

From Three-Person IVF to Genome Editing
The Science and Ethics of Engineering the Embryo

Annual Conference of the Progress Educational Trust
9 December 2015

How many people attended the conference?

More than **230**.

Who were the audience?

- **Regulators and policymakers**

Representatives of **Government** (the **Department of Health** and the **Department for Work and Pensions**), **Parliament** (the **House of Lords**), the **Human Fertilisation and Embryology Authority** and the **Nuffield Council on Bioethics** attended.

Regulators and policymakers also travelled from overseas to attend the conference, including the **Office of the Attorney General of Ireland** and the **German Ethics Council**.

- **Professional bodies and learned societies**

Representatives of the **Academy of Medical Sciences**, the **British Medical Association** and the **Royal Society** attended.

- **Researchers and Academics**

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

These institutions included **Brighton and Sussex Medical School**, **Brunel University London**, the **Cambridge Stem Cell Institute**, **Cardiff University**, the **Centre for the Advancement of Sustainable Medical Innovation**, the **Centre for Family Research**, **Cranfield University**, **Durham University**, the **Francis Crick Institute**, the **Gurdon Institute**, the **Institute for Women's Health**, the **Institute of Child Health**, **Keele University**, **King's College London**, the **London School of Economics and Political Science**, **Queen Mary University of London**, the **Sanger Institute**, **Sheffield Hallam University**, **St George's University of London**, **University College London**, the **William Harvey Research Institute** and the Universities of **Bath**, **Cambridge**, **Edinburgh**, **Exeter**, **Kent**, **Leicester**, **Liverpool**, **Manchester**, **Newcastle**, **Oxford**, **Roehampton**, **Sheffield**, **Southampton** and **Teesside**.

Academics from **Adam Mickiewicz University** in **Poland** and **Ghent University** in **Belgium** also attended.

- **Clinics and hospitals**

Clinics and hospitals sent representatives to the conference including **CARE Fertility**, the **Centre for Reproductive and Genetic Health**, **Great Ormond Street Hospital**, **Guy's Hospital**, the **London Bridge Fertility, Gynaecology and Genetics Centre**, the **London Women's Clinic**, **Northwick Park Hospital**, **Queen Charlotte's and Chelsea Hospital**, **St Bartholomew's Hospital**, and – travelling from overseas to attend – **Alto Ave Hospital** in **Portugal**.

- **Genomics industry**

Representatives of the genomics industry and related industries attended including **Caribou Biosciences**, **Desktop Genetics**, **Front Line Genomics**, **Genomics England**, **SLM Blue Skies Innovations**, **Smiths Medical**, **Touchlight Genetics** and **Illumina**.

- **Law firms**

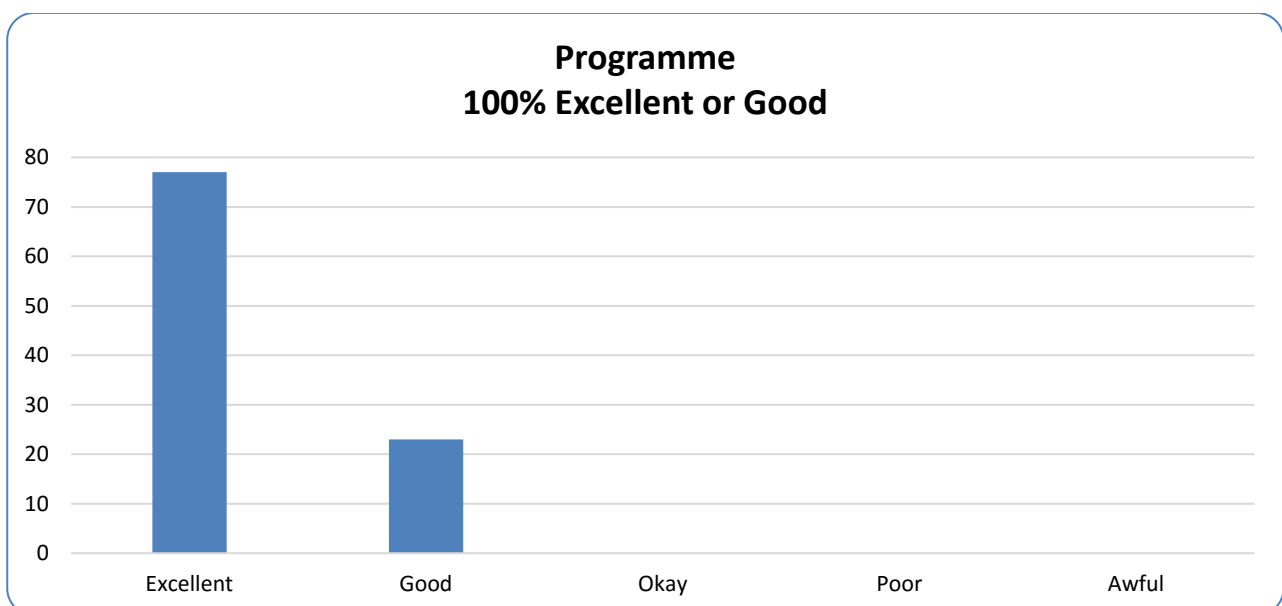
Representatives of **Hempsons, Patrick F O'Reilly Solicitors, Reynolds Porter Chamberlain, Coram Chambers** and **7 Harrington Street Chambers** attended.

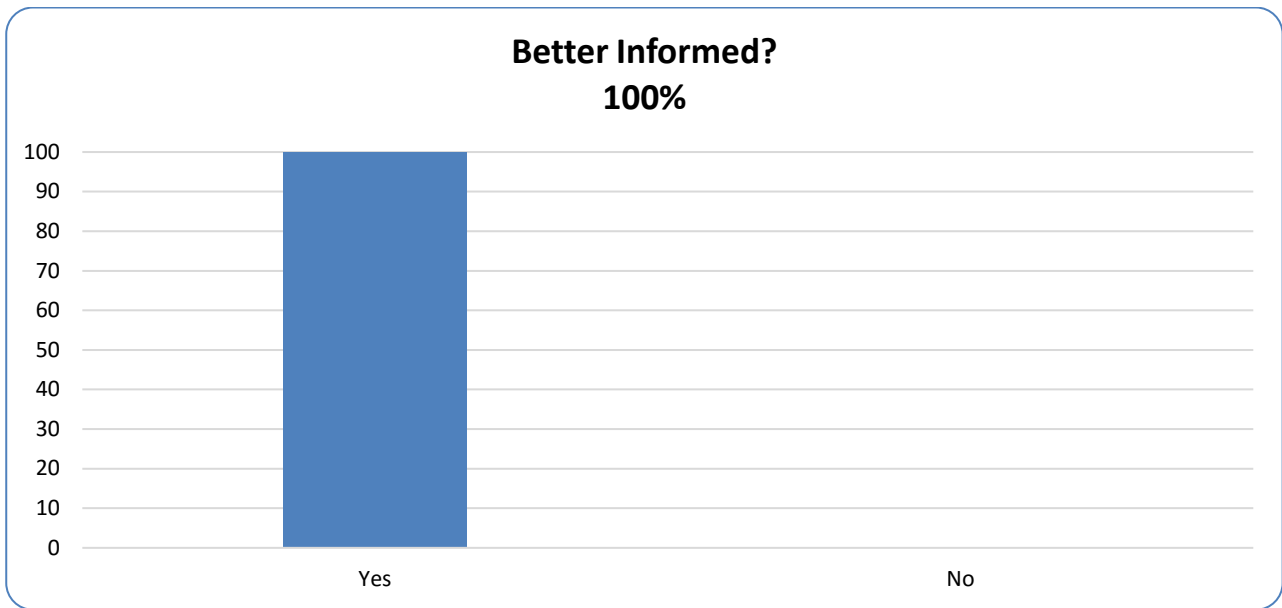
- **Others**

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

These organisations included the **Anscombe Bioethics Centre**, the **Association of Medical Research Charities**, **Brilliant Beginnings**, **Cancer Research UK**, the **Christian Medical Fellowship**, **Comment on Reproductive Ethics**, the **Cystic Fibrosis Trust**, **Genetic Alliance UK**, **Infertility Network UK**, **LIFE**, **London Futurists**, the **Science Media Centre** and the **Wellcome Trust**.

What did the audience think?





'Excellent conference – wide-ranging debate about the relevant issues'

'I thoroughly enjoyed myself. I felt the day ran extremely well and had a brilliant and engaging atmosphere. I will definitely be attending future The Progress Educational Trust events.'

'Absolutely fantastic insight into research and different viewpoints – very helpful for my dissertation.'

'I found the conference very interesting and thought-provoking.'

'The meeting was excellent. It was really refreshing to see a nice balance of science, policy and ethics mixed in with some proper debate.'

'All the speakers made important contributions. Well-rounded choices who expressed an important wide breadth of both scientific and ethical opinion'

Advance publicity

Conference speaker **Sarah Norcross**, Director of the **Progress Educational Trust**, wrote about the conference and its themes in the **Observer** newspaper.

- **Genome editing raises complex issues – banning it is not the answer**

Sarah Norcross, *Observer*, 6 September 2015

<http://www.theguardian.com/commentisfree/2015/sep/06/banning-genome-editing-is-not-the-answer>

Sarah also appeared on the **BBC1** programme **Sunday Morning Live**, on 4 October 2015, where she discussed the themes of the conference.

Several other speakers made advance appearances in the print and broadcast media in the weeks leading up to the conference, discussing its themes.

- **Professor Robin Lovell-Badge** appeared on **BBC Radio 4's Today** programme and on the **BBC World Service's Newshour Extra**, was interviewed in the **Observer**, and wrote for **Nature**.
- **Professor John Harris** wrote for the **Guardian** and **Nature**.
- **Viscount Matt Ridley** wrote for **The Times**.
- **Dr Calum MacKellar** wrote for the **Scotsman**.

The conference was attended by journalists from the **British Medical Journal**, **BuzzFeed**, **The Conversation**, the **Daily Mail**, the **Independent**, the **Lancet**, **Motherboard**, **Naked Genetics**, **Nature**, **Research Fortnight**, the **Telegraph**, **The Times** and the **Wall Street Journal**.

Media coverage

The conference was reported and discussed in the following articles, beginning with a front-page article in the **Daily Telegraph**.

- **Britain should lead way on genetically engineered babies, says Chief Scientific Adviser**

Sarah Knapton, *Daily Telegraph* (**front-page article**), 9 December 2015

<http://www.telegraph.co.uk/news/science/science-news/12042178/Britain-should-lead-way-on-genetically-engineered-babies-says-Chief-Scientific-Adviser.html>

- **Editing the genome – will society catch up with science?**

Editorial, *Lancet*, 19 December 2015

<http://www.thelancet.com/journals/lancet/article/PIIS0140-6736%2815%2901286-6/fulltext>

- **Church may back GM embryos to cure inherited diseases**

Oliver Moody, *The Times*, 14 December 2015

<http://www.thetimes.co.uk/tto/science/article4640063.ece>

- **We shouldn't be squeamish about GM embryos**

Oliver Moody, *The Times*, 2 January 2016

<http://www.thetimes.co.uk/tto/opinion/thunderer/article4654549.ece>

- **UK's approval of mitochondrial donation shows how decisions on gene editing can be made**

Nigel Hawkes, *British Medical Journal*, 18 December 2015

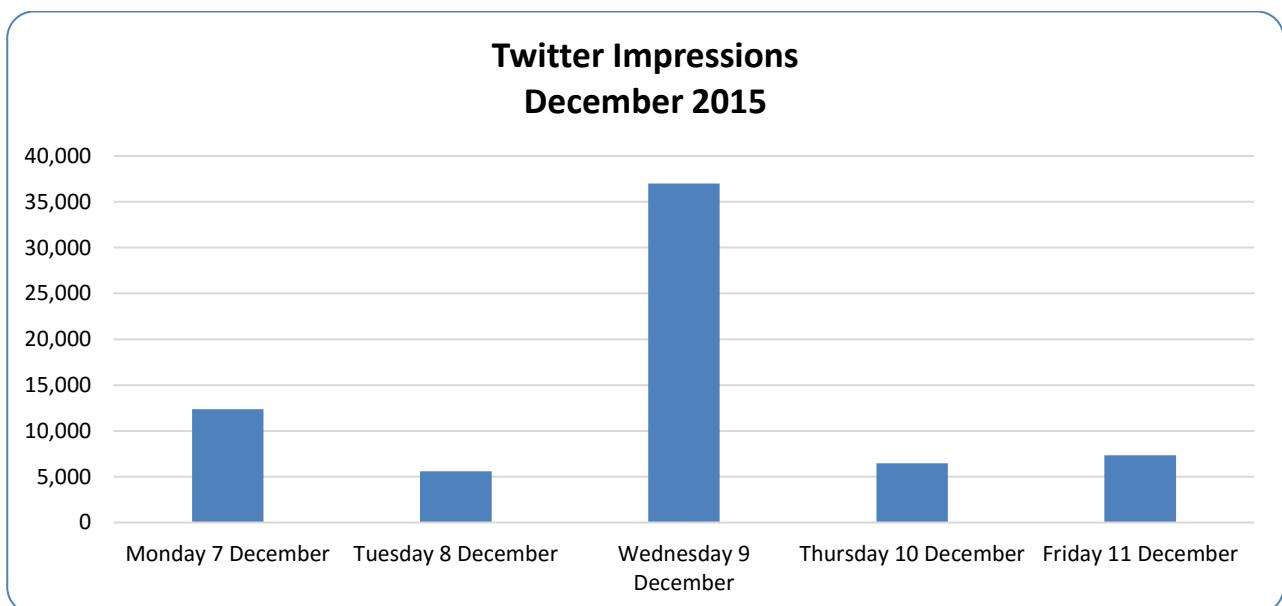
<http://dx.doi.org/10.1136/bmj.h6745>

- **Let scientists experiment on older embryos, says stem cell pioneer**
Tom Chivers, *BuzzFeed*, 9 December 2015
<http://www.buzzfeed.com/tomchivers/let-scientists-experiment-on-older-embryos-says-stem-cell-pi>
- **Genetic research needs regulation and innovation, conference told**
Anna McKie, *Research Fortnight*, 10 December 2014
<https://www.researchprofessional.com/0/rr/news/uk/innovation/2015/12/Genetic-research-needs-regulation-and-innovation--conference-told.html>

Social media

Over one-sixth of attendees tweeted from and about the conference, using the dedicated hashtag **#petconf15**. Many other Twitter users used the hashtag to follow the proceedings remotely.

The **Progress Educational Trust's** own tweets from the conference on **9 December 2015** earned **36,994** Twitter impressions.



One-sixth of attendees joined the Facebook page for the conference, where related material was posted and discussed.

Posts on the **Progress Educational Trust's** organisational Facebook page reached **6,542** people during the week of the conference.

- Social media activity during and after the conference was compiled via **Storify**:
<https://storify.com/BioNewsUK/science-ethics-engineering-embryo>
- Related material in the weeks leading up to the conference, including media appearances by conference speakers, was also compiled via **Storify**:
<https://storify.com/BioNewsUK/three-person-ivf-genome-editing>

Further dissemination

Several conference speakers and chairs developed their material from the conference into articles.

- **Professor John Harris** in the *Financial Times*:
<http://www.ft.com/cms/s/0/9fd0529e-bb6a-11e5-b151-8e15c9a029fb.html>
- **Revd Dr Brendan McCarthy** on the **Church of England's** website:
<http://cofecomms.tumblr.com/post/135196054672/genome-editing-and-splitting-the-atom>
- **Professor Azim Surani** in *The Conversation*:
<https://theconversation.com/how-close-are-we-to-successfully-editing-genes-in-human-embryos-52326>
- **Dr Roger Highfield** on the influential science website **Edge.org**:
<https://edge.org/response-detail/26580>
- Professors **Doug Turnbull** and **Robin Lovell-Badge** were both interviewed about mitochondrial donation by the *Financial Times*:
<http://www.ft.com/cms/s/2/528630ea-a25a-11e5-8d70-42b68cfae6e4.html>

Furthermore, each conference session was written about in the **Progress Educational Trust's** flagship publication **BioNews**, which has a readership of around **18,000**. Sponsors were listed at the end of each article.

- **Session 1: What Is the Germline? Understanding Enduring Changes to the Embryo**
http://www.bionews.org.uk/page_598920.asp
- **Session 2: Three-Person IVF: What Makes Mitochondrial Donation Different?**
http://www.bionews.org.uk/page_604026.asp
- **Keynote Address: Why the UK Should Be Leading the Discussion on Embryo Engineering**
http://www.bionews.org.uk/page_603809.asp
- **Session 3: Genome Editing and CRISPR: The Science of Engineering the Embryo**
http://www.bionews.org.uk/page_606553.asp
- **Session 4: Germline in the Sand: The Ethics and Law of Engineering the Embryo**
http://www.bionews.org.uk/page_609421.asp

Follow-up work with Government and Parliament

The **Progress Educational Trust** was asked to send a report of the conference to the UK's **Chief Medical Officer (Dame Sally Davies)** and to the **Parliamentary Under Secretary of State for Life Sciences (George Freeman)**.

The **Progress Educational Trust** was asked to convene a meeting in the **House of Lords** to brief Peers on genome editing. **15** Peers attended, spanning the entire political spectrum – **Conservative, Labour, Liberal Democrats, Plaid Cymru, Crossbenchers** and **Bishops** were all represented.

The success of this event was clear when the Peers who attended asked for updates and follow-up meetings from the **Progress Educational Trust**, and when Peers who were unable to attend asked for the speakers' presentations.

Follow-up work in the media

Within two months of the conference, it was announced that a licence had been granted permitting genome editing in human embryo research in the UK.

The announcement became front-page news and the **Progress Educational Trust** was poised to comment on it, with **Sarah Norcross** interviewed on TV (*BBC News*, *Sky News* and Germany's most watched news programme *Tagesschau*), on radio (on **BBC Radio 2**, **BBC Radio 5 Live**, **BBC Radio London**, **BBC Radio**

Berkshire, BBC West Midlands, LBC and Germany's ARD), and in numerous articles (published by the *Guardian*, the *Washington Post*, CNN, Reuters and Agence France-Presse among others).

The conference also left the Progress Educational Trust well-placed to comment on developments in mitochondrial donation, when the USA's National Academies of Sciences, Engineering, and Medicine published its report *Mitochondrial Replacement Techniques: Ethical, Social, and Policy Considerations*. Sarah Norcross was interviewed by *Science* magazine about the difference between US and UK approaches to regulation of this area.

Audio and video material

The Progress Educational Trust produced a number of related videos for its YouTube channel.

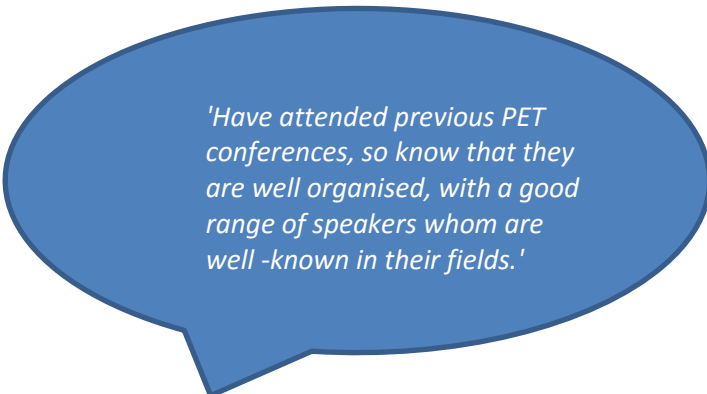
- **From Three-Person IVF to Genome Editing**
A four-minute video of conference highlights
<https://youtu.be/fTlvNkna46M>
- **Should We Be Using CRISPR/Cas9 to Experiment on Human Embryos?**
A half-hour video of a follow-up debate
<https://youtu.be/aODwpAGgDJ4>
- **Sarah Norcross discusses genome editing in human embryo research**
A video compiling numerous interviews with Sarah Norcross
<https://youtu.be/ibCfZrB-Kwo>

The conference was discussed, and conference speakers were interviewed, in two episodes of the *Naked Genetics* podcast.

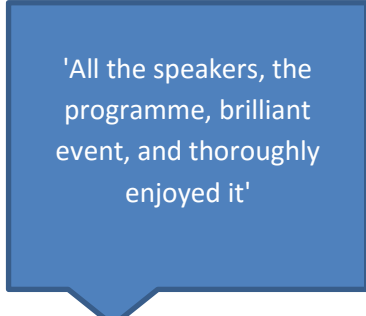
- **Crazy for CRISPR**
<http://www.thenakedscientists.com/HTML/podcasts/genetics/show/20160214/>
- **Designer Genes**
<http://www.thenakedscientists.com/HTML/podcasts/genetics/show/20160314/>

Why did people attend the conference?

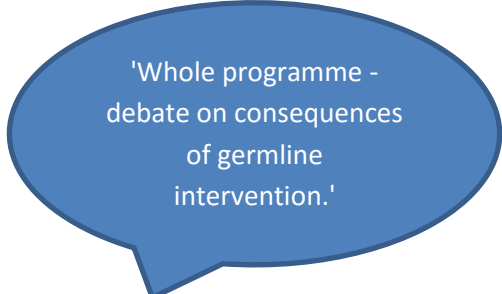
Responses included:



'Have attended previous PET conferences, so know that they are well organised, with a good range of speakers whom are well -known in their fields.'



'All the speakers, the programme, brilliant event, and thoroughly enjoyed it'



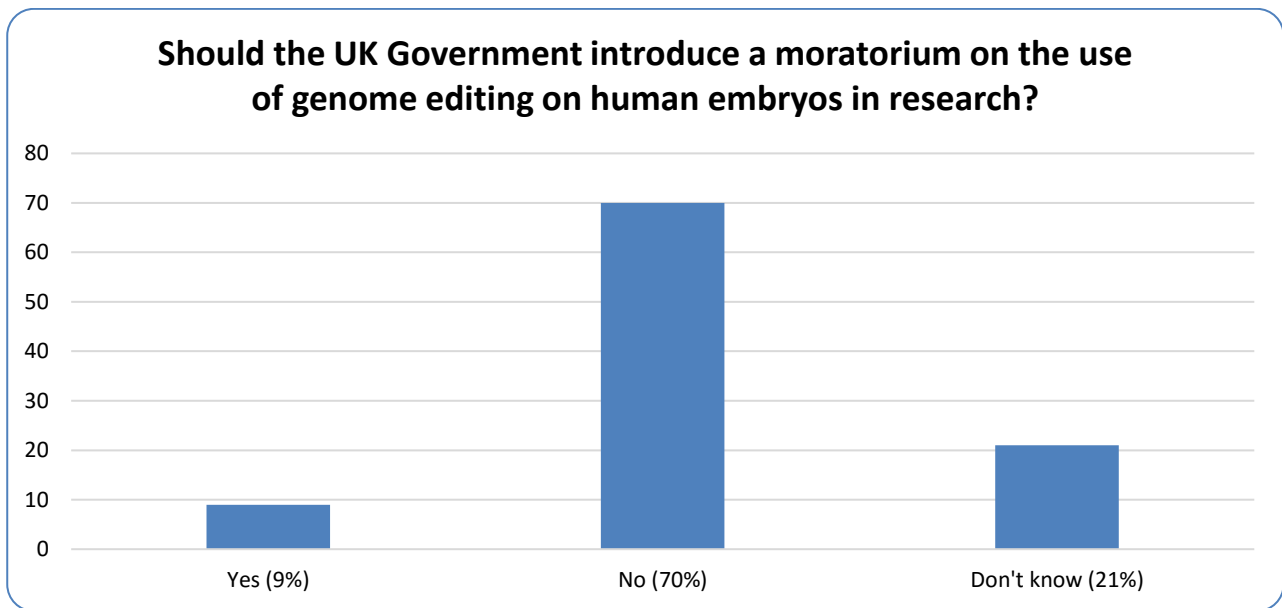
'Whole programme - debate on consequences of germline intervention.'

What did the audience think of the issues debated?

The **Progress Educational Trust's** Annual Conference is always billed as a discussion conference, with the majority of each session's running time devoted to discussion with input from the audience.

One-sixth of attendees made contributions to the proceedings from the floor, a much higher proportion than would be found at other events with a similarly-sized audience.

Besides contributing from the floor, attendees were also asked for their views on genome editing via evaluation forms.



Their responses were analysed, and these findings were disseminated to other organisations to inform their public engagement and communications work.

Who sponsored the conference?

Gold Sponsor



Silver Sponsor



Bronze Sponsors



Who spoke at the conference?



Sally Cheshire
Chair of the Human Fertilisation and Embryology Authority



Professor Bobbie Farsides
Brighton and Sussex Medical School



Fiona Fox
Chair of the Progress Educational Trust



Timandra Harkness
Science writer and broadcaster



Professor John Harris
Director of the Institute for Science, Ethics and Innovation



Dr Roger Highfield
Director of External Affairs at the Science Museum Group



Professor Emily Jackson
London School of Economics and Political Science



Professor Robin Lovell-Badge
Francis Crick Institute



Dr Calum MacKellar
Scottish Council on Human Bioethics



Revd Dr Brendan McCarthy
National Adviser Church of England



Sarah Norcross
Director of the Progress Educational Trust



Dr Tony Perry
University of Bath



Viscount Matt Ridley
Conservative Peer House of Lords



Professor Azim Surani
Director of Germline and Epigenomics Research Gurdon Institute



Professor Sir Doug Turnbull
Director of Wellcome Trust Centre for Mitochondrial Research



Professor Sir Mark Walport
Chief Scientific Adviser UK Government