



Crossing Frontiers

Moving the Boundaries of Human Reproduction

PET Annual Conference, 8 December 2017

Report for the Anne McLaren Memorial Trust Fund



Background to the Progress Educational Trust

The **Progress Educational Trust (PET)** is an independent registered charity founded in 1992 to advance public understanding of science, law and ethics in the fields of human genetics, assisted reproduction, embryology and stem cell research.

PET works to improve the choices for people affected by infertility and genetic conditions, and to promote the responsible application of science through education and debate.

Rationale for a conference on this topic

PET's key strategies include identifying the most challenging topics that fall within the charity's remit, providing a forum for discussion, encouraging meaningful public debate, and changing opinions. A fundamental objective of the charity is engaging with public, academic, clinical, policymaking and educational communities, and with the media, so that controversial areas in assisted conception, genetics and embryo/stem cell research can be better understood and can elicit public support.

PET's discussion conference '**Crossing Frontiers: Moving the Boundaries of Human Reproduction**' – which was held at **Amnesty International in London, on 8 December 2017** – explored the changing boundaries of reproductive medicine and research. In the **PET** tradition, following introductory presentations a substantial part of each conference session was devoted to soliciting questions and comments from the audience.

Overview of conference proceedings

The conference began with a **Welcome Address** by PET Director **Sarah Norcross**, who also chaired the opening session – '**The Building Blocks of Life and Law: What Is a Sperm? What is an Egg? What is an Embryo?**'. This session saw the University of Sheffield's **Professor Allan Pacey** discuss what makes a sperm a sperm, emphasising the distinction between the 'payload' – that is, the DNA – and the 'vehicle'. This distinction is increasingly important, when modern techniques (such as intracytoplasmic sperm injection) can be used to circumvent problems with the 'vehicle'.

The University of Edinburgh's **Professor Richard Anderson** discussed the challenges unique to egg cells of being kept in a suspended state from when they are formed, in the first 18 weeks after conception, to when they are needed years (often decades) later. **Dr Sue Avery** of the Birmingham Women's Fertility Centre explained how little was known about human embryos when the world's first IVF baby Louise Brown was born 40 years ago, and how definitions have had to try to keep up with the increasingly complex scenarios that technology has since made possible.

The second session, '**Creating Life in the Lab: In Vitro Gametogenesis (IVG) and Synthetic Human Entities with Embryo-Like Features (SHEEFs)**', was sponsored specifically by the **Anne McLaren Memorial Trust Fund**. It focused on increasingly complex arrangements of living cells that are now being created and studied in laboratories.

The University of Cambridge's **Professor Magdalena Zernicka-Goetz** – who in 2008 had been the first recipient of the International Society of Differentiation's **Anne McLaren Award for Outstanding Women in Developmental Biology** – discussed how she and her colleagues had recently created an embryo-like structure, by growing mouse embryonic stem cells and extra-embryonic trophoblast stem cells together in a 3D-scaffold. The aim of this exercise was to improve understanding of the crucial stages of embryo development that immediately precede implantation.

Professor Azim Surani, of the University of Cambridge's Gurdon Institute, discussed the progress of scientific efforts to create *in vitro* derived gametes. The account he gave of his most recent work, which involved growing primordial germ cells within organoids, became the focus of international news coverage in the weeks and months following the conference (see **Media impact** below).

Finally, The Francis Crick Institute's **Professor Robin Lovell-Badge** discussed the moral and regulatory status of so-called 'SHEEFs' – synthetic human entities with embryo-like features – and the opportunities and challenges that lie ahead, if SHEEFs should become more similar to human embryos proper.

The third session – '**The Wild East and the Worried West: Pioneers or Outlaws?**' – considered the international dimension of cutting-edge research and treatment, and asked whether innovation can take place responsibly outside a regulated environment. Following an introduction from session chair **Sally Cheshire**, who is Chair of the Human Fertilisation and Embryology Authority, the Wellcome Trust's **Dr Sarah Rappaport** discussed the fact that her organisation funds novel research in more than 70 countries worldwide. This is a great responsibility, and involves consideration of fair access to new technologies and the benefits these technologies can bring.

Dr Henry Malter, of the Fertility Centre of the Carolinas in the USA, reflected on a handful of children – now healthy teenagers – who carry mitochondrial DNA inherited from more than one woman. This is the result of an experimental fertility treatment he carried out a number of years ago, using cytoplasmic transfer, until this process was effectively banned by the USA's Food and Drug Administration. **Dr César Palacios-González** of King's College London then explored the uncertainties surrounding the birth, in 2016, of the world's first baby born following mitochondrial donation.

The baby was born in Mexico to Jordanian parents, following treatment carried out – in Mexico – by a Chinese clinician based in the USA. This complex situation has had significant and ongoing medico-

political ramifications. Furthermore, the techniques used in this baby's conception have often been conflated in public discussion with the earlier cytoplasmic transfer carried out by Dr Malter – in fact, the two scenarios were very different both in their purpose and in their methods. This session offered a precious opportunity to clarify the relevant distinctions and address misapprehensions.

The fourth session, '**What Next for Genome Editing? Politics and the Public**', began with **Dr Andy Greenfield** – of the Medical Research Council's Harwell research centre – emphasising the value of basic scientific research, while stressing the need for parallel debate about the ethics of genome editing. He made a case for preimplantation genetic diagnosis as a useful comparator for some of the potential future uses of genome editing in humans.

Dr Elizabeth Garner of Caribou Biosciences drew upon her experiences, at that company and elsewhere, to explain what genome editing can and cannot be used for at present – in terms of its reliability, and also in terms of regulation and ethics. **PET's** own **Sandy Starr** presented findings from the charity's recent '**Basic Understanding of Genome Editing**' project, arguing for prioritisation and consistent vocabulary in order to improve public and professional engagement with genome editing.

The final session, '**Revolutionising Reproduction: Setting a New Moral Compass**', began with the University of Oslo's **Dr Anna Smajdor** arguing that natural conception is increasingly at odds with Western values and that assisted conception may eventually become the norm. The Christian Medical Fellowship's **Philippa Taylor** then argued that even if a technology is shown to be safe, popular and expedient, it does not necessarily follow that it should be permitted. She voiced her support for somatic genome editing as a potential way to treat disease, but argued that germline editing raises insurmountable moral obstacles.

The final speaker of the day, Ghent University's **Professor Guido Pennings**, offered a very different view to this. He argued that genome editing can and should afford new possibilities of removing multiple deleterious mutations from embryos, rather than patients and practitioners being obliged to choose a single embryo for transfer when their options and their knowledge are limited.

How and why the Anne McLaren Memorial Trust Fund made a difference

- **Prestigious association**

Sponsorship from the **Anne McLaren Memorial Trust Fund** gives an imprimatur of quality to the event. Prospective delegates who are unfamiliar with the quality of **PET's** work are given confidence that the conference will be of a high standard.

- **Accessibility**

The **Anne McLaren Memorial Trust Fund's** generous support meant that **PET** was able to maintain ticket prices at the same level as the previous three years.

PET was also able to offer discounted rates to those who would have otherwise been unable to attend, including students and people who are retired or currently unemployed. In short, the conference was made more accessible.

- **Flexibility**

PET was also able to offer free places to journalists. Journalists are accustomed to free attendance, and indeed all but demand it, without always making good on their commitment to attend.

This can be challenging to accommodate but **PET** was able to take a flexible approach, resulting in several journalists attending the conference and resulting press coverage (see **Media impact** below).

- **Quality and quantity of speakers**

A large number and variety of speakers are needed for a discussion conference, to provide the audience with a sufficient range of experts to result in a meaningful and productive dialogue.

The **Anne McLaren Memorial Trust Fund's** support meant that **PET** was not overly constrained by the extra expense of speakers' travel and accommodation costs, and this in turn meant that **PET** was able to invite speakers from outside the UK.

- **Increasing awareness of the Anne McLaren Memorial Trust Fund**

The **Anne McLaren Memorial Trust Fund** was named in all conference promotional material. The conference was promoted widely via email, the web and social media – including via **Facebook** and **Twitter** – to a wide range of universities, businesses, clinics and institutions across the UK.

The conference was listed prominently on the **PET** and **BioNews** websites, as well as on other websites including those of the **Human Fertilisation and Embryology Authority**, the **Association of Clinical Embryologists** and the **Institute of Medical Ethics**.

The conference was also promoted at other high-profile events, including the annual **Battle of Ideas** festival at London's **Barbican Centre**.

Media impact

Conference attendees included journalists, writers and editors from *The Times*, *The Sun*, *New Scientist*, *Prospect*, the *British Medical Journal*, the *British Medical Bulletin*, *Research Fortnight*, *Development*, *BioEthics Online* and *Hour of Writes*, many of whom asked questions from the floor.

The following in-depth articles about the conference – covering multiple conference sessions, and quoting many of the speakers – were published in *Prospect* magazine, the *British Medical Journal* and *The Node* (an adjunct publication of the journal *Development*).

- **The end of reproductive sex?**
Philip Ball, *Prospect*, 2 January 2018
www.prospectmagazine.co.uk/blogs/philip-ball/the-end-of-reproductive-sex
- **Fear and infertility research**
Sally Howard, *British Medical Journal*, 1 February 2018
<https://doi.org/10.1136/bmj.k434>
- **The future of human reproduction: stepping back from visions of Gattaca**
Aidan Maartens, *The Node*, 16 January 2018
<http://thenode.biologists.com/future-human-reproduction-stepping-back-gattaca/>

On New Year's Day 2018, an article was published on **page 3** of the *Guardian* newspaper discussing the conference.

- **Scientists a step closer to mimicking way human body creates sperm**
Hannah Devlin, *Guardian*, 1 January 2018
www.theguardian.com/science/2018/jan/01/scientists-a-step-closer-to-mimicking-way-human-body-creates-sperm

Specifically, the article discussed research presented at the conference by **Professor Azim Surani**, and also quoted conference speaker **Professor Allan Pacey** and session chair **Dr Helen O'Neill**.

This article has in turn prompted a large number of articles and videos across the international media, including the following.

- **Sperm made by scientists could replace the real thing**
Dana Dovey, *Newsweek*, 3 January 2018
www.newsweek.com/sperm-made-scientists-could-replace-real-thing-768710

- **Science is getting us closer to the end of infertility**
Jason Pontin, *Wired*, 27 March 2018
<http://www.wired.com/story/reverse-infertility/>
- **Could same-sex couples soon conceive a child with both their DNA?**
Julie Compton, *NBC News*, 12 January 2018
www.nbcnews.com/feature/nbc-out/could-same-sex-couples-soon-conceive-child-both-their-dna-n836876
- **Artificial sperm? Researchers say they're getting closer to replication**
Denisse Moreno, *International Business Times*, 2 January 2018
www.ibtimes.com/artificial-sperm-researchers-say-theyre-getting-closer-replication-2636049
- **Same-sex couples could soon be biological parents after a huge scientific breakthrough**
Finn Oldfield, *Pink News*, 2 January 2018
www.pinknews.co.uk/2018/01/02/same-sex-couples-could-soon-be-biological-parents-after-a-huge-scientific-breakthrough/
- **Researchers hit critical milestone in growing human sperm in a dish**
Josh Davis, *IFL Science*, 2 January 2018
www.iflscience.com/health-and-medicine/researchers-hit-critical-milestone-in-growing-human-sperm-in-a-dish/
- **Researchers say they're halfway there to artificially producing sperm**
Devin Randall, *Instinct*, 2 January 2018
<http://instinctmagazine.com/post/researchers-say-they%E2%80%99re-halfway-there-artificially-producing-sperm>
- **UK artificial sperm, egg breakthrough could mean homosexuals can be biological parents**
Tyler O'Neil, *PJ Media*, 2 January 2018
<https://pjmedia.com/lifestyle/uk-artificial-sperm-egg-breakthrough-could-mean-homosexuals-can-be-biological-parents/>
- **Artificial sperm is coming**
Ian Lecklitner, *MEL Magazine*, 12 January 2018
<https://melmagazine.com/artificial-sperm-is-coming-9f5aff5afda2>
- **Artificial sperm is closer to being a reality**
Elizabeth Yuko, *SheKnows*, 12 January 2018
<http://www.sheknows.com/health-and-wellness/articles/1137632/artificial-sperm-coming>
- **Scientists are getting closer to creating artificial sperm**
JR Thorpe, *Bustle*, 6 January 2018
www.bustle.com/p/scientists-are-getting-closer-to-creating-artificial-sperm-it-could-be-a-game-changer-for-reproductive-technology-7763573
- **Artificial spermatozoa from stem cells**
Yana Kurchenko, *spinoff.com*
<https://spinoff.com/sperm>
- **Scientists are one step closer to making it possible for gay couples to have a baby related to both partners**
Attitude, 3 January 2018
<https://attitude.co.uk/article/16721/scientists-are-one-step-closer-to-making-it-possible-for-gay-couples-to-have-a-baby-related-to-both-partners/>

Besides coverage prompted by the *Guardian's* article, there was also direct international coverage of the conference, including the following piece in the Dutch publication *De Correspondent*.

- **Zonder biotech geen westerse baby's meer? Open vraag aan het vrouwvolk**
Tamar Stelling, *De Correspondent*, 15 December 2017
<https://decorrespondent.nl/7717/zonder-biotech-geen-westerse-babys-meer-open-vraag-aan-het-vrouwvolk/1443506745593-5fb0e38c>

Finally, several speakers were invited by the *British Medical Bulletin* to adapt their conference presentations into articles for that journal. At the time of writing, at least two of the speakers have accepted this invitation and their articles are due to appear in the journal in coming months.

Social media impact

PET promoted the conference using the dedicated hashtag **#petconf17**, and encouraged others to use the hashtag as well. Attendees, as well as speakers and chairs, were photographed holding up signs which read '*I'm debating the boundaries of human reproduction at #petconf17*' and these were then tweeted by PET. Some examples can be seen below.



Independently, there was lively social media discussion before, during and after the conference, much of which employed the **#petconf17** hashtag. Some examples can be seen below and overleaf.



lisa
@lisababblings

So excited for today's conference discussing the scientific and ethical boundaries of human reproduction **#petconf17**

2:00 am - 8 Dec 2017



Gurdon Institute
@GurdonInstitute

Azim Surani speaks on 'Closing the Gap between Soma and Germ Cells' at London conference today 'Crossing frontiers: Moving the boundaries of human reproduction'

2:13 am - 8 Dec 2017



Andrology Solutions
@Andrology_Sol

Fascinating sessions at **#petconf17** today on moving boundaries of human reproduction. Stem cell research, mitochondrial donation, ethics

1:28 PM - 8 Dec 2017



HFEA
@HFEA

We're at **#PETconf17** - very interesting talk on the building blocks of life and the law

4:13 am - 8 Dec 2017



Simon Rice
@simonrice14

Clicked the trending **#PETconf17** - that escalated quickly 😬

12:12 PM - 8 Dec 2017



Robert Meadowcroft

@MDUK_Robert

Can genome editing technology secure huge potential health gains in [#musculardystrophy](#), reduce risk and address ethical questions - Today's Conference [#petconf17](#)

10:03 AM - 8 Dec 2017



Beckie Smith

@beckie_smith

Instead of jumping to Huxley and Orwell, let's ask: can genome editing be used to meet the challenges we have now? [#petconf17](#)
[#genomeediting](#)

7:09 am - 8 Dec 2017



Victoria Adkins

@VickyAdkins1990

A really great event! Very informative and certainly lots to consider. [#petconf17](#)

5:46 PM - 8 Dec 2017



Annabel

@annabel_hill7

So lucky to have had the opportunity to go to [@AmnestyUK](#) for the [@BioNewsUK](#) annual conference on Moving the Boundaries of Human Reproduction today. Feeling inspired by the work of both organisations, and forever thankful that we have the right to ideas and education. [#PETconf17](#)

6:07 PM - 8 Dec 2017

Furthermore, the website **Hour of Writes** live tweeted from the conference throughout the day, and used the conference as the basis for a creative writing competition on the theme '**Boundaries of Reproduction**'. The winning entries in this competition have been published on the **Hour of Writes** website at <https://hourofwrites.com/>

Policy impact

A number of issues explored at the conference will have policy consequences, either imminently or as the relevant technologies advance in future, and attendees included a number of policymakers and regulators (see **Delegates** below).

One attendee – a representative of the **Office of the Attorney General of Ireland**, who is working on new Irish legislation in this field – made the point in subsequent correspondence with PET that *'it is extremely important to bridge the knowledge gap between legal and scientific approaches to these issues'*.

Additionally, the secretary of the **Human Fertilisation and Embryology Authority's Scientific and Clinical Advances Advisory Committee** approached PET after the conference requesting related material, as part of a horizon-scanning process to inform that Committee's 2018 workplan.

Dissemination through BioNews

Each conference session was written about in PET's flagship publication **BioNews**, which has a readership of around **18,000**, and the **Anne McLaren Memorial Trust Fund** was named as a sponsor at the end of each article. See:

- **Session 1: The building blocks of life and law – What is a sperm? What is an egg? What is an embryo?**
www.bionews.org.uk/page_96305
- **Session 2: Creating life in the lab – *in vitro* gametogenesis (IVG) and synthetic human entities with embryo-like features (SHEEFs)**
www.bionews.org.uk/page_96315
- **Session 3: The wild east and the worried west – pioneers or outlaws?**
www.bionews.org.uk/page_96325
- **Session 4: What next for genome editing? Politics and the public**
www.bionews.org.uk/page_96322
- **Session 5: Revolutionising reproduction – setting a new moral compass**
www.bionews.org.uk/page_96333

BioNews also provided rolling news coverage of related scientific developments before and after the conference, tying this coverage to the conference and using it as an opportunity for promotion. See:

- **Mitochondrial replacement therapies in Mexico and the USA – and the FDA**
www.bionews.org.uk/page_96153
- **Doubt over human embryo editing study**
www.bionews.org.uk/page_96155
- **Genome editing targets beta-thalassemia in human embryos**
www.bionews.org.uk/page_96190
- **How should we discuss genome editing in public?**
www.bionews.org.uk/page_96192
- **CRISPR used to uncover new drug targets for cancer**
www.bionews.org.uk/page_96196
- **Video Review: TED – Editing Our Evolution**
www.bionews.org.uk/page_96199
- **'CRISPR-Gold' repairs muscular dystrophy gene in mouse model**
www.bionews.org.uk/page_96206

- **RNA editing tools could create new disease therapies**
www.bionews.org.uk/page_96230
- **New advance in DNA base editing tools**
www.bionews.org.uk/page_96231
- **Canadian scientists call for end to criminal ban on germline genome-editing**
www.bionews.org.uk/page_96251
- **Real-time film shows CRISPR in action**
www.bionews.org.uk/page_96258
- **Study uses genome editing inside patient for first time**
www.bionews.org.uk/page_96265

Delegates

The conference attracted **205** delegates from a wide range of organisations and backgrounds.

- **Policymakers and regulators**

Representatives of the **Parliamentary Office of Science and Technology**, the **Human Fertilisation and Embryology Authority** and the **Nuffield Council on Bioethics** attended.

Policymakers and regulators also attended from overseas, including the **Office of the Attorney General of Ireland** (see **Policy impact** above), the **German Ethics Council**, and Italy's **Istituto Superiore di Sanità** (National Institute of Health).

- **Professional bodies and societies**

Representatives of the **Academy of Medical Sciences**, the **British Fertility Society** and the **Royal Statistical Society** attended, as did the **African Fertility Society**, the **National Fertility Society** and the **Natural Family Planning Teachers' Association**.

- **Clinics and hospitals**

Many clinics and hospitals sent representatives to the conference including **Andrology Solutions**, the **Centre for Reproductive and Genetic Health**, **City Fertility**, **Guy's Hospital**, the **Hewitt Fertility Centre**, the **Lister Fertility Clinic**, the **London Women's Clinic**, **Midland Fertility Services**, the **Oxford Fertility Unit**, **Portland Hospital**, the **Salisbury Fertility Centre**, **University College Hospital** and – from overseas – **Cryos International** and the **European Sperm Bank** (Denmark), **Gennet** (Czech Republic) and **Northwestern Reproductive Genetics** (USA).

- **Industry**

Representatives of the international biopharmaceutical, genomics and life sciences industries attended the conference, including attendees from **Ferring Pharmaceuticals**, **Finox Biotech**, **Gedeon Richter**, **Genomics England**, **GlaxoSmithKline**, **inVentiv Health**, **Merck**, **Swiss Precision Diagnostics** and **Y Combinator**.

- **Universities and academic institutions**

Undergraduates, postgraduates and academics attended the conference from universities and academic institutions across the UK, covering a range of disciplines.

These institutions included the **Babraham Institute**, **Birkbeck University of London**, **Brighton and Sussex Medical School**, the **Centre for Family Research**, the **Centre for Social Ethics and Policy**, the **Centre for the Advancement of Sustainable Medical Innovation**, **De Montfort University**, the **Francis Crick Institute**, the **Health eResearch Centre**, the **Institute for Women's Health**, **King's College London**, **Kingston University London**, **Life in Glass**, **Manchester Metropolitan University**, **Imperial College London**, **Queen Mary University of London**, the **Reproductive Sociology Research**

Group, St Mary's University, University College London, the Universities of Birmingham, Cambridge, Edinburgh, Exeter, Keele, Kent, Leeds, Liverpool, Manchester, Newcastle, Sussex and Warwick, and – from the Republic of Ireland – Trinity College Dublin.

- **Schools and sixth-form colleges**

PET is especially pleased that enterprising pupils attended the conference from **Cirencester College** (a sixth-form college) and from **Notting Hill and Ealing High School**.

- **Law firms**

Delegates attended from **Jones Maidment Wilson Solicitors, Patrick F O'Reilly Solicitors and Reynolds Porter Chamberlain**.

- **Others**

The conference was attended by a wide variety of other groups including charities, non-profit organisations, thinktanks, lobbyists and patient/public interest groups.

Such groups included the **Donor Conception Network, Fertility Network UK, Genetic Alliance UK, Genome Editing Public Engagement Synergy, the International Working Group on Microbicides, the Multiple Births Foundation, the Muscular Dystrophy Campaign, the National Gamete Donation Trust, the Science Media Centre, the Science Museum, We the Curious and the Wellcome Trust**.

PET was pleased that the audience included both vocal supporters and vocal critics of the technologies being discussed, which made for a richer debate.

Feedback from delegates

PET values feedback from delegates, and uses it to help with planning future events. Comments received by email after the conference included the following.

- *'I meant to congratulate you on an extraordinary event with remarkable science and – even more unusual – remarkable philosophy. Truly exceptional! Thank you.'*
- *'I wanted to thank you for organising such a brilliant event. The speakers were fascinating, and it was great to have such a breadth of areas of expertise to listen to which puts it all into perspective.'*
- *'The conference was excellent, and I really enjoyed it.'*

PET also received **58** completed evaluation forms from delegates, who were asked to choose from '**Excellent**', '**Good**', '**Average**', '**Poor**' and '**Awful**' when rating different elements of the day.

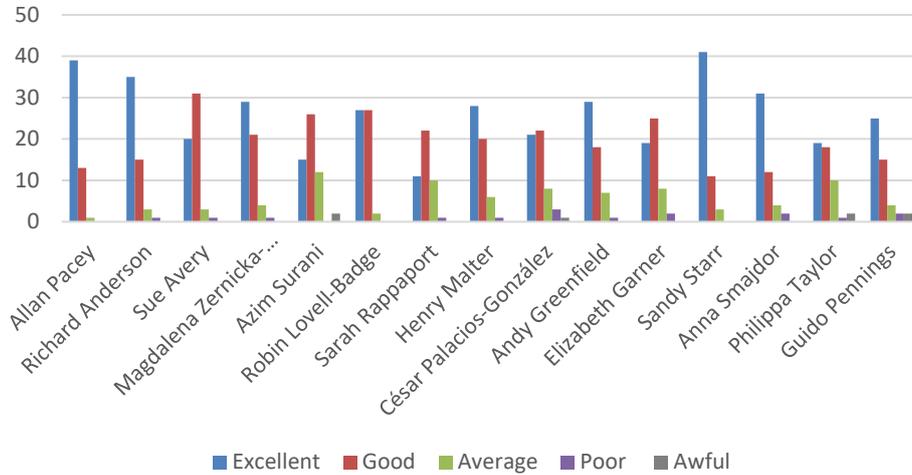
The majority thought that the speakers, the sessions, the day as a whole and the chance to voice their opinion was either '**Excellent**' or '**Good**'. For a detailed breakdown of this feedback, see **Appendix 1** overleaf.



Appendix 1: Conference Feedback

Data from evaluation forms

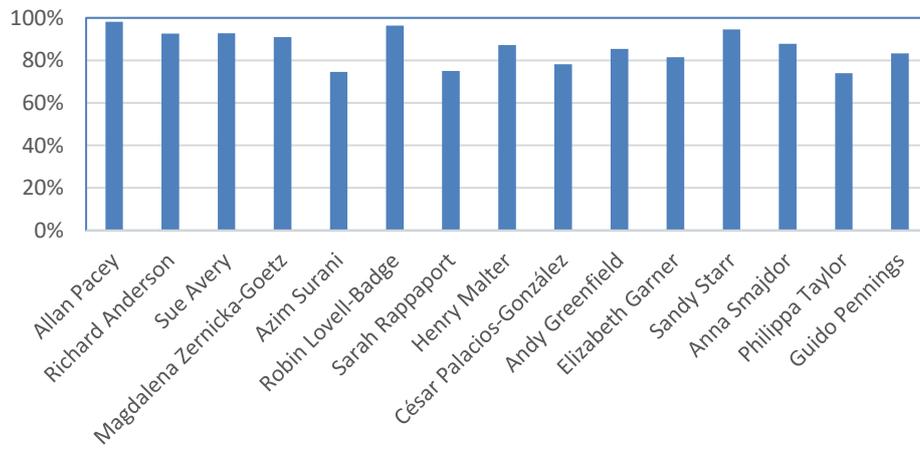
Speaker feedback



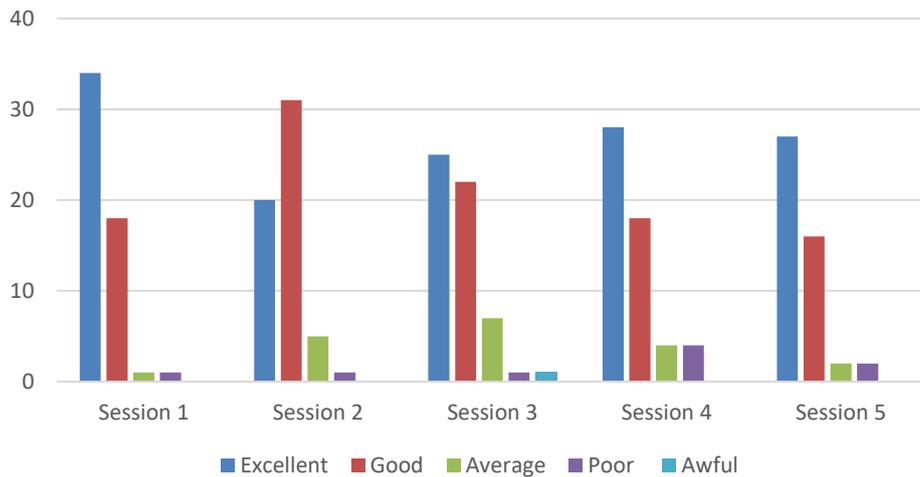
■ Excellent ■ Good ■ Average ■ Poor ■ Awful

Speaker feedback

% rated 'Excellent' or 'Good'



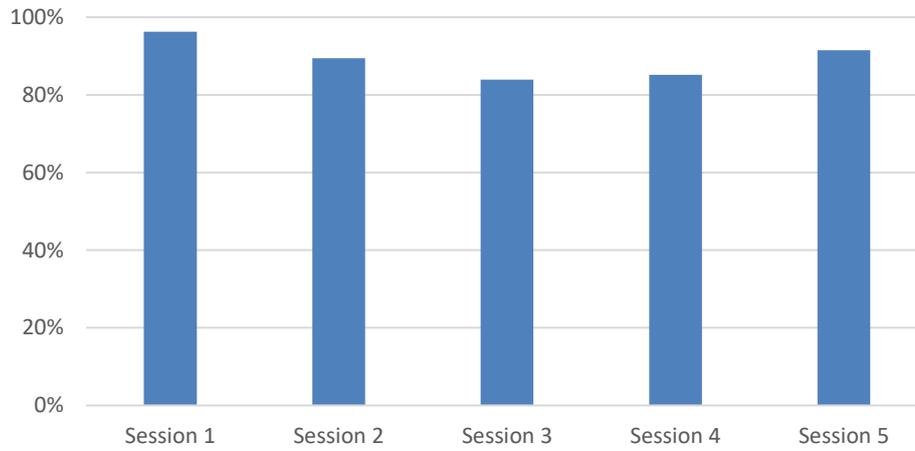
Session feedback



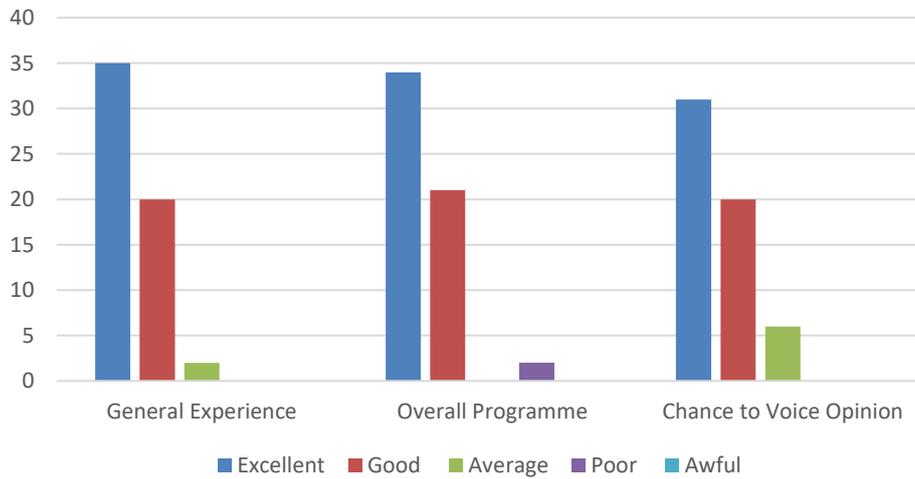
■ Excellent ■ Good ■ Average ■ Poor ■ Awful



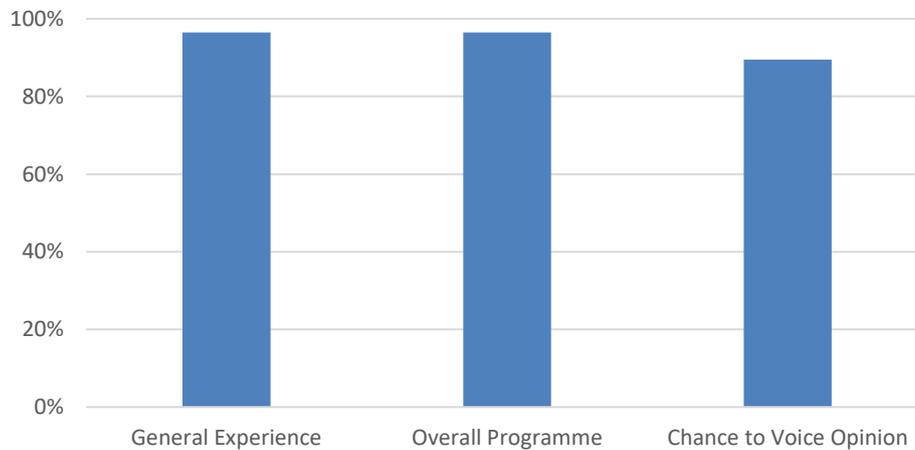
Session feedback
% rated 'Excellent' or 'Good'



Overall feedback

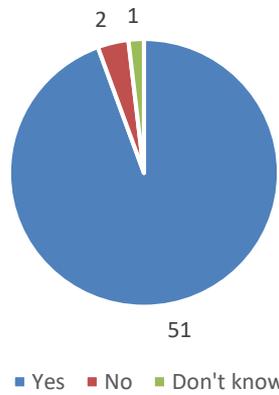


Overall feedback
% rated 'Excellent' or 'Good'

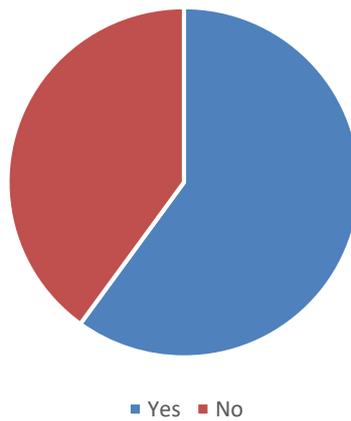




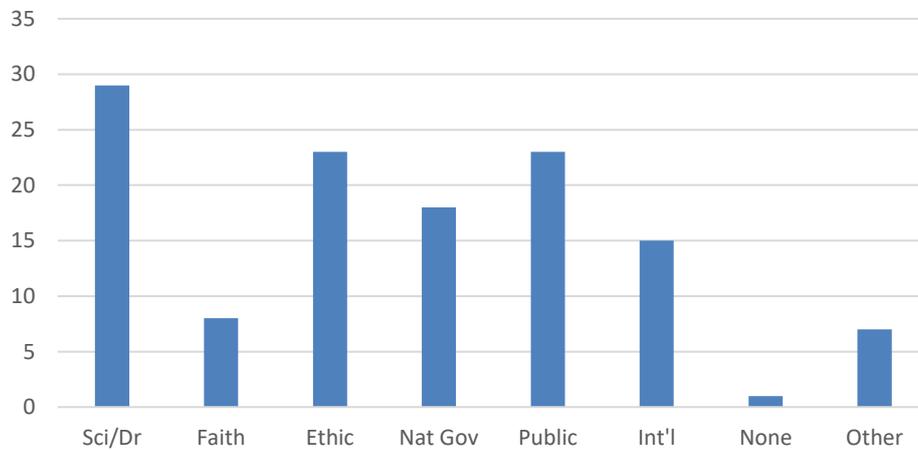
Do you think you are better informed as a result of attending this event?



Have you attended a PET Event before this one?



Who should get to decide whether and how we can create life in the lab?



Freeform comments about speakers and chairs

- *'Fiona Fox was a particularly good chair.'* – Maker of science films
- *'Speakers excellent, same as chairs.'* – Student
- *'Excellent conference!'* – Anonymous
- *'I think it would be interesting to form panels consisting of representatives from a variety of fields, rather than grouping all scientists, philosophers etc together.'* – PhD Student
- *'I wanted to see ethicists/lawyers on each panel.'* – Academic
- *'Loved that Allan Pacey's witty way to present his thoughts allows non-scientific people like me to understand the science (at least in parts!), he is clear. Magdalena Zernicka-Goetz – too complex for non-scientist like me. Elizabeth Garner – delivery was too fast for me to follow.'* – Counsellor
- *'Chair of session 3 should have been more directive in fielding questions. Problem of group "bad science" (same session) too much exposure.'* – Clinician and ethicist
- *'Not specific to particular speakers, but positioning of microphone not optimal – sound lost when they turned to face the screen.'* – Scientist
- *'Was Sue Avery's final slide alarmist/tongue-in-cheek/controversy provoking? Point was missed completely and such a strong image! Session felt ill-prepared.'* – Fertility counsellor
- *'Session 2 "science" talks too much info on slides – v interesting but hard to take it all in.'* – Scientist
- *'Session 2 probably quite a bit over the head of others (like me!) – VERY sciencey. Session 1 (and others) also science but understandable. Afternoon sessions indicate this as debate livened up again.'* – Lawyer
- *'Difficult to understand first speaker in session 2. Also difficult to understand content as I do not have a science background.'* – Student
- *'Chair of session 4 cut people off a lot, the point of it all is discussion!'* – Medical student
- *'The speakers varied very much in their ability/willingness to translate their research into language for a broad audience. Some even used the same slides they would for a scientific conference. However, I gained a lot from the sessions.'* – Genetic counsellor
- *'Very excellent selection.'* – PhD student

Was there any area you thought should have been addressed that wasn't?

- *'Artificial wombs?'* – Scientist
- *'Maybe a bit more of the gritty ethics and a bit less science.'* – Medical student
- *'Sociologists missing from conversation. Also historians of medicine/science. Both could really enhance discussion – perhaps even have these as moderators.'* – PhD student
- *'No.'* – fertility counsellor
- *'The debate about enhancement vs therapeutic use emerged regularly, and though obviously contentious and a topic in itself, it might have been worth mentioning the underlying issue that what counts as "health" is contentious, and not at all clear.'* – Student
- *'More philosophy!'* – Student
- *'No.'* – Fertility Nurse
- *'More on the ethical debate – less than the science.'* – Academic
- *'More discussion on the ethics of synthetic embryos.'* – Student
- *'No.'* – Company Director

- *'More on the sociocultural drivers behind ART – lots of scientific info but the rhetoric of "choice" for patients is somewhat problematic (patient autonomy can't be identified in a capitalist society driven by privatisation and consumerism). More ethical, philosophical debate needed.'* – Student
- *'The speakers often talked away from the microphone, at the screen rather than at the room, making it difficult to hear at times.'* – Counsellor
- *'Patient perspective – massively underrepresented. Also there was no real development of critical ethical debate and analysis – lack of rigour in chairing sessions (exceptions Sally Cheshire and Fiona Fox).'* – Fertility counsellor
- *'Patients' perspectives were underrepresented.'* – Medical research scientist
- *'Resources for good communication about new technologies – should they be developed at the same time as the technology, eg for schools.'* – Genetic counsellor
- *'The positives of genome editing.'* – Anonymous
- *'The sociological and anthropological perspective.'* – Researcher
- *'I'm not a scientist. I would have preferred fewer speakers to allow for more detail and explanation, though I accept I may be in the minority.'* – Anonymous
- *'No.'* – Press officer
- *'No.'* – Research on assisted reproduction

Were you motivated to attend this conference by a particular speaker or session?

- *'No, just overall topic.'* – PhD student
- *'I'm interested in genome editing in general. Part of my job is to know what's going on in the area.'* – Science information officer
- *'No, just total programme.'* – Fertility counsellor
- *'The first and last sessions were of particular interest to me.'* – Student
- *'Just the theme.'* – Student
- *'General interest in reproductive science.'* – Anonymous
- *'Topic is the reason I came.'* – Academic
- *'All sessions.'* – Student
- *'In general wanted to hear where we are with these new technologies, dispel media headlines, learn about other countries.'* – Counsellor
- *'Both Robin Lovell-Badge and Guido Pennings.'* – Clinician and ethicist
- *'Session 3.'* – Fertility doctor
- *'Just general catch-up on ethics of reproduction.'* – Scientist
- *'My previous experience of attending PET conferences motivated me because of the thought-provoking nature of the debates. However, unfortunately, this was not repeated today.'* – Counsellor
- *'The Wild East and the Worried West: Pioneers or Outlaws? Revolutionising Reproduction: Setting a New Moral Compass.'* – Fertility counsellor
- *'Genome editing, ethical aspects (sessions 4 and 5).'* – Scientist
- *'Artificial gametes and ethical aspects of all covered in last two sessions.'* – Lawyer
- *'The moral discussions.'* – Student
- *'Theme as a whole.'* – Medical student
- *'No, I came for the whole meeting.'* – Medical research scientist

- 'Session 5.' – Administrative officer
- 'Was most interested in hearing about genome editing but actually learned most from the other talks although did find the speakers in the genome editing session excellent.' – Genetic counsellor
- 'No, general.' – Researcher
- 'Session 1 of particular interest, but all great.' – Academic (social sciences)
- 'Philippa Taylor.' – Anonymous
- 'All of them – great line-up.' – Press officer

Are there any additional comments you would like to make?

- 'Loved hearing everyone's opinions and thoughts from different areas of science and ethics.' – Anonymous
- 'Thank you for an informative and broad-based day. Many ideas for thought.' – Fertility counsellor
- 'A thoroughly enjoyable day hearing about the innovative research, issues facing reproductive medicine as well as the ethics, all talks covered were very interesting and engaging.' – Anonymous
- 'Chairing was sometimes a bit too aggressive. Some chairs didn't engage that much. Fiona Fox was perfect!' – MSc bioethics student
- 'It was great and very informative.' – Science information officer
- 'I wanted to hear more about the new technologies and less about the words we should use to describe them.' – Maker of science films
- 'The 4th chair shouldn't have cut people off so much – she spoke over people too much.' – Medical communications
- 'Speakers should be discounted from reading their contribution. It makes the content duller, even if interesting.' – Clinician and ethicist
- 'You could have people in audience vote on their smartphones (using eg. Slido or SurveyMonkey) to contentious questions, eg on safe germline genome editing.' – Company director
- 'What is an egg Q wasn't answered. Talk was on familiar story of age-related decline in female fertility partner rather than probing Q or what constitutes an egg, as Allan Pacey did with sperm.' – Anonymous
- '10 minutes not long enough for "new" science.' – Fertility doctor
- 'Make the research findings presented in talks more relevant in terms of implications for patients: what do the findings mean or people facing fertility difficulties and going through treatment?' – Counsellor
- 'Great day – v well chaired discussions. Not enough coffee first break – but addressed swiftly!' – Scientist
- 'Good spread of male/female panellists and international. Europe?' – Lawyer
- 'An excellent meeting as usual.' – Medical research scientist
- 'The day was varied enough to provoke a broad range of interesting questions and debates – I valued the pre-reading. An addition might be the provision in the circular email of a simple glossary of some terms likely to be used frequently during the day (eg stem cells, iPSC, ICSI, PGD, etc).' – Genetic counsellor
- 'Good conference – I think 15 min sessions would be better.' – Anonymous
- 'Excellent day! Thank you.' – Press officer

Appendix 2: Conference Programme

9.30am Registration

10am **WELCOME ADDRESS**

- Sarah Norcross
-

10.05am Session 1

**THE BUILDING BLOCKS OF LIFE AND LAW:
WHAT IS A SPERM? WHAT IS AN EGG? WHAT IS AN EMBRYO?**



- **What Makes a Sperm a Sperm?** (Professor Allan Pacey)
- **Making Eggs: It's All About the Quality** (Professor Richard Anderson)
- **How to Make a Human** (Dr Sue Avery)

Chair: Sarah Norcross

10.50am Session 2

**CREATING LIFE IN THE LAB: IN VITRO GAMETOGENESIS (IVG) AND
SYNTHETIC HUMAN ENTITIES WITH EMBRYO-LIKE FEATURES (SHEEFs)**

Sponsor:

Anne McLaren Memorial Trust Fund



- **Building Embryo-Like Structures *In Vitro*** (Professor Magdalena Zernicka-Goetz)
- **Closing the Gap between Soma and Germ Cells** (Professor Azim Surani)
- **Do SHEEFs Challenge What It Is to Be Human?** (Professor Robin Lovell-Badge)

Chair: Dr Helen O'Neill

Midday Refreshments

12.20pm Session 3

THE WILD EAST AND THE WORRIED WEST: PIONEERS OR OUTLAWS?



- **Funding Scientific Frontiers: A Global Perspective** (Dr Sarah Rappaport)
- **Myths of the Wild West: Outlaws and the New Frontier** (Dr Henry Malter)
- **Mexico and Mitochondrial Replacement Techniques: What a Mess** (Dr César Palacios-González)

Chair: Sally Cheshire

1.30pm **LUNCH**

2.15pm **Session 4**

WHAT NEXT FOR GENOME EDITING? POLITICS AND THE PUBLIC



- **Carry On Editing** (Dr Andy Greenfield)
- **The Can, Can't and Won't for Genome Editing** (Dr Elizabeth Garner)
- **How to Talk About Genome Editing: Putting CRISPR in Its Place** (Sandy Starr)

Chair: Vivienne Parry

3.30pm *Refreshments*

3.50pm **Session 5**

**REVOLUTIONISING REPRODUCTION:
SETTING A NEW MORAL COMPASS**

Sponsor:

Edwards and Steptoe Research Trust Fund



- **Artificial Gametes and the End of Sexual Reproduction** (Dr Anna Smajdor)
- **Setting the Moral Compass: Are We Heading in the Right Direction?** (Philippa Taylor)
- **The Inevitable Coming of Germline Genome Editing** (Professor Guido Pennings)

Chair: Fiona Fox

5pm **CLOSE**

- **Sarah Norcross**
-

Until 6pm **DRINKS RECEPTION**

Appendix 3: Speaker and Chair Biographies



Richard Anderson is the Elsie Inglis Professor of Clinical Reproductive Science and Head of Obstetrics and Gynaecology at the University of Edinburgh's Centre for Reproductive Health, and is a Consultant in Reproductive Medicine at the Royal Infirmary of Edinburgh. He has longstanding experience in clinical research in male and female reproductive endocrinology, and his group currently investigates female reproductive lifespan, with laboratory and clinical aspects particularly related to the adverse effects of cancer treatment on fertility. Work he carried out with his team recently led to a cancer patient becoming the first woman in the UK to give birth following a transplant of her frozen ovarian tissue.



Dr Sue Avery is a Trustee at the **Progress Educational Trust**, and is Director of the Birmingham Women's Fertility Centre. She has been working in the field of infertility for more than 30 years, and her PhD was supervised by IVF pioneer Professor Sir Robert Edwards. She also has a postgraduate diploma in Law, and she was the first clinical embryologist to serve as a member of the Human Fertilisation and Embryology Authority. She was previously Scientific Director of Bourn Hall Clinic and Chair of the Association of Clinical Embryologists, and she spent more than 10 years as a member of the British Fertility Society's Executive Committee.



Sally Cheshire is Chair of the Human Fertilisation and Embryology Authority, the UK's independent regulator overseeing the use of embryos and gametes in fertility treatment and research, where she has been a board member for more than 10 years. She is also Chair of Health Education England (North), which plans and delivers quality education and training for 350,000 NHS employees. She has held a wide variety of senior roles in the health and care sector, at organisations including NHS North West, NHS North of England and the Health Research Authority. She has been awarded a CBE for services to the NHS and to fertility patients.



Fiona Fox is Chair of Trustees at the **Progress Educational Trust**, and is founder and Chief Executive of the Science Media Centre – a charity which promotes voices and views from the scientific community to the news media, when science is in the headlines. She was Chair of the Science and the Media Expert Group at the UK Government's Department for Business, Innovation and Skills, and was the only representative of the science community to appear as a witness at the Leveson Inquiry. She has a degree in journalism and more than 30 years' experience working in media relations, and she has been awarded an OBE for services to science.



Dr Elizabeth Garner is a Functional Genomics Scientist at Caribou Biosciences. She developed a keen interest in cellular DNA repair mechanisms early in her career, working at the UK's National Institute for Medical Research and at Cancer Research UK. She went on to work at the Rockefeller University in New York, where she coupled genomics with functional characterisation to understand the cell-based DNA repair failures associated with the hereditary bone marrow failure disorder Fanconi anemia. At Caribou, she continues her passion for understanding DNA repair mechanisms within the framework of genome engineering technologies.



Dr Andy Greenfield is Programme Leader in Mammalian Sexual Development at MRC Harwell, the Medical Research Council's international centre for mouse genetics, where his research focuses on disorders of sex development. He is also a member of the Human Fertilisation and Embryology Authority and of the Nuffield Council on Bioethics, and he chaired the Working Group which produced the Nuffield report *Genome Editing: An Ethical Review*. He contributed to the recent *Basic Understanding of Genome Editing* project run by the **Progress Educational Trust** and Genetic Alliance UK.



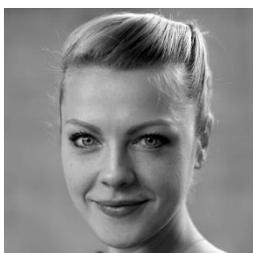
Professor Robin Lovell-Badge is Group Leader in Stem Cell Biology and Developmental Genetics at the Francis Crick Institute. Major themes of his work include sex determination, the role of Sox genes in development of the early embryo, the nervous system and the pituitary, and the biology of stem cells within these tissues. He is very active in public engagement and policy work around stem cells, genetics, human embryo research and animal research. He is a member of the Committee on Human Gene Editing of the USA's National Academies of Sciences and Medicine.



Dr Henry Malter is Laboratory Director at the Fertility Centre of the Carolinas, Clinical Assistant Professor at the University of South Carolina's School of Medicine, and Section Editor for Clinical Embryology at the journal *Reproductive BioMedicine Online*. He has been involved in assisted reproductive science for more than 30 years, working as a senior research scientist and as a clinical laboratory director/embryologist. He has been involved in pioneering research and clinical development in cell biology, mitochondrial aspects and genetic analysis.



Sarah Norcross is Director of the **Progress Educational Trust (PET)**. She is also Commissioning Editor of **PET's** flagship publication **BioNews** – www.bionews.org.uk – and Co-Chair of Fertility Fairness. She frequently represents **PET** in the print and broadcast media, both nationally (including on the *Today* programme, *BBC News*, *ITV News*, *Good Morning Britain* and *Sunday Morning Live*, as well as in broadsheet and tabloid newspapers) and internationally (on *BBC World News*, *Fala Brasil* and *Mittagsmagazin*, and in newspapers including *Die Welt*). Previously, she worked as a Barrister.



Dr Helen O'Neill is Director for the MSc in Reproductive Science and Women's Health programme at University College London's Institute for Women's Health, where she is also a member of the Embryology, IVF and Reproductive Genetics Group. She is a molecular geneticist and has researched the genes involved in sex determination, including genes crucial for the formation of ovaries. She is currently researching the morphokinetics of preimplantation embryos, and is using genome editing to improve our understanding of infertility and neuromuscular disorders.



Allan Pacey is a Trustee at the **Progress Educational Trust**, Professor of Andrology at the University of Sheffield and Editor-in-Chief of the journal *Human Fertility*, and his own research in human fertility focuses on sperm biology and andrology. He is also an accomplished science communicator and broadcaster, and has worked – both behind and in front of the camera – on feature documentaries and on programmes for BBC1, BBC2, BBC3 and Channel 4. He was previously Chair of the British Fertility Society, and he has been awarded an MBE for services to reproductive medicine.



Dr César Palacios-González is a philosopher, and a Research Associate at the Centre of Medical Law and Ethics at King's College London. His recent work has focused on the ethics of mitochondrial replacement, *in vitro* gametogenesis and chimera research. He currently works on *Reproductive Donation: Donation and Transfer of Human Reproductive Materials*, a research project funded by the Wellcome Trust. Previously, he researched and studied at the University of Manchester, the National Autonomous University of Mexico, and Mexico's Panamerican University.



Vivienne Parry is Head of Engagement at Genomics England, which was established by the UK Government to carry out the 100,000 Genomes Project, and a Board Member at UK Research and Innovation – a newly established body which brings together the Research Councils, Innovate UK and Research England. She is also a science writer and broadcaster who has written books, presented the BBC1 programmes *Tomorrow's World* and *Panorama*, been a columnist for *The Times*, the *Guardian*, *Woman's Own* and the *News of the World*, and been an agony aunt for *Good Housekeeping*.



Guido Pennings is Professor of Ethics and Bioethics at Ghent University in Belgium, where he is also Director of the Bioethics Institute Ghent. He is a member of the Belgian Advisory Committee on Bioethics, a member of the Federal Commission for Medical and Scientific Research on Embryos *In Vitro*, and a member of the Ethics Committees of the European Society of Human Reproduction and Embryology and of the Centre for Reproductive Medicine in Brussels. Much of his work focuses on ethical problems associated with medically assisted reproduction and genetics.



Dr Sarah Rappaport is a Policy Adviser at the Wellcome Trust, where the aim of her team is to influence policy developments so that researchers can be as effective as possible and so that health can be improved. Her work focuses on legislation and regulation relating to genome editing, mitochondrial donation, regulation of clinical trials, research in the NHS, and research involving embryos. Previously, she obtained a PhD in Cognitive Neuropsychology at the University of Birmingham, and went on to join the stroke research programme at St George's Hospital in London.



Dr Anna Smajdor is Associate Professor of Practical Philosophy at the University of Oslo in Norway, and also works on the project *Close Personal Relationships, Children and the Family* at Umeå University in Sweden. Previously, she was a Lecturer in Ethics at the University of East Anglia. She has worked extensively on the ethics of new reproductive technologies, and has published widely on medical and research ethics. She is interested in the relationship between nature and morality, especially in the context of medicine, scientific research and innovation.



Sandy Starr is Communications Manager at the **Progress Educational Trust (PET)**, and has organised more than 50 public events for the charity over the past 10 years. He has also represented **PET** before the Science and Technology Select Committee of the House of Commons, and he played a leading role in **PET**'s recent project *Basic Understanding of Genome Editing*. He writes for a wide range of publications – most recently *Microbiology Today* and the journal *Health Expectations* – and he serves on the Ethics Advisory Board of the world's largest autism research project, EU-AIMS.



Professor Azim Surani is Director of Germline and Epigenomics Research at the University of Cambridge's Gurdon Institute. 30 years ago, he and his colleagues discovered the epigenetic phenomenon of genomic imprinting, and went on to examine its mechanism and the functions of imprinted genes. His more recent work has established the genetic basis for germ cell specification and programming of germ cells. He obtained his PhD under IVF pioneer Professor Sir Robert Edwards, he is a Fellow of the Royal Society, and he has been awarded a Royal Medal for his work on early mammalian development and a CBE for services to biology.



Philippa Taylor is Head of Public Policy at the Christian Medical Fellowship, and a Consultant on Family and Bioethics at Christian Action Research and Education. She is also a Trustee of the Relationships Foundation, a member of the Marriage Foundation's Advisory Board, and a member of the Evangelical Alliance's Theology Advisory Group. Previously, she was Associate Director of the Centre for Bioethics and Public Policy. She has an MA in Bioethics and Law from St Mary's University, and for more than 20 years she has been speaking, writing, advising and working on a wide range of contemporary bioethics and family issues in the UK.



Magdalena Zernicka-Goetz is Professor of Mammalian Development and Stem Cell Biology at the University of Cambridge. After her PhD research at the Universities of Warsaw and Oxford, she moved to Cambridge to study development and spatial patterning in the early mouse embryo. Her research revealed that at the earliest embryonic stages, pluripotent stem cells are already biased towards particular cell types. Last year, she led research in which human embryos were cultured *in vitro* for 13 days, the longest time ever achieved. She was the first recipient of the Anne McLaren Award for Outstanding Women in Developmental Biology.
