

Impact case study (REF3b)

<p>Institution: University of Cambridge</p>
<p>Unit of Assessment: 24 Anthropology and Development Studies</p>
<p>Title of case study: Human body parts and donation: Conceptual, cultural and policy issues in the UK.</p>
<p>1. Summary of the impact (indicative maximum 100 words)</p> <p>Research in the Department of Social Anthropology concerning the ethics of the use of biotechnology has had an impact on organisations with a public voice on the ethical use and regulation of body parts for reproduction and medicine, such as the Nuffield Council on Bioethics (NCOB), and indirectly the Welsh Assembly, the UK-wide Human Fertilisation and Embryology Authority (HEFA). Further, their recommendations which have been informed by this research have had significant impact on public understanding and debate; health and well-being; and on egg donors and recipients in particular. Implementation of recommendations based on the research has seen waiting times for donor eggs halve.</p>
<p>2. Underpinning research (indicative maximum 500 words)</p> <p>The research underpinning the impact was undertaken by Professor Dame Marilyn Strathern (Professor, Department of Social Anthropology, University of Cambridge, 1993-2008) and Dr Maryon McDonald (Robinson College, University of Cambridge, 1997-present), the Department’s Comparative Studies in Biotechnology and accountability research grouping provided the context for collaboration.</p> <p>Although not originally conceived as applied research, the underpinning research took place between 2005-2010 against a backdrop of critical shortage of organs for transplantation and human gametes for use in assisted reproduction. Each year around 7500 people in the UK await transplants, with an estimated 1000 people dying as a result of the wait. The shortfall of 1000 egg donors results in longer waits and more risky choices. Such shortages, and their various implications for patients (and their families), donors (and their families), and health service utilisation, raise highly contested questions and debate about how donations of organs and gametes could be increased.</p> <p>Strathern and McDonald’s research aimed to understand both practical and conceptual issues around bodies, body parts, and biotechnology involving giving and receiving human body parts in cultural context. It relied on a particular combination of expertise:</p> <ul style="list-style-type: none"> • In comparative methods, transactions and ownership of body parts (Strathern) • European Anthropology and policy (McDonald) • Reproductive technologies (Strathern) • Organ transplantation (McDonald). <p>As anthropologists Strathern and McDonald focused on how bodies are defined and understood, and the extent to which they are bounded, owned, tradable, or giftable. The use of comparative method⁽¹⁾ helped to highlight cultural definitions of body parts,⁽²⁾ conceptual boundaries, options for increasing donation and criteria for evaluating them in the UK context. For example, funded by a Leverhulme programme grant “Changing beliefs of the human body” (2005-9), McDonald used a comparative analysis of organ donation in Europe, where consent and donation show different patterns, to re-examine the UK guidance for the diagnosis of death and its connection to post mortem organ donation.⁽³⁾ This showed that problems faced by families of the inherently relational⁽²⁾ donor may differ from the problems faced by both the medical professions and donation campaigns. Consequently there is a need to balance these differences in policy and practice.</p> <p>Comparison with assisted reproduction showed that conceptual issues pertinent to ethics and regulation are shared with transplantation; the boundary between “natural” and “social” becomes blurred, roles and states normally taken for granted are challenged, and the issue of “giving” becomes problematic.^(5,6) These conceptual issues have important practical consequences for</p>

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regulation and management of human body parts.

Key findings and insights from the research include:

- (1) identification of different potential policy solutions based on McDonald's comparative research
- (2) recognition of the importance of cultural context to such solutions being meaningful and/or appropriate
- (3) the importance of *individual altruism* to donation of body parts in the UK context
- (4) the recognition that this does not necessary preclude payment or development of other incentives where it is viewed as *compensation* to donors.

3. References to the research (indicative maximum of six references)

1. Strathern, M (2011) 'Binary License', *Common Knowledge*, 17(1): 87-103. doi: 10.1215/0961754X-2010-040
2. Strathern, M (2005) *Kinship, Law, and the Unexpected: Relatives are Always a Surprise*. Cambridge: Cambridge University Press, Chapter 5. Pp 111-134. Available from HEI.
3. McDonald, M (2011) "Deceased organ donation, culture and the objectivity of death" in *Organ Transplantation: Ethical, Legal and Psycho-Social Aspects*. Eds: W. Weimar, M.A. Bos, and J.J.V. Busschbach. Eichengrund: Pabst. Available from HEI.
4. Lambert, H and McDonald, M (2009) Eds: *Social Bodies*. NY and Oxford: Berghahn. Available from HEI.
5. Strathern, M (2002) 'Still Giving Nature a Helping Hand? Surrogacy: A Debate about Technology and Society', *Journal of Molecular Biology*, 319: 985-993. DOI:10.1016/S0022-2836(02)00352-2
6. Strathern, M (2012) "Gifts Money Cannot Buy", *Social Anthropology* 20(4): 397-410. DOI:10.1111/j.1469-8676.2012.00224.x

Grants and funding

Project (2005-09) forming part of the Leverhulme programme grant "Changing beliefs of the human body" (2005-10).

PI: Dr John Robb Department of Archaeology, University of Cambridge, Award Value £1,181,111 (our ref RG40430). Marilyn Strathern and Maryon McDonald were identified investigators of the project component of the programme and the project value was £125,792

4. Details of the impact (indicative maximum 750 words)

The direct beneficiaries of the research were organisations with a public voice on the ethical use of, and regulation on, body parts for reproduction and medicine: specifically the Nuffield Council on Bioethics (NCOB), and indirectly the Welsh Assembly, the UK-wide Human Fertilisation and Embryology Authority (HEFA). In turn, their work has had significant impact on public understanding and debate (on egg donors and recipients in particular), and through this on health and well-being.

The research underpinning the impact was subsequently disseminated to such organisations through their direct involvement with the research conducted (including their attendance at events designed to develop consensus definitions), through Strathern's role as Chair of the NCOB Working Party, and through McDonald's evidence to that Working Party; wider dissemination has occurred through publication, the sharing of best practice, and the media.

As confirmed by the NCOB:

"Marilyn [Strathern] was appointed as Chair to the Working Party because of her academic reputation, particularly in connection with her anthropological work on new reproductive technologies and on gift relationships."^(a)

In 2011 the NCOB Working Party produced a report, *Human bodies: donation for medicine and research*^(b), which set out guidance to help professionals and others consider the ethical acceptability of various ways of encouraging people to donate, both for treatment of others and for

scientific research.

Whilst the NCOB report was the result of the collective discussion and opinion of the Working Party, their overall analytical approach to the work was shaped by Strathern in particular. Strathern's guidance on the use of comparative analysis (referred to as "*analogies*" below) was essential.

The Final Report also more directly reflects engagement with Strathern and McDonald's research. For example, the guide to the full report highlights sections on international comparisons and conceptual issues around uses of money in the context of donation, and argues that it is possible to compensate donors without donations becoming purchases, as well as consider alternatives.^(d) The full Final Report makes extensive use of concepts and ideas developed by Strathern (e.g. 2002), including sections on: comparison and analogies, discussion of money in context of ethical choice, gift relationship, relational thinking (public and private) and the issue of altruism.

As summarised in a letter by the NCOB on Professor Strathern's contribution:

"Marilyn's role was crucial... both through her highly facilitative and inclusive chairing...and because of her own intellectual contribution to the thinking and analysis that underpinned the practical recommendations made in the report.

The following areas of analysis in the report derived almost exclusively from Marilyn's input:

- *the use of analogies across a wide range of forms of donation and volunteering, and in particular between the donation of eggs and volunteering to participate in a first-in-human trial (see Box 1.8 in Chapter 1 of the report);*
- *the distinctions between various forms of payment: 'purchase' of a thing; 'reward' to a person; and 'recompense' of a person (see figure 2 on p71 of the report);*
- *the analysis of the gift relationship (paragraphs 4.9 - 4.14); and*
- *the analysis of the role of money, and the very different meanings assigned to money in different contexts (paragraphs 4.15 - 4.16 and box 4.4).*

These four areas of analysis were essential in reaching our conclusions as to what role various forms of payment could legitimately play in promoting various forms of donation..."^(a)

In addition, McDonald's research was used in evidence to the Working Party^(c), drawing on Lambert and McDonald (2009). McDonald's evidence focused on relational thinking and the need for future policy and guidance to take account of different perspectives on bodies and parts, and the context in which decisions were made. Strathern's work on surrogacy and money shaped the Working Party's position on compensation, and this subsequently fed into policy (see below 7)

Following publication of the NCOB Report in 2011, Strathern helped disseminate the findings to the public and other stakeholders through the media. There was wide media coverage of the Report's concerns. In the context of organ donation for example, one BBC article attracted 371 comments before the discussion closed.^(d)

As well as informing public understanding and debate in this way, the Report also influenced both practice and guidance. (Full details appear in the NCOB's 28-page summary of the Report's impact one year after publication).^(e) The clearest example of a direct impact on practice is the adoption of the NCOB Report's recommendation by The Human Fertilisation and Embryology Authority (HFEA), the UK-wide regulator which oversees the use of gametes and embryos in fertility treatment and research, as reported by the NCOB:

"The Human Fertilisation and Embryology Authority today decided that women who donate their eggs for others' treatment should be compensated £750 per cycle, and that sperm donors should be compensated £35 per clinic visit.

"The [NCOB] Council recommended in its recent report 'Human bodies: donation for medicine and research' that lost earnings should be fully reimbursed for those donating eggs or sperm for others' treatment, so that they are not left out of pocket. The Council specifically recommended that the

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cap of £250 on recovery of lost earnings for egg and sperm donors should be removed.”^(f)

(Further, according to the Independent (20-10-2011) “The decision followed a two-year review, including a public consultation, of the medical, social and ethical issues.”^(g))

In turn, the change in practice has improved health and well-being. According to a survey of fertility clinics carried out by *The Telegraph* in November 2012^(h) – official HFEA data are not yet available – more women donated eggs as a result of the change in payments and “waiting lists have now halved”. Shorter waiting lists mean that women are less likely to seek assistance abroad (and thereby incurring greater cost and risk to health where assisted reproduction is less regulated).

The significance to this to those who rely on egg donations is illustrated by one recipient quoted in *The Guardian* in 2012: “I think of my donor every day... Our donor didn’t just bring joy into our lives, but into the lives of everyone who means the most to us”.⁽ⁱ⁾

In terms of influencing guidance, the NCOB gave evidence to the National Assembly for Wales Health and Social Care Committee on the Human Transplantation (Wales) Bill based on the Report.

The Working Party Report has also been used by the International Society for Stem Cell Research to inform the discussion of their recent position paper,^(j) using the report to argue that commercial transactions ‘are ethically highly controversial’ but compensation is not.

5. Sources to corroborate the impact (indicative maximum of 10 references)

- a) Letter from Nuffield Council on Bioethics
- b) *Human bodies: donation for medicine and research*, Nuffield Council on Bioethics, ISBN 978-1-904384-23-6, http://www.nuffieldbioethics.org/sites/default/files/Donation_full_report.pdf
- c) Written evidence provided by Maryon McDonald to the NCOB working group: <http://www.nuffieldbioethics.org/sites/default/files/files/Dr%20Maryon%20McDonald.pdf>
- d) <http://www.bbc.co.uk/news/health-15242675>, 11 October 2011
- e) http://www.nuffieldbioethics.org/sites/default/files/files/HumanBodies_report_developments_web.pdf
- f) <http://www.nuffieldbioethics.org/news/hfea-approves-increased-compensation-egg-and-sperm-donors>
- g) <http://www.independent.co.uk/life-style/health-and-families/health-news/what-price-parenthood-2373212.html>
- h) <http://www.telegraph.co.uk/health/healthnews/9696083/Fertility-treatment-waiting-times-halve-after-increased-payments-to-donors.html>
- i) <http://www.guardian.co.uk/society/2012/dec/13/egg-donation-donor-recipient-experience>
- j) ISSC (2013) Position Statement on the Provision and Procurement of Human Eggs for Stem Cell Research <http://www.ncl.ac.uk/peals/assets/documents/EPPEggProvisionHaimes0313.pdf>