

2015 Update

Rowlands Gill Women's Institute

On Thursday 5th February 2015 Erica and Ken attended a meeting of the Rowlands Gill Women's Institute (WI) to lead a discussion titled 'Eggs, ethics and exploitation'.

Around 55 WI members were present and enthusiastically engaged in discussions centred on a real-life scenario presented by Erica:

A young woman that you know – she could be your daughter, grand-daughter, niece, sister, friend, work colleague or acquaintance – tells you that she has seen a story in a newspaper asking women aged 18 to 35 to volunteer to provide eggs for research. Women who provide eggs will receive £500. She is 23 years old, thinking about volunteering and asks what you think.

- *What sorts of things would you suggest that she needs to think about?*
- *What would you advise her to do?*

The WI members, half of whom did not know previously about the recruitment by scientists of young women to provide eggs for research, raised a number of important questions that they considered such a young woman should think about. From concerns about the safety of the egg donation process to questions about the research for which the eggs are wanted, the topics raised by WI members demonstrated a careful consideration of the issues.

After this initial discussion Erica gave a short presentation, highlighting five key areas of concern in the academic literature; informed consent, undue inducement, exploitation, human dignity and the nature of the research in which the eggs were to be used.

Further open discussion then followed and around a third of the women later indicated, via feedback forms, that they had changed their minds about the advice they would offer a young woman who was considering donating eggs to research. Most women who provided feedback appear to have become more cautious in their advice, with reasons for changing their advice including; finding out exactly what was involved in donating eggs, how future health might be affected and how much more complex the issue was than they had originally thought. Only one woman reported that she would be more supportive after hearing the discussion.

The presentation and discussion was originally scheduled at 45 minutes, but the engagement of the WI members in discussion and the desire of many to participate, meant that the event lasted over an hour.

Comments received included: 'Very well presented and thought provoking.' 'Interesting and informative.' 'Interactive, lots of discussion time to reflect on very important issues.'

Project Advisory Group meeting

Tuesday 22nd September 2015 saw the second meeting of our Project Advisory Group (PAG).

In addition to Erica and Ken, those PAG members attending were: anthropologist Professor Dame Marilyn Strathern, Cambridge University; academic lawyer Professor Shaun Pattinson, Durham University; clinical geneticist Professor Frances Flinter, Guy's and St Thomas Hospital and King's College London; Dr Dan O'Connor, Head of Medical Humanities and Social Science at the Wellcome Trust; and forensic scientist Dr Sophie Carr, Northumbria University (who brings personal experience of IVF treatment to the group). Consultant gynaecologist Dr Meenakshi Choudhary from the

Newcastle Fertility Centre at Life attended in place of project co-investigator Professor Alison Murdoch. Apologies came from Professor Clare Williams, Sociology, Brunel University and ethicist Professor Jackie Leach Scully from PEALS, Newcastle University.

Erica and Ken provided a document updating the Group on progress with fieldwork, responses made to consultations, dissemination and publication activities (both undertaken and planned) and active links with other research projects. In terms of fieldwork for the project, 35 interviews had been conducted, comfortably exceeding the target of 30; these had been completed in December 2014.

Analysis is ongoing so there was a discussion of major themes emerging from the data and a draft conceptual map of the themes was tabled. Members of the PAG expressed their interest in the early findings and raised thoughtful and engaging questions about a number of issues. Marilyn asked how the lengthy and detailed aide memoire for the interviews, presented at the previous meeting, had worked in practice; one seemingly simple question that led to a long discussion of the many themes that arose during the conversations with women about their experiences of volunteering to provide eggs. Questions about the money the women received and how they used it were also discussed. In the ensuing discussion a number of interesting lines of enquiry were raised that will aid the continuing analysis of interview data.

Erica and Ken sought suggestions for ways to get project findings to the multiple audiences of scientists, clinicians and policymakers; the PAG members were very helpful in suggesting a wide range of academic and non-academic places where debate could be stimulated.

[Café Scientifique](#)

On 21st September 2015 Erica and Ken organised an event that was part of the Newcastle Café Scientifique programme. This was very well attended (standing room only, of over 60 people) and featured Dr Dan O'Connor, head of Medical Humanities and Social Science of the Wellcome Trust and Professor Neil Sheerin from The Freeman Hospital, Newcastle as speakers. Discussing the question 'Should we pay people to donate body parts?' both gave thought-provoking presentations and answered a number of questions and comments from an engaged and attentive audience. A podcast of the presentations is available at [Café Culture North East](#).

[PEALS Symposium 2015](#)

Erica and Ken welcomed 32 participants from around the UK, Europe and the USA to the PEALS 16th Annual International Symposium, organised as a key part of the dissemination of the first findings from this project. The Symposium was held on September 22nd and 23rd 2015 in Newcastle's International Centre for Life.

The central theme for the presentations and discussion was the entanglement of donors, money and body parts. Speakers and other participants were drawn from a range of academic disciplines including; anthropology, biochemistry, economics, embryology, ethics, genetics, history, law, nephrology, neurobiology, philosophy, politics and sociology. A range of jurisdictions and cultural experiences including Australia, Belgium, Denmark, Ireland, USA, Spain, Sweden, Turkey and the UK were represented. In addition to academics, many participants had regulatory, policy and practice backgrounds. These included the Belgian Advisory Committee on Bioethics, British Transplant Society, Health Research Agency, National Research Ethics Service, Human Fertilisation and Embryology Authority, Newcastle Brain Tissue Resource, Nuffield Council on Bioethics, Renal Association, Royal College of Obstetrics and Gynaecology, and UK BioBank. The Head of Regulation at the UK's Human Tissue Authority attended and the Head of Medical Humanities and Social Science at the Wellcome Trust gave the final, summative, presentation of the symposium.

Beginning with the role played by money in shaping the experiences of those who donate reproductive tissue, discussion over the two days broadened to encompass a wide range of human body parts and the complex interconnections and contradictions introduced by global tissue markets and diverse approaches to regulation.

The presentations included:

Erica Haimes and Ken Taylor, PEALS Research Centre, Newcastle University. Donors, money and body parts: the case of 'egg donation' for research.

This presentation introduced and illustrated the areas that would then be subjected to greater scrutiny and more detailed discussion across the Symposium as a whole. The presentation drew on two empirical investigations of 'egg donation for research' to explore the contestations around the terms 'donors', 'money' and 'body parts'.

Heather Widdows, University of Birmingham. Why 'who', 'where' and 'what' matters more than 'how' when it comes to 'consenting' in reproductive donation and services.

Heather's paper considered the ethical impact of context on the sale of reproductive products and services. She argued that considering the context in which such practices happen is crucial not only to understanding such practices in general, but crucial for ethical assessment of such practices.

Rene Almeling, Yale University. Sex Cells: The American Medical Market for Eggs and Sperm.

Rene joined the symposium by Skype from the USA and provided an inside look at how egg agencies and sperm banks do business. Although both men and women are usually drawn to donation for financial reasons, she found that clinics encourage sperm donors to think of the payments as remuneration for an easy 'job' while women receive more money, but are urged to regard egg donation in feminine terms, as the ultimate 'gift' from one woman to another.

Neil Sheerin, Freeman Hospital, Newcastle. Payment for organs; is it ever justified?

Neil discussed the current position in the UK with regard to payment for organs and whether there could ever be a case to allow payment to donors in a regulated system that would protect the donor and decriminalise paid donation.

Erik Malmqvist, Linköping University. Does the ethical appropriateness of offering donors money depend on what body parts they donate?

In his presentation Erik discussed two approaches to the question of whether the ethical appropriateness of monetary offers to donors depends on what body parts they are asked to provide. Taking a 'pragmatic' approach, different body parts should be treated differently to the extent that this is warranted by a concern for the health and welfare of donors, recipients and third parties, and for the quality of donors' consent. While on a 'principled' approach, certain body parts can be considered special because of their intimate relationship to identity or personhood, which makes the involvement of money in their provision inappropriate. Erik discussed the advantages and shortcomings of each approach, focusing on their ability to inform policy in this area.

Klaus Høyer, University of Copenhagen. It's all about the money - or is it? On making sense of bodily donations.

Based on his studies of blood, bone, organ, and tissue donation in Denmark and other European countries Klaus argued that it is not 'all about the money': money serves as a powerful symbol and as such easily derails analytical attention from the most pertinent hopes and concerns of the

involved actors. For people involved in actual transactions, the moral issues are often ambiguous and the solutions come across in shades of gray.

Aisling McMahon, Newcastle Law School. Human tissue donation and the patentability of downstream research: A double standard in the entitlements of donors and researchers, or a necessary compromise?

Alongside ethical issues relating to direct monetary payment for donors for the donation of body parts/tissue for medical research, lies the issue of the downstream commercialisation of resulting research. Although patents are not available on human body parts per se, they can be applied for in respect of isolated elements of the human body or those which have been produced by a technical means. Aisling considered whether and to what extent tissue donors or the public should share downstream benefits or resulting profits; and highlighted some of the difficulties which may arise in this context.

Meenakshi Choudhary, Newcastle Fertility Centre at Life. Egging the egg donation program: Research or Treatment.

Meena gave an insight into the egg donation program run at the Newcastle Fertility Centre for both research and treatment. She spoke of the challenges of recruiting egg providers and in particular of ensuring that women understand the difference between donation for research, for treatment and, in future, for mitochondrial donation?

Rebecca Dimond, Cardiff University. Mitochondria donation: treatment, enhancement or reproductive choice?

In her presentation Beck drew on interviews with patients with mitochondrial disease to explore the complex relationships between research and clinical application. She suggested that the recent debates on mitochondria disease highlighted a blurring of the boundaries between research and treatment, and that this blurring became an essential element in securing public support for novel techniques that aim to prevent some mitochondrial diseases.

Jessica Watkin, Human Fertilisation and Embryology Authority. Regulating the risk of financial inducement.

Jessica's presentation focused on the development of the HFEA's compensation policies for donation, which came into force in 2012. She explained how the aim of the new policy was to balance the need to have a compensation system in place that avoided financial inducement, without creating a barrier to donation or heavy administrative burdens on clinics.

Bronwyn Parry, King's College London. Regulation as Normative Performance.

In her paper Bronwyn examined the complexities of making regulation work commensurately in differing cultural, social and economic contexts. By paralleling the experiences of an underclass of reproductive workers located in Mumbai with those in the poorer subsectors of the UK economy she demonstrated what cannot be ordered by regulation, queried whether the role of regulation is more performative than instrumental, and opened up for debate the question of how to proceed when regulation fails.

Many participants have already commented on their enjoyment of the stimulating debates and the fresh insights gained from the interdisciplinary nature of the event.

PEALS thanks the Wellcome Trust and Newcastle University's Conference Support Fund for financing this event.

Publication

In December 2015 Erica and Ken published a paper entitled 'Rendered invisible? The absent presence of egg providers in UK debates on the acceptability of research and therapy for mitochondrial disease', in the journal *Monash Bioethics Review*. This is available to download under a 'gold' open access agreement.

By the end of July 2016 the journal reported that the paper had been viewed 248 times, suggesting it was reaching a wide international audience.