

**Translation in Healthcare – Exploring the Impact of Emerging Technologies**  
**Mathematical Institute, Woodstock Road, Oxford**  
**23 – 25 June 2015**

| <b>TUESDAY 23 JUNE 2015</b> |  |
|-----------------------------|--|
| 13:00 -<br>14:00            | <b>Conference Registration</b>   |
| 14:00 -<br>14:45            | <b>WELCOME</b><br><i>Lecture Theatre 2</i><br>Prof. Jane Kaye<br>University of Oxford, UK  |
| 14:45 -<br>16:15            | <b>PLENARY I</b><br><b>What is ‘translation’ and what are the challenges?</b><br><i>Lecture Theatre 2</i><br>Prof. Eric Juengst, University of North Carolina, USA<br>Prof. Kazuto Kato, Osaka University, Japan<br>Alastair Kent, Genetic Alliance, UK<br>Prof. Eric Meslin, Indiana University, Indiana, USA<br>Prof. Amy McGuire, Baylor College of Medicine, Houston, USA<br>Chair: Prof. Timothy Caulfield, University of Alberta, Canada |
| 16:15 -<br>17:00            | <b>Afternoon Refreshments</b>  |
| 17:00 -<br>18:30            | <b>DISCUSSION FORUMS</b><br><i>Breakout Rooms- L4, L5, C3, C4, C5, C6</i><br>Conference participants will be allocated to small groups to further explore the issues raised by the plenary panel   |
| 18:30 -<br>19:30            | <b>Welcome Drinks and Canapés</b><br><i>Common Room, Mathematical Institute</i><br>Prof. Sir Rory Collins, NDPH, University of Oxford, UK<br>Address by Prof. Julie Maxton, Executive Director of the Royal Society, Chair of HeLEX Advisory Board<br>Master of Ceremonies: Prof. Donald Chalmers, University of Tasmania, Australia   |
| 19:30                       | <b>FURTHER DEBATE</b><br>Oxford is known for the lively academic debates and conversations that take place in many of its pubs. In the spirit of this tradition, we will start our journey at the Royal Oak and move on to the Eagle and Child, where Tolkien and CS Lewis used to meet every Tuesday afternoon.   |

**WEDNESDAY 24 JUNE 2015**

08:00 -  
09:00

**Refreshments available**

09:00 -  
10:30

**PLENARY II  
The Clinic of the Future  
Lecture Theatre 2**

Prof. Nine Knoers, University Medical Centre Utrecht, Netherlands  
Prof. Timothy Caulfield, University of Alberta, Canada  
Dr. Kassim Javaid, NDORMS, University of Oxford, UK  
Clara Gaff, Melbourne, Australia (TBC)

Chair: Prof. Amy McGuire, Baylor College of Medicine, Houston, USA

10:30 -  
10:45

**Introducing ECOUTER:** Prof. Madeleine Murtagh, University of Bristol, UK  
*Lecture Theatre 2*

10:45 -  
11:15

**Morning Refreshments**

**CONCURRENT PRESENTATION SESSIONS**

|                  | <b>Innovative Engagement<br/>Room C4</b><br><i>Chair: Kazuto Kato</i>   | <b>Disruptive Technologies<br/>Room C5</b><br><i>Chair: Nils Hoppe</i>  | <b>Protecting Innovations<br/>Room C6</b><br><i>Chair: Di Nicol</i>  | <b>Personalised Medicine<br/>Room L4</b><br><i>Chair: Timothy Caulfield</i>                      | <b>Data Sharing for Translation<br/>Room L5</b><br><i>Chair: Bartha Knoppers</i>                     |
|------------------|---|---|--|--|--|
| 11:15 -<br>11:45 | <b>Teare et al.</b><br>Engagement 2.0 - Views of Biobank Participants Regarding Dynamic Consent   | <b>Rödiger</b><br>Translational Neuroscience Research: Potential Applications of Brain-Computer Interfaces in Healthcare                  | <b>Mnisi</b><br>A Normative Case for the Patentability of Human Embryonic Stem Cell Technologies                                       | <b>Dickenson</b><br>A Reality Check for Personalised Medicine: just a few errors in translation? | <b>O'Doherty et al.</b><br>Unintended Uses of Health Data: The Need for Robust Democratic Governance |
| 11:45 -<br>12:15 | <b>Thiel</b><br>Could a web-based informed consent portal help address the awkwardness surrounding 'legacy' biobanks?                     | <b>Haimes &amp; Taylor</b><br>What's in a name? Identifying multiple representations of women who provide eggs for mitochondrial research | <b>Rial-Sebbag et al.</b><br>The legal and ethical dilemma of embryonic stem cells: an impediment to translation in medicine?          | <b>Budin Ljøsne</b><br>Patient and interest organizations' views on personalized medicine        | <b>Krleza-Jeric et al.</b><br>IMPACT Observatory of Clinical Research Regarding Data Sharing         |
| 12:15 -<br>12:45 | <b>McCaughey</b><br>Avoiding HeLA: Incorporating a video animation to improve informed consent for induced pluripotent stem cell research | <b>Strange</b><br>From NIPD to NIPT: biopolitical implications of an emerging reproductive technology                                     | <b>Sterckx &amp; Cockbain</b><br>Patenting of human genes and their uses in diagnostic tests: Recent developments in the US and Europe | <b>Skopek</b><br>Fragmentation and Blurring in Personalized Medicine                             | <b>Langanke &amp; Fischer</b><br>Clinical Decision-Making and Secondary Findings in Systems Medicine |

**WEDNESDAY 24 JUNE 2015**

12:45 -  
14:45

**ACTIVITY ZONE (including LUNCH)**

ECOUTER engagement process; ELSI 2.0 Helpdesk; Artist in Residence; Talking Wall (glass walls to write thoughts on); Selfies Competition (use your mobile phones to capture the moment); Haiku/Limerick competition; Walk and Talk (take a new colleague and see the scientific sights of Oxford); Live Twitter Feed

14:45 -  
15:45

**PECHA KUCHA**

Slides move on automatically to keep everything on time. Fast, furious and fun!

**Lecture Theatre 2**

**Room L4**

**Room L5**

**Dheensa** - Children in the UK  
100,000 Genomes Project  
**Sasongko** - Practical and Ethical Challenges in Molecular Diagnostic Services of Genetic Disorders; Experiences of Universiti Sains Malaysia  
**Blasimme** - Clinical politics: new entanglements of life and power  
**Yamamoto** - How can we ensure that medical and health care systems can adapt to the social challenges of using personal data?  
**Jamal** – (TBA)

**Silverman** - Epigenetics in Health Policy: Ethical and legal considerations in the assessment of environmental harms  
**Mano** - Online health information and health changes among e-patients in Israel  
**Bell** - Hybrid forms of governance for biobanks  
**Mohammad Firdaus bin Abdul Aziz** - The Regulation of Stem cell research in Malaysia  
**Yoshizawa** - Patient Opinions on the use of ICT in Japan

**Salman** - Translating novel technologies from bench to bedside: a legal perspective on the standard of care  
**Hewitt** - Socio-legal factors effecting the integration of pharmacogenomics; the Abacavir experience  
**Ho** - Different Models in Governance: National Biobanks - a Comparative Perspective  
**Bertier** - ELSI challenges associated with clinical applications of exome sequencing: a systematic literature review  
**(TBA)** – (TBA)

15:45 -  
16:30

**Afternoon Refreshments**

16:30 -  
18:00

**PLENARY III  
My Data, Open Data, Big Data  
Lecture Theatre 2**

Prof. Bartha Knoppers, McGill University, Canada – Towards a Human Rights Foundation for Data Sharing  
Prof. Sigrid Sterckx, Ghent University, Belgium – Healthcare and Big Data in the UK: Controversies surrounding care.data  
Prof. Gil McVean, University of Oxford, UK – Using Big Data Approaches in Research  
Prof. Martin Richards, University of Cambridge, UK – Recommendations from the Nuffield Council Report on Big Data

Chair: Prof. Martin Landray, University of Oxford, UK

19:00 -  
21:30

**NETWORKING EVENT - Food Bowls and Drinks  
Natural History Museum, Oxford**

21:30

**FURTHER DEBATE**

Our starting point for this event will be the Kings Arms, one of the oldest pubs in Oxford built in 1607, frequented by many students and dons.

**THURSDAY 25 JUNE 2015**

08:00 -  
09:00

**Refreshments available**

09:00 -  
10:30

**PLENARY IV  
From Benchside to Bedside to Populations  
Lecture Theatre 2**

Prof. Mike Burgess – University of British Columbia, Canada  
Dr. Fred Kemp – ISIS Innovation, Oxford, UK  
Other panel members to be confirmed  
Chair: Prof. Roger Brownsword, King's College London, UK (TBC)

10:30 -  
11:00

**Morning Refreshments**

**CONCURRENT PRESENTATION SESSIONS**

|                  | <b>Citizen Science<br/>Room L4</b><br><i>Chair: Deborah Mascalzoni</i>                                    | <b>Hope and Uncertainty<br/>Room L5</b><br><i>Chair: Leila Jamal</i>  | <b>Governance and Translation<br/>Room C4</b><br><i>Chair: Roger Brownsword</i>   | <b>Clinical Applications of WGS<br/>Room C5</b><br><i>Chair: Mark Taylor</i>   | <b>Policy Development<br/>Room C6</b><br><i>Chair: Eric Meslin</i>   |
|------------------|---|---|---|--|--|
| 11:00 -<br>11:30 | <b>Lee</b><br>Citizen Science: Mapping Values and Relational Ethics in Crowdsourcing in Genomic Research  | <b>Dimond</b><br>Living with mitochondrial disease and responses to novel (and controversial) reproductive technologies | <b>Laurie</b><br>Liminality and the limits of law in health research regulation - what is helping or hindering translation in healthcare? | <b>Mitchell et al.</b><br>The duty of care in Next Generation Sequencing (NGS): Who owes a legal duty? To whom and to do what?                                 | <b>Peacock et al.</b><br>Public input on priority setting and the high cost of cancer drugs: results from a public deliberation event in Vancouver, BC |
| 11:30 -<br>12:00 | <b>Charbonneau et al.</b><br>Think before you spit: ELSI and the Direct-to-Consumer Genetic Testing Space | <b>Rial-Sebbag &amp; Blasimme</b><br>Translation of Stem Cells therapies: How to balance Hope and Uncertainties?        | <b>Hogarth</b><br>Regulation as Translation: the FDA and personalised medicine  | <b>Leonard</b><br>When Opportunity Knocks? A European perspective on the translation of WGS technology into the clinical setting                               | <b>Hall</b><br>Realising Genomics in Clinical Practice: a case study in Translation  |
| 12:00 -<br>12:30 | <b>Vayena</b><br>Research led by participants: towards a new social contract                              | <b>Chico</b><br>Safeguarding patient expectations - the role of the courts in the data trust deficit                    | <b>Morrison</b><br>Internal governance of consortia: a mechanism for facilitating research?   | <b>Carrieri et al.</b><br>Is there an ethical and/or legal obligation for healthcare providers to re-contact former patients in light of new genetic findings? | <b>Littler</b><br>Policy development and research behaviour: a funder's perspective  |

THURSDAY 25 JUNE 2015

12:30 -  
14:00

**ACTIVITY ZONE (including LUNCH)**

Artist in Residence Exhibition  
Results of Competitions and Awards

**CONCURRENT WORKSHOPS**

14:00 -  
15:00

**Zimmern & Meslin  
Room L4**

Personalised Prevention  
in an Era of Personalised  
Medicine: Who should  
be responsible –  
Citizens, Physicians, or  
the State?

**Burgess, Koenig &  
O' Doherty  
Room L5**

Spending our Money,  
Shaping our Futures:  
Deliberative Public  
Engagement for Policy  
and Governance

**Newson et al.  
Room C4**

Known  
Unknowns?  
Building an Ethics  
of Uncertainty into  
Genomic Medicine

**Phillips &  
Finlay  
Room C5**

DNA  
a click away:  
"Agreements"  
in DTCGT

**Kaye, Nicol &  
Chalmers  
Room C6**

Embedding  
Biobanks as  
Tools for  
Translational  
Research

15:00 -  
16:00

**PLENARY V**

**Where Do We Go From Here?**

*Lecture Theatre 2*

**Please pick up your voting handsets at the door**

Prof. Madeleine Murtagh, University of Bristol, UK  
Prof. Eric Juengst, University of North Carolina, USA  
Prof. Kazuto Kato, Osaka University, Japan  
Prof. Eric Meslin, Indiana University, USA  
Prof. Amy McGuire, Baylor College of Medicine, Houston, USA  
Prof. Sigrid Sterckx, Ghent University, Belgium  
  
Chair: Prof. Jane Kaye, University of Oxford, UK

16:00

**CONFERENCE CLOSES**

16:30

Optional Punting afternoon (weather dependent!) (Details available on the day)  
Enjoy a punt along the rivers of Oxford before returning home



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**BRISTOL**



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**wellcome**trust

Nuffield Department of  
**POPULATION HEALTH**  
Medical Sciences Division

