



**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 - 14:00	<b>Conference Registration</b>																	
14:00 - 14:30	<p><b>WELCOME</b> <i>Lecture Theatre 2</i> Welcome by Prof. Julie Maxton, Executive Director of the Royal Society, Chair of HeLEX Advisory Board Prof. Jane Kaye, University of Oxford, UK</p>																	
14:30 - 16:15	<p><b>PLENARY I</b> <b>What is ‘translation’ and what are the challenges?</b> <i>Lecture Theatre 2</i> Prof. Eric Juengst, University of North Carolina, USA Prof. Kazuto Kato, Osaka University, Japan Alastair Kent OBE, Genetic Alliance, UK Prof. Eric Meslin, Indiana University, Indiana, USA Prof. Amy McGuire, Baylor College of Medicine, Houston, USA Chair: Prof. Timothy Caulfield, University of Alberta, Canada</p>																	
16:15 - 17:00	<b>Afternoon Refreshments</b>																	
17:00 - 18:30	<p><b>DISCUSSION FORUMS</b> <i>Breakout Rooms- L4, L5, C3, C4, C5, C6</i> Conference participants will be allocated to small groups to explore the issues raised by the plenary panel</p> <table border="1"> <thead> <tr> <th><b>Room L4</b></th> <th><b>Room L5</b></th> <th><b>Room C3 -</b></th> <th><b>Room C4-</b></th> <th><b>Room C5</b></th> <th><b>Room C6</b></th> </tr> </thead> <tbody> <tr> <td>Eric Juengst and Bartha Knoppers</td> <td>Tim Caulfield and Sigrid Sterckx</td> <td>Kazuto Kato and Mike Burgess</td> <td>Alastair Kent and Madeleine Murtagh</td> <td>Eric Meslin and Donna Dickenson</td> <td>Amy McGuire and Graeme Laurie</td> </tr> </tbody> </table>						<b>Room L4</b>	<b>Room L5</b>	<b>Room C3 -</b>	<b>Room C4-</b>	<b>Room C5</b>	<b>Room C6</b>	Eric Juengst and Bartha Knoppers	Tim Caulfield and Sigrid Sterckx	Kazuto Kato and Mike Burgess	Alastair Kent and Madeleine Murtagh	Eric Meslin and Donna Dickenson	Amy McGuire and Graeme Laurie
<b>Room L4</b>	<b>Room L5</b>	<b>Room C3 -</b>	<b>Room C4-</b>	<b>Room C5</b>	<b>Room C6</b>													
Eric Juengst and Bartha Knoppers	Tim Caulfield and Sigrid Sterckx	Kazuto Kato and Mike Burgess	Alastair Kent and Madeleine Murtagh	Eric Meslin and Donna Dickenson	Amy McGuire and Graeme Laurie													
18:30 - 19:30	<p><b>Welcome Drinks and Canapés</b> <i>Common Room, Mathematical Institute</i> Prof. Sir Rory Collins, NDPH, University of Oxford, UK Master of Ceremonies: Prof. Don Chalmers, University of Tasmania, Australia</p>																	
20:00	<p><b>FURTHER DEBATE</b> 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, as well as other significant locations.</p>																	

**WEDNESDAY 24 JUNE 2015**

08:00 - 09:00	<b>Refreshments available</b>				
09:00 - 10:30	<p><b>PLENARY II</b>  <b>The Clinic of the Future</b>  <i>Lecture Theatre 2</i></p> <p>Prof. Nine Knoers, University Medical Centre Utrecht, Netherlands          Prof. Timothy Caulfield, University of Alberta, Canada          Dr. Kassim Javaid, NDORMS, University of Oxford, UK          Assoc. Prof. Clara Gaff, Melbourne Genomics Health Alliance, Melbourne, Australia</p> <p>Chair: Prof. Amy McGuire, Baylor College of Medicine, Houston, USA</p>				
10:30 - 10:45	<p><b>Introducing ECOUTER:</b> Prof. Madeleine Murtagh, University of Bristol, UK  <i>Lecture Theatre 2</i></p>				
10:45 - 11:15	<b>Morning Refreshments</b>				
	<b>CONCURRENT PRESENTATION SESSIONS</b>				
	<p><b>Innovative Engagement</b>  <i>Room C4</i>                  Chair: Kazuto Kato</p>	<p><b>Disruptive Technologies</b>  <i>Room C5</i>                  Chair: Nils Hoppe</p>	<p><b>Protecting Innovations</b>  <i>Room C6</i>                  Chair: Di Nicol</p>	<p><b>Personalised Medicine</b>  <i>Room L4</i>                  Chair: Anne Cambon-Thomsen</p>	<p><b>Data Sharing for Translation</b>  <i>Room L5</i>                  Chair: Bartha Knoppers</p>
11:15 - 11:45	<p><b>Teare et al.</b>                  Engagement 2.0 - Views of Biobank Participants Regarding Dynamic Consent</p>	<p><b>Prainsack</b>                  A Solidarity-based Perspective on Data-rich Medicine</p>	<p><b>Mnisi</b>                  A Normative Case for the Patentability of Human Embryonic Stem Cell Technologies</p>	<p><b>Dickenson</b>                  A Reality Check for Personalised Medicine: just a few errors in translation?</p>	<p><b>O'Doherty et al.</b>                  Unintended Uses of Health Data: The Need for Robust Democratic Governance</p>
11:45 - 12:15	<p><b>Thiel</b>                  Could a web-based informed consent portal help address the awkwardness surrounding 'legacy' biobanks?</p>	<p><b>Rödiger</b>                  Translational Neuroscience Research: Potential Applications of Brain-Computer Interfaces in Healthcare</p>	<p><b>Rial-Sebbag et al.</b>                  The legal and ethical dilemma of embryonic stem cells: an impediment to translation in medicine?</p>	<p><b>Budin Ljøsne</b>                  Patient and interest organizations' views on personalized medicine</p>	<p><b>Krleza-Jeric et al.</b>                  IMPACT Observatory of Clinical Research Regarding Data Sharing</p>
12:15 - 12:45	<p><b>McCaughey</b>                  Avoiding HeLA: Incorporating a video animation to improve informed consent for induced pluripotent stem cell research</p>	<p><b>Haimes &amp; Taylor</b>                  What's in a name? Identifying multiple representations of women who provide eggs for mitochondrial research</p>	<p><b>Sterckx &amp; Cockbain</b>                  Patenting of human genes and their uses in diagnostic tests: Recent developments in the US and Europe</p>	<p><b>Skopek</b>                  Fragmentation and Blurring in Personalized Medicine</p>	<p><b>Langanke &amp; Fischer</b>                  Clinical Decision-Making and Secondary Findings in Systems Medicine</p>

**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**

*Chair: Susan Wallace*

**Room L4**

*Chair: Victoria Chico*

**Room L5**

*Chair: Christopher Robertson*

**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** - Towards Equity in Genomic  
Medicine: Bridging the Evidence  
Gap for Diverse Populations

**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** - Linking Health and  
Administrative Data - is it just  
about the Legal Issues?  
**Yoshizawa** - Patient Opinions  
on the use of ICT in Japan  
**Ancillotti** - Antibiotic  
Resistance – Ethical, Legal,  
and Social Considerations

**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  
**Pereira** - Mutations are our Currency:  
The Value of Genomic Data in the  
Information Economy

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  
Prof. Sigrid Sterckx, Ghent University, Belgium  
Prof. Gil McVean, University of Oxford, UK  
Prof. Martin Richards, University of Cambridge, UK  
  
Chair: Prof. Martin Landray, University of Oxford, UK

19:00 -  
21:30

**NETWORKING EVENT – Drinks, Food Bowls and Jazz  
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  
Prof. Trudie Lang, Centre for Tropical Medicine and Global Health, University of Oxford, UK  
Dr. Patricia Marshall, Case Western Reserve University, USA

Chair: Prof. Roger Brownsword, King's College London, UK

10:30 -  
11:00

**Morning Refreshments**

**CONCURRENT PRESENTATION SESSIONS**

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

THURSDAY 25 JUNE 2015

12:30 -  
13:30

**ACTIVITY ZONE (including LUNCH)**  
Artist in Residence Exhibition  
Results of Competitions and Awards

**CONCURRENT WORKSHOPS**

13:30 -  
14:30

**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

14:30 -  
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 CLOSSES**

16:30

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

**wellcome**trust

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



Enabling research by sharing knowledge



Move your meetings online

