup> The Attorneys-General of each jurisdiction represent the Crown's interests in matters of charitable trusts and have standing to appear in proceedings concerning charities. Indeed, the Attorney-General is a necessary party to any proceedings regarding a gift to charity that is made generally or for undefined charitable purposes, or for any proceedings concerning the alteration of a charity's rules.<sup>40</sup> The representatives of charitable institutions can also appear when they are involved in the administration of the trust. A statutory right to appear has been granted in some jurisdictions to persons who have an interest in the charitable trust.<sup>41</sup> Trustees also have a right to seek advice and get directions from the court.<sup>42</sup> Advice may be sought in relation to issues concerning the management or administration of the trust property.<sup>43</sup>

Charitable trusts can charge for their services and may make a profit, as long as that profit is reinvested back into the charitable purpose.<sup>44</sup> Charities may even own other businesses not otherwise associated with the charity and run them at a profit and still claim the benefit of charitable status.<sup>45</sup> This gives the charity the benefit of running their properties like a private property owner, while at the same time recognising that the profits must be reinvested back into the charitable purposes.

Finally, an interesting feature of charitable trusts is that they can be varied when circumstances change and it is impossible or impractical to carry out the charitable objects of the trust in the way the creator of the trust originally intended. Such changes to charitable trusts are known as *cy-près* schemes. As long as the creator of the trust has expressed a general charitable intention, the court will be able to reformulate the trust so that it will be able to continue serving its underlying charitable purpose. *Cy-près* schemes can be applied in cases where the original terms of the trust have ceased to provide a suitable and effective method of using the trust property and more appropriate uses are available which accord with current policy or knowledge.<sup>46</sup>

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<sup>39</sup> The jurisdiction originates from the ancient *parens patriae* jurisdiction, which gives the Crown and the courts the power to care for infants and the mentally disabled (who were traditionally classed *idiots* and *natural fools*, or *lunatics*): *Hunter Region SLSA Helicopter Rescue Service Ltd v Attorney-General (NSW)* [2000] NSWSC 456; *Australian Incentive Plan Pty Ltd v Babcock & Brown International Pty Ltd (No 2)* [2011] VSC 43 at [7].

<sup>40</sup> P Radan and C Stewart, *Principles of Australian Equity and Trusts* (2<sup>nd</sup> ed, Sydney, LexisNexis, 2013) Chp 18.

<sup>41</sup> See *Charities Procedure Act 1812*, 52 Geo III c 101, which appears to still apply in the Northern Territory; *Trustee Act 1925* (ACT) s 94A; *Charitable Trusts Act 1993* (NSW) s 6 (proceedings to be brought with the Attorney-General's permission or with the leave of the court); *Trusts Act 1973* (Qld) s 106(2), *Trustee Act 1936* (SA) ss 60(2), 66; *Religious Successory and Charitable Trusts Act 1958* (Vic) s 61 (two or more persons with the consent of a law officer); *Charitable Trusts Act 1962* (WA) s 21(1).

<sup>42</sup> *Re Permanent Trustee Australia Ltd* (1994) 33 NSWLR 547.

<sup>43</sup> *In the Matter of Creditors' Trust of Jackgreen (International) Pty Ltd* [2011] NSWSC 748; *In the Matter of the Daquino Family Trust* [2009] NSWSC 429; *Re Saunders Nominees Pty Ltd; Ex Parte Saunders Nominees Pty Ltd* [2007] WASC 152; *The Kean Memorial Trust Inc v AG for SA (No 2)* [2007] SASC 133.

<sup>44</sup> *The Incorporated Council of Law Reporting of the State of Queensland v FCT* (1971) 125 CLR 659 at 669–70; *Crystal Palace Trustees v Minister of Town and Country Planning* [1951] 2 Ch 132; *In re Resch's Will Trusts; Le Cras v Perpetual Trustee Co Ltd* [1969] 1 AC 514.

<sup>45</sup> *Commissioner of Taxation v Word Investments* (2008) 236 CLR 204.

<sup>46</sup> *Attorney-General for New South Wales v Fulham* [2002] NSWSC 629 at [12]–[17]. In *The Cram Foundation v Corbett-Jones* [2006] NSWSC 495, a *cy-près* scheme was ordered for the use of a home which had been originally intended for the care of 'crippled' children. Changes in government policy to shift towards de-institutionalisation meant that the original terms were no longer a suitable and effective means of carrying out the donor's intention. The court agreed with a plan to use the property as a conference centre where the funds would go towards the care of children with disabilities.

## Applying a charitable trust framework to public UCB banks

Would public UCB banks be understood as having a charitable purpose? There are three bases on which it could be argued that they do.

Firstly, given the focus of public UCB banks on providing therapeutic products, it could be argued that public banks are trusts for the relief of poverty. The poverty category includes trusts for the 'impotent,' namely vulnerable people who may suffer from an illness or disability.<sup>47</sup> Gifts to hospitals and like institutions are also within the poverty category.<sup>48</sup>

Secondly, the fact that public UCB banks provide material for research means that they are trusts for education.<sup>49</sup> The term 'education' includes research.<sup>50</sup> A number of research trusts have been found to be charitable such as trusts for research into disease and trusts for cancer research.<sup>51</sup>

Thirdly, gifts for public health infrastructure can also fall within the fourth *Pemsel* category because they are trusts that are otherwise beneficial to the community.<sup>52</sup>

The combination of these three grounds means that there are very strong reasons for concluding that public UCB banks have a charitable purpose. There are equally strong grounds for saying that the public benefit test would also be satisfied. Firstly, as public UCB banks appear to be trusts for poverty and education, there would be a presumption of public benefit. Even if there were not a presumption, the fact that public UCB banks provide therapies to a large number of patients from completely diverse backgrounds would mean that the public benefit test could easily be satisfied. The fact that UCB is also provided as a research resource for the community, only adds to this conclusion.

## The benefits and costs of a charitable trust approach

The most obvious benefit to employing charitable trust approach is that it provides a legal mechanism for the regulation and enforcement of concepts of custodianship and stewardship in biobanking. The charitable trust model upgrades these ethical standards into legal ones with teeth.

Firstly, this is achieved by giving donors and general members of the public an interest in the management of the trust and the ability to approach the court if they are concerned about breaches. Secondly, the Attorney General and the Supreme Court both have the power to supervise and manage the trust, as a way of protecting the interests of the public. The charitable trust model does both of these things while still recognising the biobank's legal ownership of the tissue and its capacity to use the tissue commercially (in accordance with the terms of the trust). The combination of private rights and public interest is part of a robust regulatory model that has been tested for 800 years.

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<sup>47</sup> Examples of such trusts include, trusts for orphans (*Attorney-General (NSW) v Perpetual Trustee Co Ltd* (1940) 63 CLR 209), trusts for 'crippled children' (*The Cram Foundation v Corbett-Jones* [2006] NSWSC 495), trusts for 'retarded' or 'sub-normal' children (*Eurella Community Services Inc v Attorney General for the State of NSW* [2010] NSWSC 566), trusts for the blind: *Re Inman (dec'd)* [1965] VR 238. See also the *Charities Act 2013* (Cth), s 12(1)(a) which includes 'advancing health' as a charitable purpose. Section 14 states that 'advancing health' includes the purpose of preventing and relieving sickness, disease or human suffering.

<sup>48</sup> *In re Resch's Will Trusts; Le Cras v Perpetual Trustee Co Ltd* [1969] 1 AC 514.

<sup>49</sup> See *Charities Act 2013* (Cth), s 12(1)(b)

<sup>50</sup> *Taylor v Taylor* (1910) 10 CLR 218.

<sup>51</sup> *Estate of Schultz* [1961] SASR 377; *Re Simpson (dec'd)* [1961] QWN 50.

<sup>52</sup> *Perpetual Trustee Co Ltd v St Luke's Hospital* (1939) 39 SR (NSW) 408.

Donors to a biobank run as a charitable trust may also get the benefit of greater involvement. It would be open to the biobank to adopt charitable trust forms, such as a board of governors, donors and other members of the public would have an opportunity to be involved in the running of the bank.<sup>53</sup> A continued involved and relationship would have the possibility of reducing the ethical dilemmas of consent to future research, incidental findings and unanticipated results, because the donors will be more encouraged to stay in contact with the biobank.

The charitable trust model also is of benefit to the biobank. Under the charitable model the biobank can seek the help and advice of the courts about difficult issues of management. The biobank can also operate at a profit and maintain its charitable status. If circumstances change, new opportunities for use and research arise that were not originally conceived by trust, the biobank can approach the court and seek to amend its terms of operation via the *cy-pres* doctrine. The charitable trust model therefore provides biobanks with support and flexibility. The underlying value of altruism, which is a feature of charitable trusts, may also encourage greater feelings of trust and community support for the biobank and greater rates of donation.

The cost of adopting this model is that there will be greater oversight and accountability and this may add to the running expenses of the organisation. Charitable trusts are subject to reporting and accounting requirements, but arguably these would be not much greater than the reporting requirements that biobanks already face when operating.

### **Conclusion: biobanks would benefit from a charitable trust model**

This chapter has argued that current biobanking practices need to incorporate ethical values of custodianship and stewardship into their frameworks. Using the example of public cord blood banking, we have argued that the charitable trust model is a good model to adopt for this purpose. The charity model has the ability to balance out the private and public aspects of biobanking and incorporate a continuing concern for the interests of donors. The requirement that charitable trusts are run in the public interest is also fully compatible with the notion that biobanking occurs in a framework of community expectations and interests. A charitable trust model allows a biobank to balance out the different claims that are made to access and use tissue. While it does not resolve all the ethical concerns of biobanking, a charitable trust does provide a mechanism for donors to continue to have a relationship with their donated tissue, which is monitored and controlled by the Attorneys General and courts of higher jurisdiction. Charitable trusts law is therefore well suited as a mechanism for introducing and enforcing obligations of stewardship and custodianship.

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<sup>53</sup> Winickoff and Winickoff, above n 4 at 1182.