



# 16<sup>th</sup> PEALS International Symposium

22<sup>nd</sup> – 23<sup>rd</sup> September 2015

Donors, money and body  
parts: what are the issues?

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## Introduction

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### **Welcome!**

Welcome to the 2015 PEALS International Symposium. We are very glad that you are able to join us here in Newcastle at our 16<sup>th</sup> annual event. As in previous years, our ambition has been to bring together participants from a range of academic disciplines and from a range of interests in policymaking and in professional practice, to join together, in a collegiate and friendly atmosphere, to explore a major theme that challenges our thinking around matters of policy, ethics and life sciences.

Our focus this year is on ‘Donors, money and body parts: what are the issues?’

There is a growing global requirement for human tissue and organs for use in scientific research and medical treatment. Divergent solutions for acquiring these materials, including the paying of incentives to donate body parts, are developing under different regulatory regimes and socio-cultural conditions. Within this growing bio-economy, little is known about how those providing tissue and organs think about their role and little is understood about how the offer and receipt of different forms of money operate in this field. Also to what extent are understandings of these issues shaped by the contrasting, but also overlapping, contexts of treatment or research? And to what extent are the issues shaped by the involvement of different body parts?

This international, interdisciplinary symposium will bring together leading social and scientific researchers, clinicians, regulators, policy advisors, and other stakeholders to discuss the scientific, social, ethical, legal and regulatory issues raised by the entanglement of ‘donors’, ‘monies’ and ‘body parts’.

We are very lucky that we are being joined by colleagues from a range of disciplines (including anthropology, biochemistry, economics, embryology, ethics, genetics, history, law, nephrology, neurobiology, philosophy, politics, sociology), from a range of jurisdictions and cultural experiences (including Australia, Belgium, Denmark, Ireland, USA, Spain, Sweden, Turkey, UK) and from a range of regulatory, policy and practice backgrounds to assist these deliberations. Thank you to all of you who are contributing to this symposium by speaking, chairing sessions and participating in discussions. We are especially grateful to the Wellcome Trust, who provided the funding for this Symposium as part of the grant awarded to study the views and experiences of women volunteering to provide eggs for mitochondrial disease research. We also thank Newcastle University whose Conference Support Scheme has contributed to funding the Symposium.

We are also grateful to colleagues in the Policy, Ethics and Life Sciences Research Centre ([www.peals.ncl.ac.uk](http://www.peals.ncl.ac.uk)) for their ongoing collegiality and general support. Finally I should also like to add my personal thanks to my colleagues Ken Taylor, Tom Martin and Lisa Gilder for all their very hard work in organising and running the Symposium.

I am sure that the collective efforts of all will lead to a very enjoyable and stimulating Symposium!

Erica Haimes

September 2015

## Donors, money and body parts: what are the issues?

**Day 1: Tuesday September 22<sup>nd</sup>**

Time	Topic	Speaker
12:00 – 13:00	Registration and buffet lunch.	
13:00 – 13:20	Welcome and Introduction.	Erica Haimes
13:20 – 14:00	<b>Session 1: An illustration of the issues.</b>	<i>Chair: Shaun Pattinson</i>
13:20 – 13:50	Donors, money and body parts: the case of 'egg donation' for research.	Erica Haimes
13:50 – 14:00	Discussion.	All
14:00 – 15:20	<b>Session 2: Does it make a difference who the donors are?</b>	<i>Chair: Sophie Carr</i>
14:00 – 14:30	Why 'who', 'where' and 'what' matters more than 'how' when it comes to 'consenting' in reproductive donation and services.	Heather Widdows
14:30 – 15:00	Sex Cells: The American Medical Market for Eggs and Sperm.	Rene Almeling
15:00 – 15:20	Discussion.	All
15:20 – 15:40	Break for refreshments.	
15:40 – 17:00	<b>Session 3: Does it make a difference what body parts are involved?</b>	<i>Chair: Katharine Wright</i>
15:40 – 16:10	Payment for organs; is it ever justified?	Neil Sheerin
16:10 – 16:40	Does the ethical appropriateness of offering donors money depend on what body parts they donate?	Erik Malmqvist
16:40 – 17:00	Discussion.	All
<b>Dinner</b> 19:15 for 19:30	 <b>The Silk Room. Trinity Gardens, Quayside, Newcastle upon Tyne, NE1 2HH</b>	<b>All</b>

**Day 2: Wednesday September 23<sup>rd</sup>**

<b>Time</b>	<b>Topic</b>	<b>Speaker</b>
<b>09:00 – 09:30</b>	Coffee on arrival and registration.	
<b>09:30 – 10:50</b>	<b>Session 4: Does it make a difference what type of money is involved?</b>	<i>Chair: Marilyn Strathern</i>
09:30 – 10:00	It's all about the money - or is it? On making sense of bodily donations.	Klaus Høyer
10:00 – 10:30	Human tissue donation and the patentability of downstream research: A double standard in the entitlements of donors and researchers, or a necessary compromise?	Aisling McMahon
10:30 – 10:50	Discussion.	All
<b>10:50 – 11:05</b>	Break for refreshments.	
<b>11:05 – 11:10</b>	Symposium photograph.	All
<b>11:10 – 12:30</b>	<b>Session 5: Does it make a difference whether donation is for research or treatment?</b>	<i>Chair: Frances Flinter</i>
11:10 – 11:40	'Egging the egg donation program: Research or Treatment'.	Meena Choudhary
11:40 – 12:10	Mitochondria donation: treatment, enhancement or reproductive choice?	Rebecca Dimond
12:10 – 12:30	Discussion.	All
<b>12:30 – 13:20</b>	<b>Buffet lunch</b>	
<b>13:20 – 14:40</b>	<b>Session 6: Does it make a difference how the risks are regulated?</b>	<i>Chair: Simon Woods</i>
13:20 – 13:50	Regulating the risk of financial inducement.	Jessica Watkin
13:50 – 14:20	Regulation as Normative Performance.	Bronwyn Parry
14:20 – 14:40	Discussion.	All
<b>14:40 – 15:20</b>	<b>Discussant.</b>	<i>Chair: Erica Haimes</i>
14:40 – 15:00	Observations, reflections and 'next steps'.	Dan O'Connor
15:00 – 15:20	Discussion.	All
<b>15:20 – 15:30</b>	Closing remarks.	Erica Haimes

## Presentation Abstracts

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### Session 1: An illustration of the issues.

#### **Donors, money and body parts: the case of 'egg donation' for research.**

##### **Erica Haines and Ken Taylor**

This presentation aims to introduce and illustrate the areas that will then be subjected to greater scrutiny and more detailed discussion across the Symposium as a whole. We draw upon two empirical investigations of 'egg donation for research' to explore the contestations around the terms 'donors', 'money' and 'body parts'. The first study examined the practices of 'egg sharing' for research in which IVF patients, while undergoing treatment, volunteer to provide eggs for stem cell and somatic cell nuclear transfer research (and now also mitochondrial research) and receive a discount on their IVF fees. The second project, which is ongoing, examines the scheme in which women from the wider community (i.e. non-IVF patients) who provide eggs for research into the prevention of mitochondrial disease receive £500. Both projects focus on the often-neglected views and experiences of the women coming forward as volunteers for each scheme. Comparisons across the two studies demonstrate the highly variable and differentiated character of what seems, on the surface, to be the same practice, i.e. 'compensated egg donation for research'. The comparisons also demonstrate the highly variable nature of the key terms, 'donors', 'money' and 'eggs', and illustrate the ways in which the practices of 'donation' (or 'provision' as we prefer to call it) shape, and are shaped by, the wider social, clinical, regulatory, scientific and bio-economic landscapes in which they take place.

## Session 2: Does it make a difference who the donors are?

### **Why 'who', 'where' and 'what' matters more than 'how' when it comes to 'consenting' in reproductive donation and services.**

#### **Heather Widdows**

This paper considers the ethical impact of context on the sale of reproductive products and services. It is divided into three sections. The first considers the importance of context – social, cultural and economic. It argues 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. Given this it argues that the traditional focus on consent is not only inadequate but results in unethical and potentially exploitative practice. To make this claim four arguments against consent and for context are briefly outlined. The second section considers the implications of these arguments for the practices of sperm and egg sale and surrogacy, with particular attention to the donors. The final section broadens the paper to consider some key features of the global context, particularly power hierarchies, returning to the debate of the first section regarding desperate choices.

### **Sex Cells: The American Medical Market for Eggs and Sperm**

#### **Rene Almeling**

Unimaginable until the twentieth century, the clinical practice of transferring eggs and sperm from body to body is now the basis of a bustling market. In *Sex Cells*, Rene Almeling provides 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, Almeling finds that clinics encourage sperm donors to think of the payments as remuneration for an easy 'job'. Women receive more money but are urged to regard egg donation in feminine terms, as the ultimate 'gift' from one woman to another. *Sex Cells* shows how the gendered framing of paid donation, as either a job or a gift, not only influences the structure of the market, but also profoundly affects the individuals whose genetic material is being purchased.

## Session 3: Does it make a difference what body parts are involved?

### **Payment for organs; is it ever justified?**

#### **Neil Sheerin**

The demand for transplant organs exceeds the supply, with over 6000 patients currently waiting for a kidney transplant in the UK. Efforts to increase donation rates have had limited effect and patients continue to die waiting for a transplant. Live donor kidney transplantation is an accepted, safe option. This is most commonly from a friend or relative, but undirected altruistic donation is increasing. In the UK donation must be altruistic, with no payment made to the donor. However, in some countries, where this requirement for donation to be purely altruistic is less rigidly enforced, payment for organs does occur, often involving illegal activity and substandard donor care. I will discuss the current position in the UK with regard to payment for organs and whether there is ever a case to allow payment to donors in a regulated system that would protect the donor and decriminalise paid donation.

### **Does the ethical appropriateness of offering donors money depend on what body parts they donate?**

#### **Erik Malmqvist**

National and international policies concerning the provision of organs, tissues and cells for treatment and research express what seems like a rather uniform resistance towards offering donors money. On a closer look, however, the extent to which the involvement of money is considered permissible in fact varies considerably between policies. There are also significant differences in how the policies are interpreted and implemented in different countries/regions and clinical areas. It appears that these differences partly reflect unarticulated distinctions between different parts of the human body. This raises the question whether the ethical appropriateness of monetary offers to donors depends on what body parts they are asked to provide. In this presentation I distinguish two approaches to this question. On the '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. On the 'principled' approach, certain body parts are special because of their intimate relationship to our identity or personhood, which makes the involvement of money in their provision inappropriate. I discuss the advantages and shortcomings of each approach, focusing on their ability to inform policy in this area.

## Session 4: Does it make a difference what type of money is involved?

### **It's all about the money - or is it? On making sense of bodily donations.**

#### **Klaus Hoeyer**

In 1729 Jonathan Swift sarcastically offered a 'modest proposal' to turn problems of poverty into sources of wealth: the wealthy could *eat* the children of the poor and use the skin for lady gloves or summer boots for gentlemen. In return, the poor would earn a decent amount of money – enough to ensure a diet that would make the flesh attractive. Almost 300 years later the relationship between money and bodies continues to stir the public imagination and fuel strong reactions. However, public debates tend to portray the monetary aspects of bodily donations in black and white. There is a need for uncovering money as a cultural signifier to understand what is at stake for the people involved in bodily transactions. A first step is to acknowledge money as form of power rather than as the medium of presumably self-regulated 'markets'. Based on studies of blood, bone, organ, and tissue donation in Denmark and other European countries I will suggest that parts of Swift's sarcastic critique continues to be relevant and nevertheless argue that it is not 'all about the money': money serves as a powerful symbol and as such it 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.

### **Human tissue donation and the patentability of downstream research: A double standard in the entitlements of donors and researchers, or a necessary compromise?**

#### **Aisling McMahon**

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. An aspect of this, is the potential for downstream intellectual property rights and particularly patents arising from research on human tissue/body parts. Patents are not available on human body parts *per se*.<sup>1</sup> However, patents can be applied for in respect of isolated elements of the human body or those which have been produced by a technical means.<sup>2</sup> Such patents - if granted - vest, not in the tissue donor(s), but rather in the third party researcher(s) (and/or his/her employer depending on agreements in place). This is because it is the application of skill or the inventive step involved which is protected within the intellectual property domain and not the material tissue donation. This mirrors - to an extent - the way in which tangible property rights have been traditionally conceptualised in relation to the human body. In this latter context, ethical issues led to a general exclusion of property rights on

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<sup>1</sup> Art. 5, Biotechnology Directive 98/44EC

<sup>2</sup> Art. 5(2) Biotechnology Directive 98/44EC

human body parts *per se*.<sup>3</sup> However, property rights have been recognised – albeit in a limited manner – where the body has been changed/modified through the application of skill (*Doodeward v Spence*;<sup>4</sup> *Dobson v North Tyneside Health Authority*;<sup>5</sup> *R v Kelly*<sup>6</sup>; *AB and Others v Leeds Teaching Hospital NHS Trust*<sup>7</sup>).

Relatedly, patents can be applied for in respect of downstream products/processes arising as a result of research on donated human tissue/body parts. Moreover, although this issue has not yet been considered in the UK courts, a number of US cases (*Moore v The Regents of the University of California*;<sup>8</sup> *Greenberg v Miami Children's Hospital*<sup>9</sup>) have held that tissue donors - despite their material contribution of tissue samples - generally do not have rights in respect of such downstream patents or entitlements to shares in resulting profits. The exclusionary nature of patent rights and the control vested in patent holders in this context, also has implications in terms of who may access products/processes under patent, which may further impact upon the public/donors and/or subsequent researchers.

The paper explores whether this distinction in the treatment of tissue donors and downstream researchers is justifiable. In doing so, it also briefly considers whether and to what extent tissue donors/the public should share downstream benefits or resulting profits; and highlights some of the difficulties which may arise in this context.

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<sup>3</sup> For a discussion of tangible property rights in human tissue, see generally: Muireann Quigley, 'Propertisation and Commercialisation: On Controlling the Uses of Human Biomaterials' (2014) 77(5) *Mod L Rev* 677; Muireann Quigley, 'Property: The Future of Human Tissue?' (2009) 17 *Med L Rev* 457; J Kenyon Mason and Graeme Laurie, 'Consent or Property? Dealing with the Body and its Parts in the Shadow of Bristol and Alder Hey' (2001) 64 *Mod L Rev* 201; Shawn HE Harmon, 'A Penny For Your Thoughts, A Pound For Your Flesh: Implications of Recognizing Property in Human Body Parts' (2006) 7 *Med L Int* 329.

<sup>4</sup> *Doodeward v Spence* (1908) 6 CLR 406.

<sup>5</sup> [1996] 4 All ER 474.

<sup>6</sup> [1998] 3 All ER 741.

<sup>7</sup> [2004] EWHC 644.

<sup>8</sup> 51 Cal.3d 120 (1990).

<sup>9</sup> *Greenberg v Miami Children's Hospital* 264 F. Suppl. 2d 1064 (2003).

## Session 5: Does it make a difference whether donation is for research or treatment?

### **Egging the egg donation program: Research or Treatment.**

#### **Meenakshi Choudhary**

The demands for eggs outstrip the supply for both research and treatment. How can we help the egg providers make the right decision for themselves, for science and for couples requiring this scarce resource? Are we making them understand the difference between donation for research, treatment and in future for mitochondrial donation?

This talk will give insight into the egg donation program run at the acclaimed Newcastle Fertility Centre for both research and treatment and the challenges facing the recruitment with the egg providers being the fulcrum of paramount importance.

### **Mitochondria donation: treatment, enhancement or reproductive choice?**

#### **Rebecca Dimond**

In this presentation I draw on interviews with patients with mitochondria disease to explore the complex relationships between research and clinical application. This year, UK Parliament supported the clinical introduction of novel and controversial in-vitro fertilisation (IVF) procedures involving mitochondria donation. There is no cure for mitochondrial disease, and treatment is limited, which means reproductive technologies that can prevent a child from inheriting the disease have been widely welcomed. The UK is currently the only country in the world to legalise germ line technologies, and while newspaper headlines have been dominated by 'three parent babies' and the potential slippery slope to designer babies and human modification, a more pressing concern was how to assess the safety of these 'never been tried before' techniques. The result is that mitochondrial donation has become one of the most scrutinised techniques in recent history: three scientific reviews by an expert panel, a dialogue exercise to assess public attitudes delivered by Sciencewise, a call for evidence on the ethical issues organised by the Nuffield Council on Bioethics, a public consultation and government guidance on draft regulations led by the UK Department of Health and several debates within the Houses of Parliament. The debates about mitochondria donation raised key questions which remain pertinent to the introduction of new technologies and IVF: What does 'safe' mean in the context of novel IVF techniques? And is it possible or necessary to ensure that the (child) participant and future generations consent to 'follow up'? I suggest that the mitochondria debate highlights the blurring of the boundaries between research and treatment, and that this blurring became an essential element in securing public support.

## Session 6: Does it make a difference how the risks are regulated?

### **Regulating the risk of financial inducement**

#### **Jessica Watkin**

This presentation focuses on the development of the HFEA's compensation policies for donation, which came into force in 2012. The presentation explains how the aim of the new policy was to balance the need to have a compensation system in place that avoids financial inducement, without creating a barrier to donation or heavy administrative burdens on clinics. It sets out the new compensation rules and the findings from a post 2012 survey and report, assessing the impact of the new compensation rules.

### **Regulation as Normative Performance**

#### **Bronwyn Parry**

In this paper I reflect on the role of regulation in the assisted reproduction economy. When I began undertaking my current research into the provision of fertility services in India (including surrogacy) I assumed that regulation was not only desirable but essential, normative, in fact. Armed with an intention to assess the viability of introducing an HFEA style system of oversight into this context it came as a rude shock to discover that such a system was unlikely to work as I had imagined. Moreover, I soon discovered that this regulatory framework might not deliver its intended outcomes even in the markets for which it was first devised. In this paper I examine 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 I hope to demonstrate what cannot be ordered by regulation, to query whether the role of regulation is, arguably, more performative than instrumental, and lastly to open up for debate the question of how to proceed when regulation fails.

## Participant Biographies

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### Assistant Professor Rene Almeling

Rene is Assistant Professor of Sociology at Yale University and completed her Ph.D. in Sociology at UCLA in 2008. In her research and teaching, she focuses on issues associated with gender and medicine. Using a range of historical, qualitative, and quantitative methods, she examines questions about how biological bodies and cultural norms interact to influence scientific knowledge, medical markets, and individual experiences. Currently, she is researching and writing her second book, *Gynecology: Men, Medical Knowledge, and Reproduction* (under contract with the University of California Press). Funded by a two-year grant from the National Science Foundation, this project examines the history of medical knowledge-making about men's reproduction and its consequences for individual men. In addition, Rene is writing articles based on two original surveys, one on women's bodily experiences of *in vitro* fertilization (IVF) and the second on Americans' attitudes toward genetic risk (with Shana Gadarian, funded by a grant from the Robert Wood Johnson Foundation).

### Dr Chitvan Amin

Regulation Manager, Human Tissue Authority, UK.

### Dr Christopher Birkett

Head of Regulation, Human Tissue Authority, UK.

### Dr Rebecca Brown

Becky joined the Health Services Research Unit of Aberdeen University in February 2014 as a Research Fellow in Applied Philosophy. Working with Vikki Entwistle, Becky's research focuses on different ways of valuing healthcare and how philosophical methods may help to illuminate the value of health, health care and healthy behaviour. Becky studied Veterinary Medicine and History and Philosophy of Science at the University of Cambridge, developing interests in Bioethics, Philosophy of Biology and Philosophy of Risk. In 2013 Becky completed a PhD on 'The Ethics of Using Financial Incentives to Promote Healthy Behaviour' as part of a Wellcome Trust funded project with the Centre for the Study of Incentives in Health at Queen Mary, University of London. As well as continuing research on the ethics of health incentives and behaviour change interventions, Becky is also involved in work looking at how philosophical and ethical issues in the way infertility are conceptualised and treated.

### Dr Sophie Carr

Sophie is Principal Lecturer and Programme Director of Chemical and Forensic Sciences at Northumbria University, taking responsibility for the direction, quality and delivery of the Chemistry and Forensic suite of degree programmes. Prior to joining Northumbria she was a Senior Scientist with the Forensic Science Service, as an expert in body fluid analysis, including scene attendance, DNA and blood pattern interpretation. The majority of her case load concerned major and serious crime, attending crime scenes across the North East of England and providing expert witness testimony at Crown Court. During the latter part of her career with the Forensic Science Service Sophie also managed the violent crime and sexual offence investigation teams. 'On a personal note I have first-hand experience of the physical and emotional experiences of

IVF. Having been diagnosed with unexplained infertility I have undertaken three full IVF cycles at two different practices. Fortunately my last IVF attempt was successful and I am extremely thankful for the lovely daughter IVF brought me.'

### Dr Meenakshi Choudhary

After completing her dual accreditation in Obstetrics and Gynaecology with Sub specialist training in reproductive medicine, Meena has been practising as a Consultant Gynaecologist and Sub Specialist in Reproductive Medicine at the internationally acclaimed Newcastle Fertility Centre at Life, UK since August 2012. She was awarded PhD degree from Newcastle University in 2008 studying the role of hyaluronan proteins in early human embryo development and embryonic stem cells. She continues to maintain her research interest in reproductive ethics, oocyte/embryo donation for research, developing an oocyte donation programme for clinical mitochondrial donation and the role of maternal ageing in implantation disorders. She is also a key collaborator on a European Commission Horizon 2020 grant looking at maternal ageing and on a Wellcome Trust funded grant which aims to look at reproductive ethics in the developing world. She has recently become the HFEA Person Responsible for research for Newcastle Fertility Centre. She is the Clinical Lead for Newcastle Hospitals' early pregnancy service and has developed the Quality management system for the early pregnancy unit. She is also the lead for paediatric and adolescent Gynaecology and was elected to the UK's BritSPAG Executive Committee. She is also the Regional preceptor for the RCOG (London) advanced training module in early pregnancy and acute gynaecology and a recognised trainer for ART modules of British Fertility Society. She regularly teaches at the RCOG Basic Practical Skills course and is the Reproductive Medicine Representative on the RCOG Subspecialty Committee. She has served on several Committees including BFS Executive Committee and will be hosting the next AEPU national UK Conference in Newcastle in 2015.

### Dr Rebecca Dimond

Rebecca is a Research Fellow at Cardiff University. A medical sociologist, she has recently been awarded an ESRC Future Research Leaders grant to explore the social implications of reproductive technologies involving mitochondria transfer. Her three year project is titled 'Patient and professional understanding of risk: how complexity and uncertainty of genetic knowledge impacts on reproductive decision making'. Rebecca's work and recent studies have been within the field of medical sociology. Rebecca has worked on several research projects within Cardiff School of Social Sciences, exploring the implications of genetic disease for patients, families and professionals. Her PhD, completed in 2011 and supervised by Professor Paul Atkinson and Dr Katie Featherstone, examined the social construction of a rare genetic disorder, 22q11 deletion syndrome. This was a multi-sited ethnography, drawing on observation of clinical consultations and conferences, and interviews with families and health professionals. Before this, she worked as a research assistant examining communication strategies of patients and carriers of haemophilia. Following her PhD, she worked as a research associate focusing on the patient experience of mitochondrial disease in the context of emerging reproductive technologies (PI Professor Ruth Chadwick). Rebecca gained an MSc in Social Science Research Methods whilst studying for her PhD and has a BSc and MA with the Open University. Rebecca is one of the organisers of the Medicine, Science and Culture group (MeSC) within SOCSI and is a co-convenor of the BSA Medical Sociology (Wales) group.

### Professor Cath Exley

Cath is Professor of Qualitative Health Research and Acting Director of the Institute of Health and Society at Newcastle University. She is a medical sociologist and an experienced qualitative health researcher committed to delivering both high quality research and education. She provides a social science perspective and methodological expertise to clinical research questions, postgraduate research supervision and postgraduate and undergraduate teaching. Cath's research is concerned with examining people's - patients and carers - experiences of, and decisions about, health and health care. Her work focuses primarily on those living with chronic illness, and spans a range of clinical areas including: palliative care, transplantation, old age psychiatry, primary care and oral health care. Cath leads the IHS Medical Sociology discipline group and the British Sociological Association Special Interest Group in Applied Qualitative Health Research.

### Professor Frances Flinter

Frances is a consultant Clinical Geneticist and Caldicott Guardian at Guy's & St Thomas NHS Foundation Trust and with a personal chair in Clinical Genetics at King's College London. She trained at Guy's Hospital Medical School and worked in paediatrics before a 3 year doctoral research post in the Paediatric Research Unit at Guy's mapping the gene for Alport's syndrome (hereditary nephritis with deafness) led to specialisation in clinical genetics. Her particular interests include the genetics of inherited renal disease and pre-implantation genetic diagnosis (PGD). Frances is the consultant geneticist on the Guy's PGD team, which is the largest and most successful in the UK; more than 600 healthy babies have now been born as a result of this programme. From 2000 – 2007 Prof. Flinter was the clinical director of the Evelina Children's Hospital and she was chair of the Medical Genetics Clinical Reference Group (NHS England) from 2011-2015. Frances was a member of the Human Genetics Commission (HGC) from 2005 -2012 and chaired two working parties on the regulation of Direct-to-Consumer (DTC) genetic testing and preconception genetic screening; she was also a member of the HGC working group that produced a report on reproductive decisions and genetic technologies called 'Making Babies'. Frances worked with the Nuffield Council on Bioethics as a member of the working party that wrote the report on 'Novel techniques for the prevention of mitochondrial DNA disorders' and has just been invited by the HFEA to review applications for mitochondrial replacement therapy.

### Professor Erica Haimes

Erica Haimes is Executive Director (August 2013 onwards) of the PEALS (Policy, Ethics and Life Sciences) Research Centre, where she was also the Founding Executive Director (1998-2008) and Professorial Fellow (2008-13). She is also Professor of Sociology, Newcastle University. Her research interests include: interdisciplinary research on social, ethical and legal aspects of the life sciences; reproductive and genetic technologies; the socio-ethical aspects of the provision of human tissue for research, and the relationship between states, families and medicine with a focus on assisted conception. She also provides policy and practice guidance in the above fields, through her memberships of: the Ethics and Policy Committee of the International Society for Stem Cell Research (2010-2014), the Ethics Committee of the Royal College of Obstetricians and Gynaecologists (2011- 2016) and through her appointment to the Nuffield Council on Bioethics (from March 2013). Erica has been a member of various policy and practice advisory bodies including: the Interim Advisory Group (Ethics and Governance) for UK Biobank; the Ethics and Governance Council for UK Biobank; the MRC's International DNA Banking Advisory Committee; the Nuffield Council on Bioethics Working Party on the care of premature babies. Erica runs the PARTS (Provision and Acquisition of Reproductive Tissue for Science) International Research Network.

### Professor Andy Hall

Andy is Associate Dean of Bioresources at Newcastle University. After qualification as a clinical haematologist he developed a research programme in childhood leukaemia before becoming the Director of the Northern Institute for Cancer Research. He has a longstanding interest in the use of tissues for research and is the Designated Individual for the Newcastle University HTA research licence and a member of the Board of the Human Tissue Authority. He has served on several national grant awarding committees and currently chairs the scientific advisory board for the Bone Cancer Research Trust and sits on the National Institute for Health Research Career Development, Senior Research and Transitional Research Fellowship panel.

### Dr Cathy Herbrand

Cathy Herbrand holds a PhD in Sociology from the Université libre de Bruxelles. She has recently joined the Reproduction Research Group of the School of Applied Social Sciences at De Montfort University as an Early Career Research Fellow. She was previously a Visiting Fellow at the SSHM Department at King's College London and at the BIOS Research Centre at London School of Economics and Political Science, as well as a Postdoctoral Researcher at the University of Ottawa. Her research interests lie in the sociological and anthropological study of family, biotechnologies and genetics, with a particular focus on reproductive decision-making, multi-parenthood and gender issues. Cathy is currently undertaking research on reproductive choices in the context of mitochondrial disorders. Her previous work explored multi-parenthood through the study of gay and lesbian families' experiences and regulation in Belgium. Cathy is also an appointed member of the Belgian Advisory Committee on Bioethics (2014-2018).

### Professor Klaus Høyer

Klaus is a Professor in the Health Services Research Section of the Department of Public Health at the University of Copenhagen. He is interested in the organization and regulation of the healthcare system, in particular with respect to introduction of new medical technologies. His area of expertise is ethics as a form of regulation in relation to human body hybrids, i.e. objects either derived from or expected to go into human bodies. He has worked mainly with research biobanking, stem cells, property issues, forensic biobanking, public-private partnerships and public perceptions of genetics. He is the author of *Exchanging Human Bodily Material: Rethinking Bodies and Markets* (Springer, 2013).

### Dr Debbie Lett

Debbie is currently Manager of the Newcastle Brain Tissue Resource, a large research tissue bank based within Newcastle University which receives, stores and supplies donated tissue. In 2014 the resource supplied in excess of 20,000 samples to approved researchers all over the world. She has a background as a nurse, with more than 25 years' experience in old age psychiatry and research. In the early 1990's she was instrumental in setting up the current system in Newcastle which enables potential brain donors, both with or without dementia and neurodegenerative diseases, to register during life to donate tissue for research after their deaths. She is also a member of an NHS ethics committee and has a particular interest in the ethical aspects of tissue donation for research.

### Dr Laura Machin

Laura is a Senior Lecturer in the Medical School of Lancaster University. Her research interests rest within the social and ethical aspects of medicine. Her time as a postgraduate, whereby she focused on the social and ethical aspects surrounding reproductive medicine, in particular gamete and embryo donation, has been instrumental in shaping her research activities. Laura has since explored reproductive medical tourism, as well as the moral and political aspects of umbilical cord blood banking, during her postdoctoral period. Consequently, research interests have extended to incorporate the social and ethical aspects of the donation of body parts, blood and tissue. Since arriving at Lancaster, Laura has supervised MRes students on healthcare professionals' decision making around organ donation, and is currently exploring the use of donated deceased bodies to teach anatomy to medical students with Drs Dawn Goodwin and Adam Taylor. She is particularly interested in exploring what is meant by terms such as 'dignity', 'respect for bodily integrity', and 'emotional detachment' in the context of anatomy teaching in medical education. Throughout her research activities, Laura always adopts an applied approach, whereby she considers the policy and practice implications of the topic under study. This is reflected in her collaboration with the National Gamete Donation Trust to examine gamete donors' satisfaction with the donation process, and the dissemination of the findings arising from the political and moral economy of umbilical cord blood banking project with Professor Nik Brown (University of York) and Dr Danae McLeod.

### Ms Julia Maddison

Julia is a Clinical Research Coordinator in the Wellcome Trust Centre for Mitochondrial Research in Newcastle University. She assists Principal Investigators, Research Associates and PhD students with their clinical research activities. She works to set up and coordinate their clinical research studies throughout the study's life time, including end of study reporting and the archiving process. Julia co-authors and manages the submissions of research protocols and supporting documents to Funders, National Research Ethics Committees, UK regulatory authorities and Research and Development offices to gain approvals required before enrolment of participants into a study or database. She also manages a national natural history study and patient registry within mitochondrial disease with multiple sites across the UK. Julia is also the manager of the 'Excess Diagnostic Archive' that allows local, national and international researchers to access samples such as blood, urine, skin and muscle for their research projects.

### Dr Erik Malmqvist

Erik is a Lecturer in Philosophy of Medicine and Medical Ethics at Linköping University. Formerly in the Department of Medical and Health Sciences (2012-14), he has been in the Department of Thematic Studies, Technology and Social Change, since 2014. His main research interests are bioethics and research ethics. Most of Erik's recent work has addressed ethical issues in organ and tissue transplantation, clinical trials, assisted reproduction and vaccination. He draws on analytic moral philosophy as well as phenomenology and hermeneutics in order to analyze these issues. He also takes an interest in more theoretical questions about exploitation, commodification and individual responsibility for collective harm.

### Dr Aisling McMahon

Aisling joined Newcastle Law School in February 2014. Her principal areas of research are medical law and intellectual property law. She is currently in the final stages of doctoral research at the University of Edinburgh. Her thesis is entitled "An institutional analysis of the application of the morality provisions in the 'European' patent system" and is supervised by Professor Graeme Laurie and Mr. Gerard Porter. She was awarded a Principal's Career Development Award

from the University of Edinburgh to support this research. Aisling was previously a Research Fellow on the AHRC funded Banking (On) the Brain Project in the University of Edinburgh. This inter-disciplinary project explored whether and how conceptions of the brain emanating from key Arts and Humanities disciplines and scientific research was reflected in the legal framework for brain-banking in the UK. She was also a seminar leader for Medical Jurisprudence and Advanced Legal Methods in the University of Edinburgh. From 2010-2011 she was a Judicial Researcher carrying out legal research for members of the Irish Judiciary based in the Four Courts Dublin. Prior to this, she tutored contract law, criminal law and sociology of law at the National University of Ireland Galway.

### Professor Alison Murdoch

Professor Alison Murdoch is a Consultant Gynaecologist and Head of the Newcastle Fertility Centre @ Life. Founding the Department of Reproductive Medicine in 1991, Alison has directed its growth and development into the leading Fertility Centre in the North East of England and beyond. In addition she is a former Chairman of the British Fertility Society and member of the Nuffield Council on Bioethics.

### Professor Therese Murphy

Thérèse is Professor in the School of Law at Queen's University Belfast. Her work focuses on human rights law and practice. She is particularly interested in questions concerning health and human rights, including both the human right to science and new health technologies and human rights. She is also interested in human rights method. And, together with Professor Noel Whitty from the University of Nottingham, she writes about criminology and human rights, with a particular focus on prisoners' rights. Thérèse's books include *Civil Liberties Law: The Human Rights Act Era*, written with Noel Whitty and Stephen Livingstone; *New Technologies and Human Rights*; and *European Law and New Health Technologies*, which she edited with Dr Mark Flear, Dr Anne-Maree Farrell and Professor Tamara Hervey. Her latest book is *Health and Human Rights*. It was published by Hart in the summer of 2013, marking 10 years of the series 'Human Rights Law in Perspective'. Thérèse has written reports for national and international bodies, including UNAIDS, the Department of Health and the EU's Fundamental Rights Agency. She is a longstanding member of the editorial board of the *Human Rights Law Review*, and for many years she acted as an advisor to the British Council.

### Dr Dan O'Connor

Dan is the Head of Medical Humanities at the Wellcome Trust. He moved to the Trust from the Johns Hopkins Berman Institute of Bioethics and is working to enhance the impact of the Trust's recently expanded Medical Humanities portfolio. As a faculty member at the Berman Institute, Dan was responsible for public engagement alongside his teaching and academic work. He has a PhD in the History of Medicine (University of Warwick) and a Postdoctoral Fellowship in Bioethics and the History of Medicine (Johns Hopkins University), as well as experience in the commercial sector, where he translated academic research into strategic action plans for social media.

### Professor Bronwyn Parry

Bronwyn is Professor in Social Science, Health & Medicine and Director of Undergraduate Studies in the Department of Social Science, Health and Medicine, King's College London. Bronwyn's primary research interests lie in investigating how human-environment relations are being recast by technological, economic and regulatory change. She has developed expertise in a number

of key areas: the rise and operation of the life sciences industry, informationalism, the commodification of life forms, posthumanism, applied bioethics, legal approaches to the regulation of nature, and the public understanding and reception of science. Her first book *Trading the Genome: Investigating the Commodification of Bio- information* revealed how biological materials are collected for use in the US pharmaceutical industry and how the engineered artefacts derived from them - cell lines, tissues samples and sequenced DNA - are then traded internationally as part of a new global resource economy in 'bio-information'. She subsequently received a major grant from the Wellcome Trust to investigate the social, ethical, and legal complexities that attend the creation and operation of human tissue banks in the UK, completing this work through a three year ethnography of the Addenbrooke's Hospital Brain bank. Bronwyn was elected to the Nuffield Council on Bioethics in 2007 and has contributed to reports on the forensic use of bio-information, the recent crisis in public health in the UK and dementia care. She has also undertaken comparative work on the role of international regulatory regimes and acted as a consultant for the UN and the UK government in this capacity.

### Dr Shaun Pattinson

Shaun is Professor of Medical Law and Ethics at Durham University. He joined the Law School as Reader in Law in 2006 and was promoted to Chair in 2013. He was previously Lecturer (2000-2005), then Senior Lecturer (2005-2006) at the University of Sheffield. Shaun founded Durham CELLS (Centre for Ethics and Law in the Life Sciences) in December 2011. He has been a visiting scholar at the universities of Helsinki and Maastricht. Shaun has a law degree from the University of Hull, and a Master's degree (in Biotechnological Law and Ethics) and Ph.D from the University of Sheffield. Shaun's research interests are primarily in the area of medical law and ethics. His principal publications are *Influencing Traits Before Birth* (2002) and *Medical Law and Ethics* (4th edn, 2014). The second edition of *Medical Law and Ethics* was awarded the 2010 Minty Medico-Legal Society Prize for best medico-legal book. Shaun is currently co-editing *Ethical Rationalism and the Law* (Hart Publishing) with Patrick Capps, and writing a monograph, *Revisiting Landmark Cases in Medical Law* (Routledge). Shaun has been appointed to the Nuffield Council on Bioethics (the closest that the UK has to a national bioethics committee) for a 3-year term from March 2015. He has participated in many research projects and external committees. He is, for example, currently a member of the External Advisory Board for the Canadian National Transplant Research Program (CNTRP), principal investigator on a Wellcome Trust engagement project, and co-organiser of the Ethical Rationalism and the Law project. Shaun has given papers at many UK universities and in Australia, Belgium, Canada, Croatia, the Czech Republic, Finland, Germany, the Netherlands, and the US. He edited *Medical Law International* from July 2005 to July 2011.

### Dr Vincenzo Pavone

In 2006, Vincenzo joined the Institute of Public Policies of the Consejo Superior de Investigaciones Científicas, becoming member of the *Scimago* research group on science, technology and innovation and of the international research network on science and technology PRIME (Policies for Research and Innovation in the Move towards the European Research Area). He is also member of the 'Science and Democracy Network' coordinated by the University of Harvard, and of the ENSSER (The European Network of Scientists for Social and Environmental Responsibility). His research interests include: history of science and of Scientific Utopias; historical and sociological study of the role played by the ideology of scientific humanism in the creation, developments and actions of international organizations like UNESCO; the role of normative ideas in the production and endorsement of research and technology policies, with special focus on the new biotechnologies related to human genetic engineering; the evaluation of social and political implications of the new agricultural, biomedical and security biotechnologies; public and professional understanding of science; the mutually constitutive relationship between neoliberal

knowledge production regimes, bioethics and public policy of science and technology and the development of an area of political science focusing on the interaction between science, democracy and society in order to address this phenomenon not only from a sociological but also from a political perspective.

### Professor Neil Sheerin

Professor of Nephrology, Institute of Cellular Medicine, Newcastle University. Renal Specialty Group lead for Northumberland, Tyne and Wear. Member of the Renal Association, British Transplant Society. Neil leads the renal clinical research group at the Freeman. This is a team of research nurses, a study co-ordinator and data manager, who actively participate in a wide range of NIHR portfolio clinical trials in all aspects of Nephrology and Transplantation. The infrastructure and research staff support allows clinical staff to develop their own clinical studies and for clinicians to be part of important national studies. Neil's own clinical research integrates with basic science, but also includes studying the severity and cause of the symptoms experienced by patients with kidney disease.

### Professor Bob Simpson

Bob is Professor in the Department of Anthropology of Durham University, a member of Durham CELLS (Centre for Ethics and Law in the Life Sciences) and Fellow of Wolfson Research Institute for Health and Wellbeing. Bob is a social anthropologist whose current research interests focus on Bioethics, Biomedicine and Biotechnologies in developing world contexts. One of the main research settings in which he has explored the encounter between challenging technological developments and local systems of values and beliefs is Sri Lanka. Between 2002 and 2004 he held a Wellcome Trust Biomedical Ethics Fellowship which enabled him to carry out research into the reception of new reproductive and genetic technologies. He is currently working on the ethics of experimentation and the governance of scientific research in Asia through an ESRC/DfID funded project: Biomedical Health Experimentation in South Asia. Recently completed projects include: Infertility and the New Reproductive Technologies among British Pakistani Moslems and International Science Collaborations and Bioethics. He was also Principal Investigator on a Researcher Development Initiative project to develop workshops and resources supporting third year PhD students writing up Qualitative data: 'Writing Across Boundaries'. This project also provides support for students from Sunderland, Teesside and Northumbria as well as Durham and Newcastle.

### Professor Dame Marilyn Strathern

Marilyn is an Emeritus Professor of Social Anthropology in the Division of Social Anthropology at the University of Cambridge. Between 1998 and 2009 she was Mistress of Girton College, and she held the William Wyse Professorship of Social Anthropology at Cambridge from 1993-2008. Her research interests have been divided between Melanesian and British ethnography: Papua New Guinea has been a principal area of fieldwork, from 1964 to most recently in 2006, although she is also intrigued by developments in knowledge practices in the UK and Europe. Initial work on gender relations led in two directions: feminist scholarship and the new reproductive technologies, and legal systems and intellectual and cultural property. Over the last twenty years she has published on reproductive technologies, intellectual and cultural property rights and interdisciplinarity. She came to Cambridge as an undergraduate at Girton studying Archaeology and Anthropology, and stayed on there as a research student and then PhD candidate. Professor Strathern was made a Fellow of the British Academy in 1987 and a Dame Commander of the British Empire in 2001. She was awarded the Rivers Memorial Medal, Royal Anthropologist Inst. (1976), the Viking Fund Medal, Wenner-Gren Foundation for Anthropological Research (2003),

the Huxley Medal (2004), and the 30th Anniversary Independence Medal, Papua New Guinea (2005). She has been awarded several Honorary degrees from universities in the UK and abroad.

### Dr Ken Taylor

Ken is a Research Associate in the PEALS Research Centre, Newcastle University, engaged in empirical socio-ethical research on the views and experiences of women who are asked, or volunteer, to provide reproductive tissue to scientific research. He has worked on projects relating to the use of human foetal tissue in gene mapping, embryo 'donation' to and egg 'sharing' with stem cell scientists and is currently working on a Wellcome Trust-funded project on egg provision to mitochondrial disease research. He recently spent a year working with the REF 2014 team in the Medical Faculty of Newcastle University, researching and writing impact case studies on a number of topics. Ken's PhD explored aspects of the politics of genetically modified crops and the governance of new genetic technologies. Before undertaking his PhD, he worked at the Scottish Crop Research Institute, Dundee, studying cereal quality attributes and running the DNA sequencing and peptide synthesis service.

### Dr Ilke Turkmendag

Ilke is a Research Associate in the Department of Sociological Studies at Sheffield University and a visiting researcher at PEALS in Newcastle University. She is interested in the social, ethical and legal aspects of the life sciences, new reproductive technologies in particular, and the ways in which these technologies are constructed in the public sphere and policy making. Ilke's interdisciplinary background enables her to apply insights from medical sociology, science and technology studies, bioethics, and law. She has published papers on the removal of gamete donor anonymity in the UK; the role of patient support groups in policymaking; cross border reproductive care movements by the UK patients; Turkish assisted conception regulations; and the right to personal identity claims in donor conception. She also examined science claims-making activities in the UK during the debate over mitochondrial replacement techniques. Her current research focuses on ethical, legal and social implications of emerging new reproductive technologies and public understanding of epigenetics. In August 2011, Ilke was granted one of only two Mildred Blaxter postdoctoral fellowships funded by the Foundation of Sociology of Health and Illness to disseminate the findings from her PhD thesis.

### Professor Luke Vale

Luke is the Health Foundation Chair in Health Economics and Deputy Director of Newcastle University's Institute of Health and Society, where he currently leads the Health Economics Group. He is a researcher with an international reputation in economic evaluation and health technology assessment and has contributed significantly to the growth in the use of systematic reviews and economic modelling in this field. This expertise is built on over 15 years of health economics experience. Prior to joining Newcastle University Luke led an independent academic group that conducted appraisals of new and existing diagnostic and therapeutic interventions for the National Institute of Health and Clinical Excellence (NICE).

### Dr Jessica Watkin

Policy Manager, Human Fertilisation & Embryology Authority, UK.

### Professor Heather Widdows

Heather is the John Ferguson Professor of Global Ethics and works on Global Ethics, Bioethics, Virtue Ethics and Feminist Theory. She is particularly interested in the ethical issues which arise in the context of globalization, including those of technological development, war and terrorism, poverty and development as well as bioethical issues; particularly, those of reproductive, research and genetic ethics. In 2005 she was awarded a visiting fellowship at Harvard University, where she worked on issues of moral neo-colonialism. She has led a number of funded projects on issues of property in the body; reproductive rights; human tissue; war on terror and ownership and governance of the genome. Her current primary project is on the moral philosophy of beauty and she holds a Leverhulme Major Research Fellowship for the next two years to complete her book *Perfect Me!* (under contract with Princeton University Press). She is also PI on the AHRC-funded 'Changing Requirements of Beauty Network'. Currently Heather serves as a member of the Nuffield Council on Bioethics and was on the REF 2014 Philosophy Sub-Panel. Previously she was a member of UK Biobank Ethics and Governance Council (2007 to 2013) and co-lead 'Saving Humans', one of the two inaugural themes of the University's Institute of Advanced Studies.

### Dr Simon Woods

Simon is Senior Lecturer and Co-Director of the Policy Ethics and Life Sciences Research Centre (PEALS). PEALS is engaged in research teaching and outreach on the ethical and social implications of the life sciences and Simon's contribution is across this range but with special responsibility for teaching and learning. Simon has 10 years clinical experience as a cancer nurse and holds bachelor and doctoral degrees in philosophy. He has conducted empirical and conceptual research and has taught and published widely in the health care ethics field. His interdisciplinary research interests focus on social, ethical, and legal aspects of the life sciences, with particular reference to human embryonic and fetal tissue, genetic and other medical technologies; translational research, research ethics and governance, social philosophy and bioethics; palliative care and end of life issues. Simon is currently a National Ethics Advisors' Panel Member, (NHS) Health Research Authority: National Research Ethics Service. He has been Chair of the Project Ethics Council, TREAT-NMD EU FP6 Network of Excellence (2008-2013); NHS Research Ethics Committee Vice-Chair (Newcastle and North Tyneside 1, 2008-2013); and University of Northumbria Research Ethics Committee Lay Member (2003 -2008).

### Dr Katharine Wright

Katharine is Assistant Director of the Nuffield Council on Bioethics, currently leading a project on the ethical issues arising out of the growing use of cosmetic procedures. Her background is in health policy, law and ethics: before taking up her current post, she spent nine years at the UK House of Commons, briefing MPs of all political parties on health issues, and then four years in the NHS, monitoring the effect of the Human Rights Act on health law in England. During this time she was also seconded to the English Department of Health to work on patient consent. Her work at the Nuffield Council has included consideration of ethical issues arising in dementia; in the donation of all forms of bodily material for treatment or research; the sharing of information in the context of people born as a result of the donation of gametes and embryos; and the involvement of children and young people in clinical research.