

## **Future Debate: Who owns your genome? Notes for speakers**

### **Event Details**

Date: Tuesday 20 September 2016  
Title: Future Debate: Who owns your genome?  
Public and private uses of data  
Booking link: <https://www.eventbrite.co.uk/e/future-debates-who-owns-my-genome-tickets-27404507620>  
Venue: Henry Wellcome Auditorium, Wellcome Collection, 183 Euston Road, London, NW1 2BE. Details on how to get there [here](#).

### **Timeline**

- 18.00: Speakers Arrive and sound check.  
Please make your way to the Williams Lounge downstairs in the Wellcome Collection.
- 18.00 - 18.45: Welcome refreshments
- 18.45 - 18.55: Welcome Introductions from BSA  
Future Debates animation shown
- 18:55 - 19.05: Keynote from Professor Mark Caulfield
- 19:05 - 20.15: Debate
- 20.15 - 21.00: Drinks Reception

### **Event Outline**

This debate is the final flagship event of the Future Debates series. Taking place all over the UK, this series has consisted of over 25 regional debates on the topic of genomic data privacy.

Future Debates events are part of the British Science Association (BSA)'s work to make science a fundamental part of British society and culture. We want to empower many more people – not just scientists – to constructively engage in debates over the applications and implications of science in their lives, their local economy and the UK's future.

*This flagship debate concerns genomic data, thinking about how we balance the benefits of genomic medicine to society with its inherent risks. Debate will cover access and management of such data, exploring the tensions between public benefit and private profit, institutional trust and the limits of data security in the digital age.*

### **Format**

Future Debates' brings specialists, stakeholders and the public to engage in constructive, lively and enjoyable debates about the issues on society's horizon. The format of this event reflects this spirit, and members of the public are encouraged to join the discussion, having frequent opportunities throughout the debate to pose their questions to the panel and the floor. The chair will be responsible for prompting

this debate, creating a balanced discussion between speakers and audience, and providing provocations to the panel.

Each speaker will have up to 5 minutes to introduce themselves and their own views and perspectives on this topic before the discussion opens. Please keep this brief and do not prepare a PowerPoint presentation.

## Content

The debate is orientated around the central themes of trust and security. Within these overarching topics, several questions may be discussed:

- Who should have access to our genomic data?
- What institutions can we trust to store genomic data securely?
- What are the risks of storing genomic information?
- Do the benefits of genomic data outweigh these risks?
- What are the trade-offs to giving private companies access to genomic information?
- Where should we draw the line for genomic data use and storage?

## Speaker Biographies

Chair: **Fiona Fox**, director of the Science Media Centre.

Speakers:

**Professor Sir Mark Walport**, Government Chief Scientific Adviser and Head of Government Science and Engineering Profession.

Mark Walport is the Chief Scientific Adviser to HM Government and Head of the Government Office for Science. Sir Mark's responsibilities include providing scientific advice to the Prime Minister and members of Cabinet and advising the government on aspects of policy on science and technology. Previously, Sir Mark was Director of the Wellcome Trust and before joining the Trust he was Professor of Medicine and Head of the Division of Medicine at Imperial College London. He has undertaken independent reviews for the UK Government on the use and sharing of personal information in the public and private sectors.

**Dr Anna Middleton**, Head of Society and Ethics Research, Wellcome Genome Campus, Cambridge.

Anna Middleton explores the social and ethical impact of genomics on people. Continually asking - how is society responding to genomic technology? She utilises both quantitative and qualitative research methods to gather empirical data on attitudes, beliefs and values about genomics. Anna is also an experienced genetic counsellor and current Vice-chair of the Association of Genetic Nurses and Counsellors in the UK and ROI.

**Dr Anders Sandberg**, Research Fellow, Future of Humanity Institute, University of Oxford.

Anders Sandberg's research at the Future of Humanity Institute centres on management of low-probability high-impact risks, societal and ethical issues surrounding human enhancement, estimating the capabilities of future technologies, and very long-range futures. Topics of particular interest include global catastrophic risk, cognitive biases, cognitive enhancement, collective intelligence, neuroethics, and public policy.

**Timandra Harkness**, writer, comedian, broadcaster and author of *Big Data: does size matter?*

Timandra Harkness is a writer, comedian and broadcaster, who has been performing on scientific, mathematical and statistical topics since the latter days of the 20th Century. She has written about travel for the Sunday Times, motoring for the Telegraph, science & technology for WIRED, BBC Focus Magazine and Men's Health Magazine, and on being 'Seduced by Stats' for Significance (the Journal of the Royal Statistical Society). She is a regular on BBC Radio, resident reporter on social psychology series The Human Zoo as well as writing and presenting documentaries and BBC Radio 4's FutureProofing series. In her spare time Timandra is studying for an Open University degree in Mathematics & Statistics.

## Research

The BSA has also conducted research into the views of the public around genomic data privacy that provide interesting food for thought for the debate. Of the questions asked to attendees of the previous events in the series:

How happy would you be to share your genome (whole set of DNS) with...	...university researchers?	... pharmaceutical companies?	...the NHS?	...Insurance companies?
<b>Not at all happy</b>	7%	24%	8%	68%
<b>Not very happy</b>	8%	13%	11%	17%
<b>Neither happy nor unhappy</b>	15%	29%	15%	12%
<b>Quite happy</b>	23%	16%	27%	2%
<b>Very happy</b>	48%	18%	39%	1%

A deliberative dialogue workshop discussing genomic medicine also gives an insight into the public's views on trust and genomic data, as discussed in the following excerpt of a report into the event:

*Participants took a very positive view of the NHS, which they saw as a trustworthy institution. This trust did not necessarily extend to the government, which was often regarded as separate from the NHS. Some participants worried that the NHS was being eroded, which affected the strength of their confidence. Views and attitudes regarding the NHS stood in sharp contrast to participants' opinions of the private sector, which was universally distrusted. For many participants, the mere fact that organisations in the private sector operated to make a profit made them untrustworthy, leading participants to be quite dismissive of the private sector's involvement in the development of genomic medicine.*

*The public dialogue workshop saw many participants struggling to reconcile their hopes for scientific progress with their scepticism about the competence and motivations of organisations involved. Occasionally, participants reflected on the difficulty of avoiding private sector involvement in medical research, but at other times they disregarded the current system, embracing instead a vision of a society where health research and development flourish while being funded, governed and carried out exclusively by trusted public institutions.*

*This desire for trusted public institutions to lead in the future of genomic medicine was particularly apparent in participants' statements about sharing their own genomic data. When their focus was on medical research and improvements to individuals' healthcare, some participants declared themselves ready to share their genome on the spot. However, when their conversations concentrated on data sharing and management, participants often expressed a great degree of caution, which no safeguards seemed to be able to alleviate.*

## **Contacts**

Points of contact on the evening will be:

- Rosie Waldron (BSA): 07811 756 888 / [rosie.waldron@britishscienceassociation.org](mailto:rosie.waldron@britishscienceassociation.org)
- Jacob Ohrvik-Stott (BSA): 07494 597 902/ [jacob.ohrvik-stott@britishscienceassociation.org](mailto:jacob.ohrvik-stott@britishscienceassociation.org)