

Project Update

November 2010

Dr Ken Taylor joined the project as Research Associate in September 2008 and guided the study through a full ethics review, gaining favourable opinions from the local NHS Research Ethics Committee and the Newcastle upon Tyne Hospitals Trust, Research and Development Department.

Fieldwork has been ongoing since 2008 and Erica has conducted a number of interviews with volunteers for the scheme, some of whom went on to share eggs and some of whom did not. These interviews have proved to be as rich and valuable as was hoped for and further efforts are being made to recruit interviewees from amongst a wider group of women who have expressed interest in the egg sharing scheme. A strategy to identify and invite women who can provide insights from comparable experiences has also been crafted and interviews with these women and clinic staff took place in early 2010. Ken has begun the analysis of various documentary materials, such as media reports, to understand the context within which the interviewees' experiences are situated.

Key audiences were identified to whom the results of this study, and the comparative insights from the Wellcome Trust embryo donation study, have been disseminated. Both Erica and Ken have presented papers to regulators, scientists, clinicians, patient group representatives, social scientists and ethicists at national and international conferences and workshops. Analysis of the interviews has been completed and a programme of peer reviewed publications has been undertaken.

November 2011

In February 2011 we hosted the 12th PEALS Annual International Symposium in Newcastle with the aims of communicating our key findings to practitioners and policymakers and advancing applied and theoretical debates on the uses of human reproductive tissue in research and treatment. The Symposium was opened by Professor Sir Liam Donaldson, a previous Chief Medical Officer of England and Wales. Participants from the UK, Australia, Canada, Germany and Belgium stimulated a range of lively debates; the discussion provoked by the contrast between empirical findings, such as ours, and normative approaches in the academic literature (for example whether reduced price IVF treatment in exchange for eggs for research exploits women) was of especial interest.

The research itself, and the Symposium, have been particularly timely given the 2010-11 Human Fertilisation and Embryology Authority consultation on the payment of gamete providers and the Nuffield Council on Bioethics Working Party on the donation of human tissue and organs for treatment and research. Members of the HFEA and its Executive were active participants in the Symposium and the Chair of the NCoB Working Party, Professor Marilyn Strathern, provided the final keynote presentation.

Two other events were held in parallel with the Symposium:

- a meeting of our Project Advisory Group (PAG), and
- a Café Scientifique.

The former was a chance to talk through our early findings with three of the PAG members, and Erica and Ken wish to express their thanks for the constructive discussion. The PAG members, together with a number of international delegates to the Symposium then participated in a Café Scientifique, public discussion. This event was well attended by interested members of the public from the North East and generated lively debate on the subject of the 'uses of human reproductive tissue in research and treatment'.

Fieldwork was completed early in the year and a thematic analysis of interviews has been conducted, leading to the identification of five core themes, and 14 other related themes, that are forming the basis of future publications. The first article accepted for publication (in *Sociology of Health and Illness*) was on the subject of 'exploitation'.

During 2011 key findings from the project were presented widely. Ken spoke at the 'Exploring the ELSI Universe' conference at the University of North Carolina, USA and presented posters at both the European Society of Human Reproduction and Embryology annual meeting in Stockholm and the Stem Cells Europe conference in Edinburgh. Erica discussed findings with colleagues on the Ethics and Public Policy Committee of the International Society for Stem Cell Research at their annual meeting in Toronto and at their international workshop at the Brocher Foundation in Geneva. She also presented initial findings to the Innogen Research Centre in Edinburgh University and at the European Association of Centres of Medical Ethics annual conference in Istanbul.

Erica was invited by the Nuffield Council on Bioethics Working Party on 'Human bodies: donation for medicine and research' as a participant in their Experts' Opinion Forum on public versus private benefit from donation in November 2010. In further international dissemination activities, Erica was Visiting Professor at Otago University, New Zealand in March 2011 and engaged in a full programme of meetings and presentations throughout the country.

Funding for the project ended in July 2011 and our final report to the MRC was submitted at the end of October. However, work continues on the analysis, drawing together the results of this and Erica's ongoing embryo donation project, thanks to the generous funding of the Wellcome Trust. A series of Briefing Sheets are being prepared for distribution to policy-makers, practitioners and all interested parties via this website.