Genomic Nations

PEALS 17th Annual International Symposium

20th – 21st September 2016

Great North Museum, Newcastle upon Tyne

Contents

Introduction

Welcome

Welcome to the 2016 PEALS International Symposium. We are delighted that you are able to join us here in Newcastle at our 17th annual event. In keeping with the PEALS approach we aim to facilitate processes of exchange and dialogue to enable the sharing of diverse perspectives and to open up a space in which to think in new ways about policy and practice. Our formula for the international symposium is to bring together an invited group of speakers and participants from across academic disciplines and from a range of parties with interests in ethical scrutiny, policy making and in professional practice. We hope that we have created a collegiate and friendly atmosphere, in which to explore a major issue that is preoccupying our thinking around matters of policy, ethics and life sciences.

The focus this year is on 'Genomic Nations' a theme that provokes a number of debates and questions. The issue of genetic essentialism has been defined, re-defined and rebutted yet genetic essentialism seems to have re-emerged in a new form. The idea of a genomic nation invokes notions of citizenship and responsibility as well as new normative claims of solidarity. Major projects like the 100,000 Genomes Project require mass co-operation towards a common good, a discourse that echoes the promissory goods, that genetics has long-since tantalized us with. The step change in the development of new genetic technologies including faster and cheaper whole genome sequencing and combined with a growing capacity for data sharing now seems set to deliver those goods. Yet for those citizens whose 'solidarity' is required important questions remain. Families living with genetic disease want tangible and direct benefits, a diagnosis, and the possibility of treatment. They want reassurance that their 'sensitive personal data' will not be merely subsumed and traded as a national economic resource. No doubt these and many other issues will be touched upon during the course of the symposium.

We are delighted to bring together colleagues from medicine, science, sociology, philosophy, law, economics, and technology studies, from patient organisations and public interest groups from across the UK and Europe. We thank you for taking the time to join us in Newcastle and for taking part as speakers, chairs and participants.

We are grateful to colleagues in the Policy, Ethics and Life Sciences Research Centre (www.peals.ncl.ac.uk) for their ongoing collegiality and general support but would like to express special thanks to Tom Martin for his patience, efficiency and professionalism. We would also like to thank Newcastle University for its financial support for the symposium.

PEALS International Symposium 2016

Genomic Nations

20 September 2016

Time	Topic	Speaker
12:00 – 13:00	Registration and buffet lunch	
13:00 – 13:20	Welcome and Introduction	Pauline McCormack, Simon Woods
13:20 – 14:00	**Session 1: Genomics: where are we now. What do we aspire to?**	Chair: Simon Woods
13:20 – 13:50	The routinisation of genomics	John Burn
13:50 – 14:00	Discussion	All
14:00 – 15:20	**Session 2: International approaches – social, legal and ethical**	Chair: Pauline McCormack
14:00 – 14:30	Data, body material and the person: Where is the common ground for the international regulation of genomic research?	Christian Lenk
14:30 – 15:00	Generating economic evidence to inform the introduction of Whole Genome Sequencing: some challenges and solutions	Katherine Payne
15:00 – 15:20	Discussion	All
15:20 – 15:40	Break for refreshments	
15:40 – 17:00	**Session 3: Genomic citizenship and solidarity**	Chair: Erica Haimes
15:40 – 16:10	Patienthood in precision medicine: From citizen-worker to precarity?	Anne Kerr
16:10 – 16:40	Patients, publics and participation	Sarah Cunningham-Burley
16:40 – 17:00	Discussion	All
19:15 for 19:30	**Dinner at Blackfriars Restaurant** http://www.blackfriarsrestaurant.co.uk/	**All**

21 September 2016

Time	Topic	Speaker
09:00 – 09:30	Coffee on arrival and registration.	
09:30 – 10:50	**Session 4: Patients, publics and policy**	Chair: Christopher McKevitt
09:30 – 10:00	Genomics and the Promise of Insight	Alastair Kent
10:00 – 10:30	The impact of receiving feedback from the Australian Ovarian Cancer Study (AOCS): some lessons for genome sequencing research?	Nina Hallowell
10:30 – 10:50	Discussion	All
10:50 – 11:05	Break for refreshments	
11:05 – 11:10	Symposium photograph	All
11:10 – 12:30	**Session 5: Genomics for public good**	Chair: Jackie Leach Scully
11:10 – 11:40	Regulation of Genomics	Helen Wallace
11:40 – 12:10	Clinical actionability and the problem of translational research	Michael Arribas-Ayllon
12:10 – 12:30	Discussion	All
12:30 – 13:20	**Buffet lunch**	
13:20 – 14:40	**Session 6: What's on the horizon for genomics?**	Chair: Matthias Wienroth
13:20 – 13:50	Utopia and Genomics Revisited	Richard Tutton
13:50 – 14:20	Epigenetics and responsibility: Hype or paradigm shift in bioethics?	Kristien Hens
14:20 – 14:40	Discussion	All
14:40 – 15:00	**Thematic Round-up**	*Chair:* Pauline McCormack, Simon Woods
15:00 – 15:20	Discussion	All
15:20 – 15:30	Closing remarks	

Presentation Abstracts

Session 1: Genomics: where are we now, what do we aspire to?

John Burn

The Routinisation of Genomics

The emergence of next generation sequencing and the ongoing developments in technology such as point of care analysis of circulating free DNA mean that genomic analysis is becoming cheap and easily accessible. Interpretation of the meaning of changes in the sequence remains a challenge. This needs free exchange of clinical information but this risks breach of confidentiality.

We face risks of either restrictive legislation, especially in the area of prenatal testing or a potential free-for-all leading to adverse outcomes such as selective termination of females, employment bias based on disease susceptibility and excessive and inappropriate use of medical investigations in the worried well. This presentation will examine what is available now and in the near future and examine likely reactions based on culture, religion and politics in different healthcare settings.

Session 2: International approaches – social, legal and ethical.

Christian Lenk

Data, body material and the person: Where is the common ground for the international regulation of genomic research?

Genomic research is becoming a more and more common research tool for the different medical disciplines like for example cardiology, endocrinology, neurology and oncology . This means also that an increasing number of patients and study participants, often in multi-centre, international research studies, take part in genome research. Given, that the present research discussion takes place on an international level, the question regarding a homogeneous international regulation of genome research in ethics and law comes up. How well are we equipped for a consistent evaluation of genome research in different countries and can we identify a common ground regarding this important question? And what normative principles can be identified and used by researchers to organise genome research?

As such, genomics is a new scientific or medical discipline which has to be evaluated concerning possible risks and benefits and how different areas or entities of normative value are affected by it. In the planned contribution, three of these entities will be examined regarding the implications of genomic research, namely data, body material and the person. From the ethical point of view, only the concept of the person can thereby serve as an immediate source for ethical guidance, and personal data and body material are – according to a modern, secularized view – only of ethical relevance insofar they have a relation to the person. Therefore, we find different possible states of data and body material regarding this

relation, for example with anonymised or pseudonymised data. Additionally, it is expected in the framework of modern research, that the study participant is able to govern the handling of her data and body material by giving her informed consent and exert the idea of informational self-determination.

Regarding the international regulation of genomic research, especially international conventions and guidelines occupy an important place. These show in general a number of similar elements for research governance like the information of the study participant, the informed consent, the minimisation of risk regarding the participant's physical and social integrity and the transfer of data and body material. Other areas are less clear, for example, whether incidental findings have to be communicated to study participants and how to deal with the interests of third persons. Interestingly, the national legislation shows partly a kind of divergence to the practices in international research, regarding for example the "no property principle" in body material. In some cases (like for example in Germany), huge areas like genetic research are explicitly exempted from the law on genetics diagnoses, leaving researchers and patients perplexed behind. However, the planned contribution will plead in favour of a top-down regulation approach which should enable actors in the field to find an adequate regulation for a research study regarding the named common elements which can be identified on an international level.

Katherine Payne

Generating economic evidence to inform the introduction of Whole Genome Sequencing: some challenges and solutions.

Whole genome sequencing (WGS) has arrived. There is widespread consensus that increasing numbers of individuals will stand to benefit from new genomic-based diagnostic tests that use WGS. The 3Gb-Test consortium was formed to examine multifarious issues relating to the introduction of WGS from the perspective of European healthcare systems. A key role of 3Gb-Test was to assess how best to generate economic evidence within the more general framework of Health Technology Assessment (HTA) to inform the introduction of WGS-based diagnostic tests into clinical practice. Healthcare systems around the world have finite resources at their disposal. Decision-makers working within these systems strive to allocate scarce resources in the most effective manner with the broad aim of improving health. Determining the relative value-for-money (or cost-effectiveness) of an intervention is a crucial type of evidence to inform decision making under such resource constraints. In this presentation I will, viewing WGS-based diagnostic tests as a complex intervention, first present the key challenges likely to arise when producing economic evidence. I will then illustrate how using the PICO (Population, Intervention, Comparator and Outcomes) mnemonic can provide a framework and a solution to address some of these challenges. The solutions will centre on the challenges that arise when generating economic evidence for WGS-based diagnostic tests given the complexity of the technology and the vast possible range of applications.

Session 3: Genomic citizenship and solidarity.

Anne Kerr

Patienthood in precision medicine: From citizen-worker to precarity?

Precision medicine is transforming the experiences of patients and those at risk of common disorders such as cancer. Improved diagnostics and more targeted therapies offer the promise of individually tailored solutions to illness and impairment. As part of these transformations, patients are increasingly participating in an array of genomic trials and studies, as well as contributing to a plethora of engagement exercises and activities in clinical, digital and public settings. This involves a range of new kinds of emotional and clinical labour on the part of patients and their families as they navigate the uncertainties of their condition and their obligations to family, community and nation. In this paper we compare and contrast these new kinds of activities and obligations with the wider transformation in the contemporary economy: the shift from citizen-worker to precarious labour which is characterised by uncertain labour practices and identities, networked activism and struggles and a burgeoning sense of ontological insecurity. We consider whether and in what ways the era of precision medicine mirrors these trends and reflect on the implications of our conclusions for efforts to support and enable patients and their families to navigate healthcare and contribute to research and policy.

Sarah Cunningham-Burley

Patients, publics and participation.

Drawing on the experience of exploring public participation in biobanks, data linkage and cancer genomics research, this paper will explore the diverse ways in which patients and publics are invited and encouraged to be active participants in health related research. These sites of participation include formal patient and public involvement initiatives, engagement in social scientific and clinical research, and opportunities through social media. The processes of involvement frame the possibilities that participation affords and construct particular subject positions for patients and genomic citizens. The embedding of a participatory turn into the governance of genomic and other data intensive health research gestures towards co-production and partnership which may shore up citizen/science relations and the social contract on which they depend.

Session 4: Patients, publics and policy.

Alastair Kent

Genomics and the Promise of Insight.

Notwithstanding the rapid advances in our ability to sequence DNA in recent years, many patients and families still experience long delays before they receive a diagnosis. A significant number of families may wait years. Some never get a diagnosis. This uncertainty can have profound consequences for those affected and their families. Against this background, genomics is a potentially game-changing technology, holding out the prospect of a speedy accurate diagnosis for patients and families, and with this the potential for significantly better

management of currently intractable conditions. Sorting out the hope from the hype, and following through on the implications of this new knowledge for the organisation and delivery of health care will be a challenge for the Health Service, the professional community, industry and other stakeholders if the legitimate expectations of patients and families are to be met and the potential of genomics in health care is to be realised.

Nina Hallowell

The impact of receiving feedback from the Australian Ovarian Cancer Study (AOCS): some lessons for genome sequencing research?

The generation of clinically significant genetic data during research studies raises a number of ethical issues about the feedback of information to research participants. Little is known about research participants' experiences of this practice. My presentation will present data collected during a recent Australian study which looked at participants' and next of kins' response to receiving notification of the existence of familial/personal genetic results generated during a BRCA prevalence study. Parallels will be drawn between this case and the disclosure of additional or secondary findings generated during genomic sequencing.

Session 5: Genomics for the public good.

Helen Wallace

Regulation of Genomics.

For 15 years, debate has raged about the regulation of genomics, including patient and consumer protection from misleading claims, protection of privacy, and prevention of discrimination and potentially undesirable effects of commercial exploitation. New EU regulations covering data protection and diagnostic and predictive medical tests (including genomics and software) have recently been adopted. The talk will cover a brief history of genomic regulation and discuss whether existing and new regulatory safeguards are adequate and, post-Brexit, the extent to which they may apply in the UK.

Michael Arribas-Ayllon

Clinical actionability and the problem of translational research.

The application of whole genome and whole exome sequencing has transformed the clinical utility of a genetic test. In recent years the term ‘clinical actionability’ has appeared as a key criterion for reporting out findings of genome analysis. Actionability is not merely a synonym for clinical utility but signals a distinctive sociotechnical regime of genomic medicine – a new way of assigning molecular entities to categories that reconfigure relations between laboratories, clinicians and patients. Actionable regimes mark a shift towards a focus on molecular hypotheses, narratives of genetic causality and bioclinical decision-making. In this paper, I explore two examples in which actionability have practical implications for clinical management: cancer genetics and reporting out VUSs. The framework of actionable regimes is useful for thinking about the research initiatives of Genomics England and its recent efforts to balance public good with private interest. Lastly, I consider the underside of actionability – the

epistemic uncertainty arising from incidental findings – as the basis for questioning the commitment of translational research towards the clinical management of uncertainty.

Session 6: What's on the horizon for genomics?

Richard Tutton

Utopia and Genomics Revisited.

The opening session of the symposium asks the question: 'what do we aspire to?', thus taking us into the domain of not only what is possible, but also what kind of future we want. In invoking normative claims about the future, we are touching on the terrain of utopia. This year marks the quincentenary of Thomas More's Utopia, so in this talk I want to explore the relationship between utopia, eugenics and genomics. My aim is to bring together sociological discussions of utopia (Levitas, 1990, 2013), with the work of historians, sociologists and bioethicists on eugenics and genomics. In popular terms, utopia is often described as either an impracticable fantasy or 'idle dream' or, if acted upon to make real, a form of totalitarianism. However, Levitas argues that utopia is embedded in a wide range of human activities and, at its most basic, is the expression of the desire for a better way of being. I suggest that we can see medicine and science as one, highly significant form, in which this desire finds expression in western culture. Beginning with the eugenics movement, utopian visions of future societies became entangled with visions for changing the genetic make-up of human beings. Therefore, I trace the relationship between eugenics and utopia and reflect on today's claims about genomics and utopia. I conclude with exploring how we might use the critical resources of utopia to open up a discussion about our preferred futures, when it comes not only to what kind of society, but also to what kind of people, could and should exist in the future.

Kristien Hens

Epigenetics and responsibility: Hype or paradigm shift in bioethics?

Epigenetics has been heralded as a paradigm shift in molecular and evolutionary biology. Although the traditional concept of genetics as a unidirectional coding system ('The Central Dogma') is still prevalent in much popular and scientific discourse, scientists have acknowledged that many traits and diseases are influenced by environmental exposure triggering epigenetic changes, and that epigenetic mechanisms may have evolutionary significance. In this talk I discuss whether and how these new findings really do have the potential to shift the way we think about responsibilities. What is the ethical difference between having an epigenetic explanation and an unexplained environmental causation? First, the timeframe in which potentially harmful effects can happen is expanded. Environmental influences may affect future children not only during pregnancy, but also before people even consider having children. Does this increase individual responsibility or is there a heightened collective responsibility to ensure a consistent environment for harmless procreation over a lifetime, for example by making sure that people do not live close to highways? The potential heritability over generations of epigenetic changes complicates the issue further: should women (and men) change their behavior if this possibly affects the health of their

grandchildren or great-grandchildren? Should this fact be part of policy decisions? Another aspect of epigenetics, which has been demonstrated in cancer treatment, is that epigenetic changes may be reversible. Does reversibility relieve people or society of part of their responsibility? Do we invest in restorative (curative) strategies rather than preventive strategies, or do we invest in both? I argue that knowledge about epigenetics challenges simple accounts of pubic and individual responsibility, and that bioethical reflection that wants to consider the full impact of these new findings should also focus on the challenges of 'dealing with complexity'.

Participant Biographies

Dr Michael Arribas-Ayllon

Michael Arribas-Ayllon is a senior lecturer at Cardiff University. His research interests include medical sociology and science studies. He has conducted research on genetic testing, genetic counselling and psychiatric genetics. He is the author of *Genetic Testing: Accounts of autonomy, responsibility and blame* (Routledge, 2010) and is currently writing a monograph on psychiatric genetics.

Dr Virginie Bros-Facer

Virginie Bros-Facer is the Research Infrastructure Project Manager for EURORDIS, the European organisation for rare diseases. Her responsibilities include managing patient engagement activities related to infrastructures and technologies facilitating rare disease research such as patient registries, biobanks, clinical bioinformatics and genomic technologies as well as ethical issues surrounding this research. Prior to joining EURORDIS, Virginie worked for several research funding organisations in the UK, including as Director of Medical Research for Sparks, a children's medical research charity based in London. Virginie holds an MSc and a PhD in Neuroscience from King's College London and also worked at the UCL Institute of Neurology on several research projects aiming to develop new therapeutic strategies for motor neuron disease and other neuromuscular disorders.

Professor Sir John Burn MD FRCP FRCPE FRCPCH FRCOG FMedSci

Professor of Clinical Genetics, Newcastle University, Newcastle upon Tyne, UK. Consultant Clinical Geneticist in the Northern Genetics Service since 1984, Professor of Clinical Genetics, Newcastle University, over 400 publications. Knighted for services to Medicine and Healthcare 2010. Chief Investigator CaPP, the international Cancer Prevention Programme, which has shown aspirin can prevent hereditary colorectal cancer. Conceived and helped create the Millennium Landmark Centre for Life. Former chair British Society for Genetic Medicine, and of European Society of Human Genetics. Senior Investigator, National Institute Health Research. Director Collaborative Group for Genetics in Healthcare and chair of Department of Health Rare Disorders Databases and Registries Advisory Group. Non-executive director NHS England.

Dr Lorraine Cowley

Lorraine has an oncology nursing background and is a Principal Genetic Counsellor at the Northern Genetics Service, Newcastle upon Tyne Hospitals NHS Foundation Trust; Associate Clinical Lecturer at the Institute of Genetic Medicine, Newcastle University and Visiting Scholar in PEALS (Policy, Ethics and Life Sciences), where, she has just concluded a Wellcome Trust short-term leave award for clinicians. Her research interests are around the social implications of genetic testing for cancer susceptibility which was the subject of her PhD. She is currently

working on a research proposal to explore how genetic counsellors respond to patients' moral approaches to genetic testing.

Professor Sarah Cunningham-Burley

Professor Sarah Cunningham-Burley is Professor of Medical and Family Sociology, Dean, Molecular, Genetic and Population Health Sciences, Edinburgh Medical School and Assistant Principal, Research-led Learning, University of Edinburgh. Her research spans the study of health and family life and the analysis of social and cultural context of health and medicine. Her methodological expertise is in qualitative research. She was elected to the Academy of Social Sciences in 2012, the Royal Society of Edinburgh in 2014 and the Faculty of Public Health in 2015. Sarah is strongly committed to public engagement in and about research and to knowledge exchange with the policy and practice community. She was one of the founding directors of the Centre for Research on Families and Relationships and also co-founded the journal 'Families, Relationships and Societies' (The Policy Press). She currently heads the public engagement research programme on the research use of health relevant information, within the FARR Institute@Scotland and is co-lead on the public engagement programme for the Administrative Data Research Centre - Scotland. She holds a Wellcome Trust Senior Investigator Award in Society and Ethics, jointly with Professor Anne Kerr, University of Leeds, involving a five year programme of work 'Translations and transformations in patienthood: cancer in the post-genomic era'.

Dr Sandi Dheensa

Dr Sandi Dheensa is a social scientist in Clinical Ethics and Law at Southampton (CELS), researching the ethical and social implications of genomic medicine. Her first position at CELS was conducting a study in which she empirically and normatively explored consent and confidentiality in genetic and genomic medicine. Her second position has been to lead an ESRC-funded investigation about healthcare professionals' duty to re-contact former patients about new genomic findings. She is concurrently doing a Wellcome Trust-funded study exploring patients and professionals' views and experiences of the 100,000 genomes project. In particular she is interested in how the project, and the NHS genomic medicine service to which it will lead, will build trust and evolve responsibly. She draws on this research in her teaching to undergraduate medical students and genomic medicine masters students. Sandi is active member of the Ethics and Social Science GECIP and contributor to UK Genethics Forum.

Professor Erica Haimes

Erica Haimes was Executive Director (August 2013 onwards) of the PEALS (Policy, Ethics and Life Sciences) Research Centre, where she was also the Founding Executive Director (1998-2008) and Professorial Fellow (2008-13). She is also Professor of Sociology, Newcastle University. Her research interests include: interdisciplinary research on social, ethical and legal aspects of the life sciences; reproductive and genetic technologies; the socio-ethical aspects of

the provision of human tissue for research, and the relationship between states, families and medicine with a focus on assisted conception. She also provides policy and practice guidance in the above fields, through her memberships of: the Ethics and Policy Committee of the International Society for Stem Cell Research (2010-2014), the Ethics Committee of the Royal College of Obstetricians and Gynaecologists (2011- 2016) and through her appointment to the Nuffield Council on Bioethics (from March 2013). Erica has been a member of various policy and practice advisory bodies including: the Interim Advisory Group (Ethics and Governance) for UK Biobank; the Ethics and Governance Council for UK Biobank; the MRC's International DNA Banking Advisory Committee; the Nuffield Council on Bioethics Working Party on the care of premature babies. Erica runs the PARTS (Provision and Acquisition of Reproductive Tissue for Science) International Research Network. From September 1, 2016 Erica will be Emeritus Professor of Sociology, based in PEALS, having taken early retirement.

Dr Nina Hallowell

Nina is a medical sociologist with a longstanding interest in bioethics. She has held research posts at the University of Cambridge and the Institute of Cancer Research and teaching posts at De Montfort University, the University of Edinburgh and Newcastle University. Her research focuses upon the social and ethical impact of technological innovations upon individuals, families and society; particularly the introduction of DNA testing in various clinical and research contexts. The main themes of her work include: ethical and social issues in cancer genetics, the introduction of genetic testing for common diseases, the relationship between bioethics and empirical research, lay and professional experiences and perceptions of clinical research and the ethical issues arising. She holds honorary positions In the Centre for Health Equity, University of Melbourne and The Centre for Population Health Sciences, University of Edinburgh, and has longstanding collaborations with researchers in these institutions. She was appointed in 2016 to work with Researchers in Ethox and the BDI to develop a research programme that explores the ethical issues arising from the use of big datasets in health research.

Dr Kristien Hens

Kristien Hens is a bioethicist whose work focuses on ethical issues related to genetics, reproductive medicine, feminism, disability studies and neurodiversity (autism, ADHD). She is currently working as a postdoctoral researcher at the Philosophy Department of the University of Antwerp investigating the ethical issues of the genetics and epigenetics of autism. She is also a research fellow at the Centre for Biomedical Ethics and Law of the KU Leuven. Before that she worked as postdoctoral researcher on the ethics of embryo selection, at Maastricht University, and as a PhD student at the KU Leuven on the ethics of the use of stored tissue samples from children for research. She has published in several medical and ethical journals, including Journal of Medical Ethics, Human Reproduction and European Journal of Human Genetics.

Dr Ruth Horn

Ruth Horn is a University Research Lecturer of Oxford University. She holds an Ethics and Society Wellcome Trust Fellowship. In her current project she carries out comparative research on advance directives in England, France, and Germany; Ruth is also a researcher on the PAGE (Prenatal Assessment of Genomes and Exomes) Ethics Research Programme.

Dr Kimberly Jamie

Kimberly came to Durham in January 2014 to take up a lectureship. Prior to this she was a Research Fellow in the Science and Technology Studies Unit (SATSU) at the University of York, which is where she completed her PhD between 2009 and 2012. Her research interests are in the fields of health, medicine and professional practice. She has particular interests in personalised medicine; genetics; young peoples' health beliefs, particularly around cancer; cultural understandings of medicines; and the everyday work practices of pharmacy and oncology.

Alastair Kent OBE

Alastair Kent is Director of Genetic Alliance UK. Alastair came to Genetic Alliance UK over 20 years ago because he was excited by the challenge that new knowledge in genetics created - the idea that, for people affected by a genetic condition, yesterday's science fiction is tomorrow's clinical service improvement. Trying to transform these possibilities into positive outcomes whilst reducing the potential for abuse is an incredible challenge, and he feels incredibly privileged to work in this field. The fact that Genetic Alliance UK is now a respected and authoritative voice for patients and families is something about which he feels pride, and also a huge sense of responsibility. It is a challenge that excited him on the first day he became aware of the impact of genetic disorders and which continues to excite him today.

Professor Anne Kerr

Anne Kerr is Professor of Sociology; Head of School Leeds University. Anne works in the fields of science and technology studies and the sociology of health and illness, with a special focus upon gender, genetics and biomedicine. Anne is Director of the Centre for Health, Technologies and Social Practice and Head of School.

Prof. Dr. Christian Lenk

Professor Dr Christian Lenk studied philosophy, political sciences and social anthropology at the University of Hamburg, Germany (Magister Artium 1998). He concluded his Ph.D. thesis at the University of Münster, Germany, in the field of medical ethics in 2002 (Dr. phil.). The title of the thesis was Therapy and Enhancement. He has had research stays at Marburg University, Germany (1998-99), Swansea University, Wales / UK (2008-09), and Zürich University, Switzerland (2011). He has received stipends and research grants from the German Ministry

for Education and Research (BMBF), the Leverhulme Trust (UK), and the European Commission. Christian has given numerous lectures at home and abroad and has published approximately 100 publications in the area of medical ethics and applied philosophy, including in the European Journal of Paediatrics, Journal of Medical Ethics and Medicine, Health Care and Philosophy, among others. His research interests comprise issues from medical ethics (enhancement, research ethics, research ethics committees), technology assessment (ethical, legal, and social implications) and philosophy (justice, theory of science).

Dr Pauline McCormack

Pauline is a Senior Research Associate in PEALS with interests in medical sociology particularly, social and ethical approaches to new technologies, patient activism and rare disease. Current projects include an exploration of patient and families' expectations of developments in rare disease research, particularly applications of new technologies such as genomics and big data, with the RD-Connect project. She is also working on 'When Technology Fails Patients', exploring people's experiences with failed metal on metal hip implants and the surrounding regulatory and policy landscape. Pauline chairs the multidisciplinary Rare Disease Patient and Ethics Council and with Simon Woods she leads a Genomics England Clinical Implementation Partnership on Patient Involvement.

Professor Christopher McKevitt

Christopher McKevitt is Professor of Social Sciences and Health at King's College London. After completing a PhD in social anthropology at the London School of Economics, he began working in health research including HIV/AIDS and sexual health, doctors with illness, and stroke. He and his team are currently working closely with basic and clinical scientists, investigating the social production of new knowledge, emergent concepts and practices of 'involvement', and implications of these for citizenship, morality and re-enchantment.

Professor Alison Metcalfe

Alison Metcalfe is Professor of Health Care Research and Vice Dean for Research at King's College London, Florence Nightingale Faculty of Nursing & Midwifery. Alison followed the traditional hospital based training route and was registered as a nurse in 1987. In 1989 Alison commenced a full-time joint honours degree in psychology and biology at Keele University, whilst working part-time as a nurse in a variety of clinical roles. Following completion of her undergraduate degree in 1993, she obtaining a MRC /BBSRC studentship in biomolecular science. Post-doctorally, Alison worked in research management within the UK's NHS including becoming a deputy director for R&D and the lead for nursing and allied health professional research. In 2001, she became a research fellow at the University of Birmingham and pursued her own research interests. From 2002 onwards, Alison developed a programme of funded research activity that focuses on genetic risk communication between health professionals and families but also within families at different life stages from antenatal to end of life care,

and examines the impact the risk information has on people's lives. Alison also completed a Postgraduate Diploma in Family Therapy and continues to work in clinical practice. The outcomes of this work have been published in the leading relevant journals, with over 60 publications to date and the findings used to inform clinical practice nationally and internationally.

Professor Michael Parker

Michael Parker is Professor of Bioethics and Director of the Ethox Centre at the University of Oxford. He has a long-standing research interest in the practical ethical issues arising in the clinical and research uses of genetics and genomics. He is Chair of the Ethics Advisory Committee for Genomics England and the UK's 100,000 Genomes Project and was the Chair of the Chief Medical Officer's Ethics Advisory Group on Genomics which led up to the establishment of the 100,000 Genomes Project. In 2001, together with Anneke Lucassen, Angus Clarke and Tara Clancy, Michael established the Genethics Club, which is a national ethics forum for genetics professionals and laboratory staff across the UK to discuss difficult ethics issues and share good practice. In 2012, this experience was published as 'Ethical Problems and Genetics Practice by Cambridge University Press.' Since 2004, Michael has also been working on ethical issues in the use of genomic approaches to research in global health, with partners in Thailand, Vietnam, Kenya, Malawi, and South Africa.

Professor Katherine Payne

Katherine was awarded a personal chair in health economics at The University of Manchester in August 2010. She is based within the Manchester Centre for Health Economics. She holds honorary positions with: the School of Pharmacy, University of Nottingham; PHG Foundation, Cambridge; Central Manchester University Hospitals NHS Foundation Trust; and Nowgen, Manchester. Ongoing and recent projects include: evaluating an integrated model of service delivery and the use of new sequencing technologies for the diagnosis of inherited retinal dystrophies; identifying and costing pathways of care for people with inherited ataxia; building an economic model to identify the most appropriate interval for breast cancer screening; economic evaluation of stratified breast screening programmes; developing an approach to the health technology assessment of whole genome sequencing; economic evaluations of different applications of stratified medicine in rheumatoid arthritis, psoriasis and lupus; and using stated preference methods to value the balance between the risks and benefits of healthcare interventions. Katherine has also been a member of funding review panels on the economics of genomics and precision medicine for: the UK; Canada; France; The Netherlands; Luxembourg. She was a member of a NICE Technology Appraisal Committee between October 2003 and 2012.

Professor Nadeem Qureshi

Professor Nadeem Qureshi co-leads the Applied Genetics and Ethnicity Research Group in the

University of Nottingham. Nadeem is recognised as an expert in Primary Care Genetic and Genomics health service research. He leads an internationally recognised group that focuses on translation of genetics/genomics into clinical practice, developed in tandem with advances in genomic technology and emerging screening policies. Nadeem has been actively involved in teaching medical students on preclinical courses at both the University of Nottingham undergraduate and graduate-entry medical schools, and on the combined clinical course. He also supervises both local and overseas PhD students.

Professor Jackie Leach Scully

Jackie Leach Scully is Executive Director of the Policy, Ethics and Life Sciences Research Centre, and Professor of Social Ethics and Bioethics at Newcastle University. She has held guest or visiting positions at the University of Sydney Medical School, University of Technology Sydney, Macquarie University, Netherlands Institute of Human Rights at Utrecht University, and Humboldt University, Berlin. Her research interests are in feminist bioethics, disability bioethics, new reproductive and genetic technologies, humanitarian and identification interventions in disasters, public bioethics, and identity. She is Editor in Chief of the *International Journal of Feminist Approaches to Bioethics (IJFAB*).

Dr Ingrid Slade

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Dr Richard Tutton

Dr Richard Tutton is Senior Lecturer in the Department of Sociology and the co-Director of the Centre for Science Studies at Lancaster University. He formerly worked in the ESRC Centre for the Study of Economic and Social Aspects of Genomics (Cesagen) (2007-12). He has worked on various aspects of the social and cultural contexts of genomics research, particularly in relation to issues of citizenship, personhood, race, and expectations about the future. He is the author of Genomics and the Reimagining of Personalized Medicine (Ashgate, 2014).

Dr Helen Wallace

Dr Helen Wallace is the Director of GeneWatch UK, a not-for-profit organisation which aims to ensure that genetic technologies are used in the public interest. Helen has published and spoken widely on issues of gene test regulation and privacy and has been involved in relevant policy debates for 15 years.

Dr Matthias Wienroth

Matthias Wienroth is Research Fellow at the Northumbria University Centre for Forensic Science, and Visiting Researcher at the Policy, Ethics and Life Sciences Research Centre, Newcastle University. He began his work on science and technology studies during his PhD on research practices in nanotechnology, and continued studying this field's governance as research associate at Durham University from 2009. In 2010/11, he was also Robert W. Gore Materials Innovation Project Scholar (Chemical Heritage Foundation, Philadelphia, PA) before moving to Newcastle University to work on medical technology governance issues, and to Edinburgh University to attend to aspects of genomics in society, where he was PI on a pilot project bringing together artists and scientists, and edited (together with Eugenia Rodrigues) 'Knowing New Biotechnologies: Social Aspects of Technological Convergence' (Routledge, 2015). He is PI of the Economic and Social Research Council (ESRC) 'Seminar Series on genetics, technology, security and justice. Crossing, contesting and comparing boundaries.' Matthias Wienroth studies science–society relationships and the practices and opportunities of cross-disciplinary knowledge production for socially responsible technology development.

Dr Simon Woods

Simon is Senior Lecturer and Co-Director of the Policy Ethics and Life Sciences Research Centre (PEALS). Simon has a longstanding interest in medical ethics and bioethics more broadly. His research explores the social and ethical aspects of new and emerging biotechnologies. Simon has been work-package leader, or ethics advisor to ten EU projects and several with a focus on rare disease genomics in which issues related to the care and treatment of children have been central. Simon holds bachelor and doctoral degrees in philosophy and over the past 13 years he has pursued a career of teaching and research within bioethics. Simon has considerable expertise in the ethics and regulation of bioscience research; he has been a member and vice-chair of NHS research ethics committees and is a member of the National Research Ethics Service National Ethics Advisors' Panel.