

# Creating an ethical framework for improving policy on human tissue donation



**Professor Farsides' work with the Human Fertilisation Embryo Authority's National Donation Strategy Group focuses on investigating obstacles to egg, sperm and embryo donation and establishing guidance for good practice in clinics.**



'The recommendations, the support they received from all professions and the consequent success of the NHS in achieving the 50 per cent increase in donors which we hoped for, was achieved in part because of the humanity, the reasoning from ethical principles and the common sense Bobbie Farsides brought to the debate, both round the Taskforce table and through the work of the Donation Ethics Committee.'

Elisabeth Buggins, Chair of the UK Organ Donation Taskforce

**The work of Professor Bobbie Farsides at Brighton and Sussex Medical School identifies ethical and clinical issues faced by healthcare practitioners and informs policy-making and clinical practice in relation to solid organ donation and transplantation and the donation and use of embryos, eggs and sperm for treatment and research.**

## Overview

The potentially emotive and controversial issue of human tissue donation in medicine and science, including solid organ donation and the use of embryos and stem cells in research, consistently garners headlines and generates public debate. A comprehensive understanding of the ethical issues of human tissue donation is key to influencing policy decision-making that leads to the development of the best possible regulations governing these issues.

Bobbie Farsides, Professor in Clinical and Biomedical Ethics (Clinical Medicine) at the University of Sussex, is an academic ethicist who has had a direct influence upon clinical practice and policy-making in healthcare and biomedicine. Her work focuses on the experience of healthcare professionals and scientists operating in morally contested fields, and combines mixed empirical methods and philosophical medico-legal analysis in a novel approach. In this context, Professor Farsides introduced and developed the use of Ethical Discussion Groups, where practitioners who have been previously observed and interviewed



in their professional setting participate in group discussions facilitated by an ethicist. The data generated from such interventions have helped identify both the complex ethical, legal and clinical issues that practitioners experience in their working lives and workable solutions to help address these issues.

By interacting with professionals working in assisted reproductive services, embryology and stem-cell research, particularly in relation to donation for research and treatment, Professor Farsides has addressed questions of how and when to approach clients with regard to donation, how to define an embryo as 'spare', how to conceptualise and then acquire consent for embryo donation for treatment and research, and how best to construct robust regulatory frameworks that govern this area. The findings of this work have been particularly influential in prompting professional bodies to revisit the basis upon which an embryo is defined as being 'spare' and, therefore, available for research.

Professor Farsides is also a major expert contributor to the national debate regarding solid organ donation, including defining the appropriate basis for consent to organ donation. Furthermore, her work with organisations such as the Organ Donation Taskforce (ODT) has been highly influential in the development of donation strategy in the UK.

## Achieving impact

The impact of Professor Farsides' work has widespread and far-reaching implications in developing guidelines and recommendations for tissue donation, and the basis of ground-level practical advice and guidance offered to practitioners.

The 2008 report of the ODT, reporting on barriers to organ donation, made recommendations to improve donation rates by 50 per cent, a target that NHS Blood and Transplant announced it had achieved in 2013. Professor Farsides made significant contributions to several of the reports and documents that cumulatively resulted in this improvement. Additionally, she was the first ethicist appointed to the UK Donation Ethics Committee and was a major contributor to the ethical content and recommendations published in *An Ethical Framework for Controlled Donation after Circulatory*

*Death*, helping to make them 'fit-for-purpose' in the clinical setting. The guidance outlined in the report addressed the specific legal and ethical issues faced by healthcare professionals caring for potential organ donors and has been the basis for an increased willingness and ability of staff to facilitate donation after circulatory death.

Professor Farsides' work has also had major impact in other areas of human tissue donation. As a member of the Nuffield Council on Bioethics Working Party on Human Bodies in Medicine and Research (2011) she was key contributor to the drafting of an ethical framework for informing recommendations made by the committee. Their report has been cited by key policy-makers, most notably the Human Fertilisation Embryo Authority (HFEA), as influential in raising the level of payment to egg donors. Subsequently, in 2012, she was appointed to the HFEA's National Donation Strategy Group – a body charged with investigating the obstacles to egg, sperm and embryo donation and establishing guidance for good practice in clinics. Working closely with the Chair, Professor Sheila McLean, Farsides has helped establish the underlying ethical principles informing this group's work and has collaborated on the production of practical tools to enhance the provision of information and processes for obtaining consent within clinics.

## Future impact

Most recently Professor Farsides has returned to her long-term interest in research ethics, chairing the Nuffield Council on Bioethics Working Party on Children's Participation in Research and contributing to the work of the new Wellcome Trust Global Health Centre at Brighton and Sussex Medical School by developing and expanding her work on Rapid Ethical Appraisal (REA). In both contexts, her work will contribute to the advancement of ethically sound scientific and medical research in both the developed and developing world.

## Funding and partnership

Key research funding has included a Wellcome Trust Biomedical Ethics Strategic Award (2009-2014): The ethics of translational research: from 'unnatural entities' to experimental treatments, and an NIHR Programme Grant: Increasing the Acceptability and Rates of Organ Donation Among Ethnic Groups (September 2009).

Professor Farsides is a member of the following committees and working groups: Brighton and Sussex University Hospitals Trust Organ Donation Committee, UK Donation Ethics Committee, MRC Brain Bank Network Steering Committee, Emerging Science and Bioethics Advisory Committee (ESBAC), HFEA's National Donation Strategy Group, and SaBTO's (Advisory Committee on the Safety of Blood, Tissues and Organs) Cell-based Advanced Therapies Working Group.

## Working with us

If you are interested in working with us, please contact:

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For information about research on medical ethics and humanities, visit:

**[www.bsms.ac.uk/research/our-research/medical-ethics/](http://www.bsms.ac.uk/research/our-research/medical-ethics/)**