


# Past, Present, Future: the Ethics and Governance of Big Biobanks conference

**UK Biobank  
Ethics and  
Governance  
Council**

3-5 November 2014

Wellcome Trust, 215 Euston Road, London NW1 2BE



**Monitor  
Advise  
Safeguard  
Report**



19:00 – 19:30 Registration and drinks

19:30 – 19:40 **Welcome** *Professor Roger Brownsword*

19:40 – 20:30 **Lecture with Q&A: 'Biobanks – can ethics keep pace with the science?'** *Professor Alastair Campbell*

## Conference

Tuesday 4 November 2014

9:30 – 10:00 Registration

10:00 – 10:10 **Welcome and introduction** *Professor Roger Brownsword*

10:10 – 10:30 **UK Biobank in 2014 and beyond** *Professor Sir Michael Rawlins*

10:30 – 11:45 **Governance of UK Biobank: the EGF and the EGC** *Chair and respondent: Professor Bartha Maria Knoppers*

Drafting the Ethics and Governance Framework *Professor Alastair Campbell*

The Ethics and Governance Council (EGC) as a 'critical friend' *Professor Graeme Laurie*

Today's governance challenges for the EGC *Professor Roger Brownsword*

*Response and discussion*

11:45 – 12:15 Break

12:15 – 13:30 **Learning from the governance experience of others: case studies** *Chair and respondent: Dr Jonathan Hewitt*

Estonian Genome Project *Professor Andres Metspalu*

Taiwan Biobank Ethics and Governance Council *Professor Michael Tai*

ALSPAC Ethics and Law Committee *Professor Madeleine Murtagh*

Framingham Heart Study *Dr Dan Levy*

*Response and discussion*

13:30 – 14:30 Lunch

14:30 – 16:00 **Feedback** *Chair and respondent: Dr Jasper Bovenberg*

Wellcome Trust and Medical Research Council Framework on feedback *Ms Katherine Littler*

Framingham Heart Study *Dr Dan Levy*

Deciphering Developmental Disorders project *Dr Anna Middleton*

UK Biobank's policy and the role of the EGC *Dr Sheelagh McGuinness*

*Response and discussion*

16:00 – 16:30 Break

16:30 – 18:00 **Genomic data and governance: case studies** *Chair and respondent: Professor Mike Parker*

UK10K *Dr Lucy Raymond*

1958 Birth Cohort *Professor Paul Burton and Professor Madeleine Murtagh*

UK Biobank *Professor Sir Rory Collins*

*Response and discussion*

19:30 Conference dinner

9:00 – 10:30	<p><b>Governing access</b></p> <p>Access governance mechanisms</p> <p>Access in practice at UK Biobank</p> <p>Role and experience of the EGC in relation to access</p> <p><i>Response and discussion: What are the appropriate responsibilities of an oversight body in relation to access?</i></p>	<p><i>Chair and respondent: Dr William Lowrance</i></p> <p><i>Professor Martin Bobrow</i></p> <p><i>Professor Sir Rory Collins and Mr Jonathan Sellors</i></p> <p><i>Professor Søren Holm</i></p>
10:30 – 11:00	Break	
11:00 – 11:45	<p><b>Engaging participants</b></p> <p>UK Biobank practice and the challenges faced</p> <p>The EGC's experience of participant engagement: To engage or not to engage?</p> <p><i>Response and discussion: To what extent, if any, is it the role of an oversight body to engage participants?</i></p>	<p><i>Chair and respondent: Dr Mairi Levitt</i></p> <p><i>Mr Andrew Trehearne</i></p> <p><i>Mr Andrew Russell and Mr David Walker</i></p>
11:45 – 12:30	<p><b>Participant follow-up through medical and health-related records</b></p> <p>Governance challenges for linkage to medical and health-related data: UK perspective</p> <p>UK Biobank approach and experience</p> <p><i>Response and discussion</i></p>	<p><i>Chair and respondent: Mr Peter Singleton</i></p> <p><i>Professor Graeme Laurie</i></p> <p><i>Dr Cathie Sudlow</i></p>
12:30 – 13:30	Lunch	
13:30 – 15:00	<p><b>Data sharing between cohort studies</b></p> <p>Frameworks for data sharing</p> <p>Data security and management</p> <p>Nuffield Council on Bioethics Working Party on biological and health data</p> <p><i>Response and discussion</i></p>	<p><i>Chair and respondent: Dr Susan Wallace</i></p> <p><i>Professor Jane Kaye</i></p> <p><i>Professor Paul Burton</i></p> <p><i>Professor Martin Richards</i></p>
15:00 – 15:30	Break	
15:30 – 16:45	<p><b>The ethics and governance of big biobanking: the future</b></p> <p>P3G and the Global Alliance for Genomics and Health</p> <p>International Society for Biological and Environmental Repositories</p> <p>BBMRI-ERIC</p> <p>ELSI 2.0</p> <p><i>Response and discussion: How, going forward, should the experience of ethics and governance bodies be disseminated and shared?</i></p>	<p><i>Chair and respondent: Professor Nils Hoppe</i></p> <p><i>Professor Bartha Maria Knoppers</i></p> <p><i>Ms Marianna Bledsoe</i></p> <p><i>Professor Jan-Eric Litton</i></p> <p><i>Professor Jane Kaye</i></p>
16:45 – 17:00	Closing remarks	<i>Professor Roger Brownsword</i>
17:00	Close	

# Speaker and Chair affiliations

## **Ms Marianna Bledsoe**

Co-Chair, International Society for Biological and Environmental Repositories Science Policy Committee

## **Professor Martin Bobrow**

Chair, Expert Advisory Group on Data Access

## **Dr Jasper Bovenberg**

Practicing attorney in The Netherlands, specializing in life sciences

## **Professor Roger Brownsword**

Chair, UK Biobank Ethics and Governance Council (EGC)

## **Professor Paul Burton**

Professor of Infrastructural Epidemiology, Bristol University

## **Professor Alastair Campbell**

Director, Centre for Biomedical Ethics, National University of Singapore and first chair of the EGC

## **Professor Sir Rory Collins**

Principal Investigator and Chief Executive, UK Biobank

## **Dr Jonathan Hewitt**

EGC Vice Chair and Clinical Senior Lecturer at Cardiff University

## **Professor Søren Holm**

EGC member and Professor of Bioethics, Manchester University

## **Professor Nils Hoppe**

EGC member and Professor of Life Sciences Regulation, Hannover University

## **Professor Jane Kaye**

Director of HeLEX, Oxford University

## **Professor Bartha Maria Knoppers**

Director, Centre of Genomics and Policy, McGill University, Canada Research Chair in Law and Medicine and founder of P3G

## **Professor Graeme Laurie**

Professor of Medical Jurisprudence, University of Edinburgh and second Chair of the EGC

## **Dr Mairi Levitt**

Department of Politics, Philosophy and Religion, Lancaster University

## **Dr Dan Levy**

Director, Framingham Heart Study and Professor of Medicine, Boston University

## **Ms Katherine Littler**

Senior Policy Adviser, Wellcome Trust

## **Professor Jan-Eric Litton**

Director-General, BBMRI-ERIC

## **Dr William Lowrance**

Consultant in health research ethics and policy

## **Dr Sheelagh McGuinness**

EGC member and University Fellow, Birmingham Law School

## **Professor Andres Metspalu**

Director, Estonian Genome Centre

## **Dr Anna Middleton**

Genetic Counsellor and Ethics Researcher, Wellcome Trust Sanger Institute

## **Professor Madeleine Murtagh**

Chair, ALSPAC Ethics and Law Committee and Professor of Social Studies of Health Science, Bristol University

## **Professor Mike Parker**

Professor of Bioethics, Oxford University and Chair, Genomics England Ethics Advisory Committee

## **Professor Sir Michael Rawlins**

Chair, UK Biobank Board of Directors

## **Dr Lucy Raymond**

Reader in Neurogenetics and Consultant in Medical Genetics, Cambridge University

## **Professor Martin Richards**

Chair, Nuffield Council on Bioethics Working Party on biological and health data and formerly EGC Vice Chair

## **Mr Andrew Russell**

EGC members and formerly Chief Executive, the Association for Spina Bifida and Hydrocephalus

## **Mr Jonathan Sellors**

UK Biobank Company Secretary

## **Mr Peter Singleton**

Director, Cambridge Health Informatics Limited

## **Dr Cathie Sudlow**

Chief Scientist, UK Biobank

## **Professor Michael Tai**

Taiwan Biobank EGC member and Professor of Bioethics and Medical Humanities, Chungshan Medical University

## **Mr Andrew Trehearne**

Head of Communications, UK Biobank

## **Mr David Walker**

EGC member and a writer specializing in public policy and management

## **Dr Susan Wallace**

EGC member and Lecturer of Population and Public Health Sciences, Leicester University

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If you have any comments or questions about the EGC, or would like to subscribe to the Annual Review, please contact the EGC Secretary.

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**Dr William Lowrance**

Earned Ph.D. from the Rockefeller University (New York City) in the life sciences, with dissertation in organic chemistry. Shifted to working on social aspects of science. Served as faculty or fellow, teaching and conducting research, at Harvard, Stanford, and Rockefeller Universities. Wrote the books: *Of Acceptable Risk: Science and the Determination of Safety*; *Modern Science and Human Values*; and *Privacy, Confidentiality, and Health Research*. Chaired committee that drafted the UK Biobank Ethics and Governance Framework.

**Dr Sheelagh McGuinness**

Please see EGC member biographies

**Professor Andres Metspalu**

Andres Metspalu M.D, Ph.D. is the director of the Estonian Genome Center and full professor of biotechnology of University of Tartu. He graduated from the University of Tartu in 1976 as physician, obtained Ph.D. in 1979 in molecular biology. He was as a postdoc at Columbia University in New York and Yale University in 1981-82. He has published more than 300 papers. He is inventor on several patents and has started 3 biotech companies. He has been project coordinator, local PI or WP leader of over 10 EU programs. He has worked at Baylor College of Medicine, Houston, as visiting faculty (1993-1994) and in year 2000 at IARC (Lyon, France) as a recipient of the International Visiting Senior Scientist Award. From 1996 to 2008 A. Metspalu was also the founder and head of the Molecular Diagnostic Center of the Tartu University Hospital. Metspalu is one of the founders and directors (2002-2007) of the P3G international consortium of biobanks. He has numerous awards incl. Estonian science prize in 1980 and 2003, 3rd Class Order of the Estonian Red Cross, L'Ordre des Palmes Académiques from French Republic, and Dr,h. c. from Vilnius University.

**Dr Anna Middleton**

Dr Anna Middleton has had two parallel careers – the first as a practicing genetic counsellor, the second as a senior social scientist exploring the impact of genetic technology on people. She currently works at the Wellcome Trust Sanger Institute in Cambridge, UK; as the only social scientist on campus she leads an international, mixed methods research project which explores attitudes towards sharing incidental findings from sequencing studies. She is a previous vice-chair of the Genetic Counsellor Registration Board (UK and ROI) and a current committee member of the Association of Genetic Nurses and Counsellors.

**Professor Madeleine Murtagh**

Professor Murtagh is an established social scientist of population/public health with a PhD in social science and public health, a background in communication studies and public health practice, and a reputation for high quality original research. She has developed a nationally and internationally recognised research profile in social science applied to problems of engagement, evidence and decision making in health care and translational research. Professor Murtagh is currently director of the transdisciplinary D2K (Data to Knowledge) Research Group, which focuses on the design, development and application of studies, methods, tools and infrastructures to support the generation, management, evaluation and analysis of data and information, and their conversion into knowledge. She brings a social science lens to studies of: (1) knowledge generation and stakeholder participation in population health science and technology; (2) stakeholder relations in population health research and decision making; and (3) development of methods to support transdisciplinary