

Biographies of EAGDA members

Chair: Professor James Banks (Institute for Fiscal Studies)

James Banks is Professor of Economics at the University of Manchester, Deputy Research Director of the Institute for Fiscal Studies (IFS) and a Trustee of the Nuffield Foundation. He directed the IFS research into consumption and savings (1992-1999), served as IFS Deputy Director (1997-2002) and was Professor of Economics at UCL prior to coming to Manchester in 2010. He has published widely on a broad set of issues within the economics of ageing, including the empirical modelling of household consumption and saving over the life-cycle; retirement and pension choices; health, physical and cognitive functioning and their association with labour market and broader socioeconomic status; the dynamics of work disability; and the nature of expectations of retirement, health and longevity.

Professor Banks is Co-Principal Investigator of the English Longitudinal Study of Ageing and works in close collaboration with ageing studies around the world to design, collect and analyse public-use data on older populations. He serves on the International Scientific Advisory Boards of national ageing studies in China (CHARLS), India (LASI), Japan (JSTAR and Ireland (TILDA) and is chair of the Scientific Advisory Committee of the UK Household Longitudinal Study (Understanding Society). He is also a member of the UK governments Pension Statistics Task Force and a member of the Lead Expert Group for the Government Office for Science Foresight Project into the Challenges and Opportunities of an Ageing Society.

Professor Paul Burton (University of Bristol)

Paul Burton is Professor of Infrastructural Epidemiology at the University of Bristol and is co-leader of the transdisciplinary D2K (Data to Knowledge) Research Group. Previously he was a Senior Biostatistician and Head of the Division of Biostatistics and Genetic Epidemiology at the Institute for Child Health Research, Australia (1992-1999) and he was Chair in Genetic Epidemiology at the University of Leicester (1999-2013). Specific research includes: the development of logic-based and quantitative approaches to data harmonization (DataSHAPER); the development of a novel parallelized model-based approach to pooled individual-level data analysis that avoids the need to physically share or transfer raw data (DataSHIELD); and the development of simulation based approaches to power calculation to facilitate realistic sample size calculations (as used in the design of UK Biobank).

His research program is funded primarily under BIOSHARE-EU (FP7, Large Scale Integrating Project) on which he is Science Co-ordinator, a project grant from MRC/Wellcome Trust that supports development of 1958 Birth Cohort as a data and sample provider, and by the ALSPAC maintenance grant (MRC/Wellcome Trust). Paul Burton is chair of the International Scientific Steering Committee of the Public Population Project in Genomics (P3G) and of the national Access Committee for the three CLS British Birth Cohorts, including the 1958 Birth Cohort. He is a member of the International Scientific Advisory Board of UK Biobank, the International Oversight Committee of the Canadian Longitudinal Study of Ageing, and of the data access committees of the Wellcome Trust Case Control Consortium and the ESRC funded Understanding Society. He is also a central member of the leadership team of Maelstrom Research, which aims to support data harmonization and integration.

Professor Rosalind Eeles (Institute of Cancer Research)

Rosalind Eeles is Professor of Oncogenetics at The Institute of Cancer Research and an Honorary Consultant in Clinical Oncology and Cancer Genetics at The Royal Marsden NHS Foundation Trust, London. Prior to becoming head of The Cancer Genetics Team at the ICR Professor Eeles was an Assistant Professor at the University of Utah in Salt Lake City, United States, where she studied

hereditary prostate cancer. She has been instrumental in ensuring new discoveries in cancer genetics immediately benefit patients, particularly in her specialty areas of BRCA-mutation carriers and prostate cancer. Professor Eeles is a clinician as well as a scientist, running both a laboratory at The Institute of Cancer Research (ICR) and a Cancer Genetics Clinic at the ICR's partner hospital, The Royal Marsden NHS Foundation Trust. Professor Eeles has set up an international consortium – known as PRACTICAL – that gives researchers access to genetic samples from large numbers of prostate cancer patients. She co-leads the International Cancer Genome Consortium effort in prostate cancer sequencing.

She has sat on several genetics advisory committees, including the Department of Health Genetics Advisory Committee, has given evidence to the House of Lords' Select Committee on genomic medicine and edited a special edition of the Familial Cancer journal on delivering cancer genetics services.

Dr Mark Elliot (University of Manchester)

Mark Elliot has worked at the University of Manchester since 1996 and is postgraduate director for the School of Social Sciences. The main focus of his research has been statistical confidentiality as well as privacy, disclosure and attitudes in research. Much of his research has focused on developing mechanisms for data dissemination and sharing that benefit public good whilst protecting individual privacy. He was director of the Centre for Cultural Studies Research (CCSR) and he founded the Confidentiality and Privacy Research Group (CAPRI), for which he has managed a number of research projects. Mark is one of the co-investigators of the administrative data service and has also lead on the UK Anonymisation Network.

Dr Paul Flicek (European Bioinformatics Institute)

Paul Flicek is a Team Leader and Senior Scientist of the European Molecular Biology Laboratory and leads the Vertebrate Genomics Team at the European Bioinformatics Institute (EMBL's Hinxton Outstation) near Cambridge, England. He is cluster leader for the collection of EBI resources focused on Genes, Genomes and Variation and in this role provides strategic leadership of the four faculty groups that provide all of EBI's genomics and variation databases and resources. Since 2001 he has been an Honorary Faculty of the Wellcome Trust Sanger Institute, where he has worked on aspects of genome annotation and comparative genomics.

He is currently joint head of the Ensembl project and also has leadership roles in data management activities for the 1000 Genomes Project, the International Human Epigenome Consortium (IHEC) and the International Mouse Phenotyping Consortium (IMPC). Paul's research is focused on comparative regulatory genomics and the evolution of transcriptional regulation. He is also interested in the large-scale infrastructure required for modern bioinformatics including storage and access methods for high throughput sequencing data. He has played a role in a number of major international projects including ENCODE and the mouse, chicken, and gorilla genome projects.

Dr Mark Guyer (formerly National Institutes of Health, USA)

Mark Guyer has recently retired as the director of the Division of Extramural Research of National Institutes of Health (NIH), where he was responsible for overseeing the entire NHGRI extramural program. This program administers research and training grants and cooperative agreements, and plans a wide range of scientific activities to advance genomics, including the study of the ethical, legal and social implications of advances in genomics and genetics.

Dr. Guyer has been associated with scientific administration of the Human Genome Project since its inception at the NIH. He first served as a staff liaison to the planning process when he was a Program Director at the National Institute of General Medical Sciences (NIGMS), and then was one of the

initial staff when the Office of Human Genome Research was established in 1988. He has served in many capacities during the evolution of the agency from office through centre to institute status, and has participated in all phases of the NHGRI's scientific activities, from sequencing through Ethical, Legal and Social Implications (ELSI) Research. Among his primary activities was the development of the NHGRI's series of five-year plans for the HGP in the United States, in 1990, 1993, 1998 and 2003.

Professor John Hobcraft (University of York)

John Hobcraft is a Professor of Social Policy and Demography at the University of York and a strategic advisor of data resources for the ESRC. He has a broad interest in social, psychological, health and biological sciences and has worked extensively on demographic methods in developed and developing countries. His research has encompassed substantial work on fertility and reproduction, infant and child mortality, and partnership behaviour and on the consequences of these for policy and population change.

Professor Hobcraft has played an active role in shaping the design and analysis of prospective cohort and panel studies. This includes: Chair of the Consortium Board and Network of National Focal Points for the Generations and Gender Programme; Vice-Chair of the Governing Board for Understanding Society and member of its Data Access Committee; Chair of the Scientific Committee and membership of the Governing Board for the Centre for Longitudinal Studies (CLS) Birth Cohort Studies and member of the Governing Board for the new UK Birth Cohort Study.

Professor Tim Hubbard (King's College London)

Tim Hubbard joined King's College London as Head of the Department of Genetics and Molecular Medicine and overall Director of Bioinformatics for King's Health Partner/ King's College London. He is Professor of Bioinformatics in the School of Medicine and has built an extensive research career in genomics and bioinformatics. Professor Hubbard previously worked at the Wellcome Trust Sanger Institute for 16 years, where he led the Vertebrate Genome Analysis Project and was Head of Informatics. In 2013, he was seconded part time as a specialist adviser to NHS England, and has continued to play a lead role in delivering the genomics for health programme.

He is Interim Director of Bioinformatics at Genomics England, the company recently setup by the Department of Health to implement the Government's 100,000 Genome Project - a project to sequence the personal DNA code, or genome, of up to 100,000 patients over the next five years. Before joining the Sanger Institute Tim worked mainly on protein folding, classification and design. Since 2007 Tim has been the principal investigator of GENCODE, a scale up programme of the ENCODE project, which brings together HAVANA, Ensembl and seven external groups to generate the reference geneset for the human genome.

Peter Knight (Department of Health)

Peter Knight is Deputy Director for Research Contracting, Information Intelligence and Stakeholder Engagement in the Research and Development Directorate at the Department of Health. Peter joined the Department in April 2010 having established the Research Capability Programme in 2008 that established a secure research data service now operated by the MHRA call the Clinical Practice Research Datalink. Prior to his these roles Peter was a Managing Director and interim Chief Executive at Winchester and Eastleigh Health NHS Trust.

Professor Bartha Maria Knoppers (McGill University, Canada)

Bartha Knoppers is Director of the Centre of Genomics and Policy, Faculty of Medicine, Department of Human Genetics, McGill University, Canada Research Chair in Law and Medicine 2001-, the holder of Chaire d'excellence Pierre Fermat (France) (2006-2008), and named Distinguished Visiting Scientist (Netherlands Genomics Initiative) (2009-2012).

Professor Knoppers was the former Chair of the International Ethics committee of the Human Genome Organization (HUGO), (1996-2004), and member of the International Bioethics Committee of the United Nations, Educational, Scientific and Cultural Organization (UNESCO) which drafted the Universal Declaration on the Human Genome and Human Rights (1993-1997). Co-Founder of the International Institute of Research in Ethics and Biomedicine (IIREB) (2000 – 2009), she founded the Population Project in Genomics (P3G) and CARTaGENE in 2003. From 2000-2006 she served on the Board of Genome Canada, became Chair of the Ethics Working Party of the International Stem Cell Forum, Co-Chair of the Sampling/ELSI Committee of the 1000 Genomes Project (2008-) and a member of the Scientific Steering Committee of the International Cancer Genome Consortium (ICGC) (2009-).

Professor Mark McCarthy (University of Oxford)

Mark McCarthy is Robert Turner Professor of Diabetes at the University of Oxford and Consultant Endocrinologist at the Oxford Radcliffe Hospitals Trust, Oxford, UK. Professor McCarthy leads the diabetes research group based at both the Oxford Centre for Diabetes, Endocrinology and Metabolism ([OCDEM](#)) and the Wellcome Trust Centre for Human Genetics ([WTCHG](#)). Biobanking, bioinformatics, computational biology, human genetics and statistical genetics are amongst some of his key interests. Professor McCarthy trained in Medicine at Cambridge University and St Thomas' Hospital in London, and completed his medical residency and internships at the Royal London Hospital. Prior to moving to Oxford in 2002, he was appointed as Professor of Genomic Medicine at Imperial College, London.

Professor McCarthy has served on the editorial board of many international journals and on the SAB of REACTOME, ENSEMBL and other international efforts, and plays a leading role in a number of international consortia including DIAGRAM, GIANT, MAGIC, EGG, CEED3, ENGAGE, EAGLE and the Global Diabetes Consortium. He currently serves on the council of HUGO, the Human Genome Organisation and is involved in management of the Wellcome Trust Case Control Consortium.

Professor Andrew Morris (University of Edinburgh)

Andrew Morris is Professor of Medicine, Director of the Institute of Public Health and Informatics and Vice Principal of Data Science at the University of Edinburgh, having taken up position in August 2014. Prior to this Andrew was Dean of Medicine at the University of Dundee.

Andrew's research interests relate to the application of informatics to study the epidemiological and molecular aetiological basis of diabetes and its complications. He is Director of the Farr Institute in Scotland funded by the MRC and nine other funders and Convenor of the UK Health Informatics Research Network, representing a £39M investment in health informatics research. Andrew is a Governor of the Health Foundation, a leading UK charity that supports quality improvement in health care. Andrew also chairs the Informatics Board at UCL Partners, London.

Baroness Onora O'Neill

Onora O'Neill combines writing and lecturing on political philosophy and ethics with a range of public interests and activities. She comes from Northern Ireland and has worked mainly in Britain and the US. She was Principal of Newnham College, Cambridge from 1992-2006, President of the British Academy from 2005-2009, chaired the Nuffield Foundation from 1998-2010 and has been a crossbench member of the House of Lords since 1999 (Baroness O'Neill of Bengarve). In 2012 she was a member of the Royal Society working party on Science as an Open Enterprise, before joining the council of the MRC in 2012.

She currently chairs the Equality and Human Rights Commission. Her books include *Constructions of Reason, Autonomy and Trust in Bioethics*, *A Question of Trust* (the Reith Lectures) and *Rethinking Informed Consent in Bioethics* (jointly with Neil Manson). She currently lectures and writes on

accountability and trust, on ethics and science policy, on justice and borders, on the future of universities, the quality of legislation and the ethics of information and communication, including media ethics.

Ms Melanie Wright (University of Essex)

Melanie is an Associate Director at the UK Data Archive and is overall director of Data and Support Services which cover activities of data ingest, metadata creation and standards implementation, finding aids, user registration, data access and core help desk support. She is also Principal Investigator and Director of the ESRC Secure Data Service and leads the Ingest and Secure Lab teams of the UK Data Service's data resources. She also directs the Administrative Data Service, the overarching coordinating service of the Administrative Data Research Network. Melanie also served President of IASSIST (International Association of Social Science Information Service and Technology) from 2007-2011.

Funder Representatives:

Cancer Research UK

Fiona Reddington

Dr Fiona Reddington is Head of Clinical and Population Research Funding at Cancer Research UK. Fiona obtained her BSc (Pharmacology) at University College Dublin and her PhD (Neurophysiology) from Kings College London (UMDS). From there, Fiona joined the NHS as a project manager and went on to manage a Cancer Centre at University College London. Management roles at a national cancer network and the National Cancer Research Institute Informatics Initiative followed where Fiona was part of the team to win the inaugural Times Higher Research project of the Year award.

Fiona joined Cancer Research UK in 2008. She has responsibility for the CRUK research portfolio in the areas of clinical trials, population research, prevention and early diagnosis. She represents the charity on matters relating to data sharing and the management boards of a number of external initiatives such as the National Prevention Research Initiative and UKCRC Public Health Centres of Excellence.

Jamie Enoch

Jamie Enoch is a Research Funding Manager at Cancer Research UK, focussed on data sharing. He is working with CRUK staff and grantees to enable implementation of CRUK's data sharing policy across the Basic Science, Clinical and Population Research domains. Previously he worked as a Research & Policy Analyst for the UK Collaborative on Development Sciences, a partnership of UK research funders with interests in scientific and health research in low- and middle-income countries. He has a background in languages and social science, having completed an MSc in Globalisation and Latin American Development at UCL.

Economic and Social Research Council

Rebecca Fairbairn

Rebecca Fairbairn is a research policy specialist. She has led on UK government initiatives covering a range of academic disciplines and areas of policy- from Parliamentary engagement to research conduct and PhD funding. Rebecca's career has focused on the UK Research Councils (the UK's biggest public sector funders of research) and the Foreign and Commonwealth Office. In 2008 Rebecca went to New Delhi to develop the strategy, and set up the operations, for the RCUK Office in India, with its first Director. She then moved to Bangalore, South Asia's 'Silicon Glen', with the FCO

to head the UK government's Science and Innovation Network (S&IN) in South India. During her three years in Bangalore, Rebecca was Deputy Head of Mission at the British Deputy High Commission. She has also advised government on opportunities for the UK knowledge base in Latin America. Rebecca has recently moved from leading ESRC's Knowledge Exchange strategy to leading its strategic development of biosocial partnerships, resources and capacity building.

Claire Feary

Claire Feary is the Policy Manager in the Capability Team at the ESRC. She has extensive experience in research management and policy development, and has managed a portfolio of research, infrastructure and training investments. Claire is the ESRC contact for Data Access, including overseeing the development and delivery of access arrangements for the ESRC's Longitudinal Studies. Claire is also leading on various activities to support partnership development, resources and capacity in the ESRC's Biosocial Research agenda.

Medical Research Council

Geraldine Clement-Stoneham

Geraldine is a knowledge and information manager at the MRC. She published an ESF-EMRC Science Policy Briefing in 2012, highlighting the need to accelerate the adoption of open access to research articles in the biomedical sciences across Europe.

Jon Fistein

Jon Fistein is part-time clinical programme manager at the MRC, where his work combines managing and running funding calls with providing advice on legal, ethical and clinical issues, particularly relating to research data use. Since 2010 Jon has been a council member and Director of UK Council for Health Informatics Professions, which aims to provide the knowledge, skills and tools to enable information to be collected, managed, used and shared safely to support the delivery of healthcare and promote health. Jon has extensive experience working in healthcare management at a senior level. He is qualified as a medical doctor and as a barrister, has completed an Open University MBA and is a PRINCE2, MSP and Change Management Practitioner.

Wellcome Trust

Katherine Littler

Katherine Littler is a senior policy advisor at the Wellcome Trust, where she has worked in the policy department since 2005. She has a background in medical law and ethics. Since joining the Trust, she has worked extensively on regulatory issues, including the revision of the Human Tissue Act and the Human Fertilisation and Embryology Act. Katherine is also leading work at the Trust on data access and governance mechanisms for genetics/genomics research, cohorts and longitudinal studies. She is a key adviser on ethical issues, with particular expertise in biobanks and cohort studies and currently sits as the Trust's observer on the UK Biobank Ethics and Governance Council. Katherine also has experience of public engagement: both in terms of commissioning work to understand public attitudes and developing strategies to influence public opinion.

David Carr

David Carr is a Policy Adviser at the Wellcome Trust. In this role, he co-ordinates strategic planning activities and leads on work to develop and communicate Trust policy in several areas, including data sharing, open access publishing and genetics. In 2001, he worked on secondment at the World Health Organisation in Geneva, where he assisted in the preparation of the Advisory Committee on Health Research (ACHR) report on Genomics and World Health. Prior to joining the Trust in 1999, David worked as a project researcher at a scientific consultancy firm in Cambridge. He has undergraduate and masters degrees in genetics from the University of Cambridge.

Natalie Banner

Natalie Banner is a Policy Officer at the Wellcome Trust and primarily provides the Secretariat for EAGDA. She undertakes a range of work relating to research ethics and governance, including providing support for the Global Forum on Bioethics in Research and the H3Africa consortium's Ethics and Regulation Working Group. She is also extensively involved in issues around the use of patient data, managing a major project exploring public, patient, health professional and research cohort participant attitudes towards commercial organisations accessing health, medical and genetic data. Natalie has a background in the medical humanities, having completed a postdoctoral research fellowship in the philosophy of psychiatry at King's College London prior to joining the Wellcome Trust in 2013.