

Policy  
Ethics  
And  
Life  
Sciences



**PEALS 20<sup>th</sup> Anniversary International  
Symposium: The Past, Present and Future of  
Bioethics**

**21<sup>st</sup> November 2019**

**Great North Museum, Newcastle Upon Tyne**



## Contents

Introduction .....	4
Programme .....	5
Welcome Address .....	6
Session Speakers.....	6
Session 1: Peals: Foundation and Early Progress.....	6
Session 2: Peals into the Second Decade: Collaborative Ventures.....	8
Session 3: Peals in the Present: Expanding Horizons.....	10
Session 4: Peals and a Future Bioethics Agenda.....	12
The Panel.....	14
The Exhibition .....	16
The Artist.....	16
The Performers .....	17
<i>Performance 1</i> .....	17
<i>Performance 2</i> .....	17
Delegates .....	18

## Introduction

Dear Colleagues and Friends,

A very warm welcome to the 2019 PEALS International Symposium and our 20<sup>th</sup> anniversary celebration event. We are very glad that you are able to join us here in Newcastle. As in previous years, our ambition has been to bring together participants from a range of academic disciplines and from a range of interests in policymaking and in professional practice, and as always we are spoiled for choice, for speakers, for chairs and participants. Short of holding a major international conference we could not hope to create space to hear from all the people, friends, colleagues and collaborators who we would have liked to join us on this special occasion. So we have kept the event to its usual size and format but hope that during the course of the day everyone will have an opportunity to contribute, and in true PEALS style, bring their voice to the table.

Our focus this year, fitting for a 20<sup>th</sup> anniversary event is: 'The Past, Present and Future of Bioethics'.

We do of course want to celebrate PEALS contribution to bioethics (not insubstantial over 20 years!) but this event is not just about nostalgia. In reflecting on some of PEALS early work we will have an opportunity to revisit some of the key issues and questions that have shaped the bioethics landscape. Are the issues still relevant, have they been resolved or are they now obsolete? We will hear from colleagues and collaborators about what has preoccupied their research in recent years and in true bioethics style we will turn to scan the horizon and discuss the future challenges and future direction for bioethics. We are joined by colleagues and friends old and new but are particularly pleased that we will have an opportunity to hear from colleagues who are likely to be the next leading scholars in the field.

Welcome and enjoy!

From all the PEALS team.

Please use [#PEALS20](#) when tweeting.

## Programme

21<sup>st</sup> November 2019

Time	Theme	Speaker
10:00 – 10:30	Registration and Refreshments	
10:30 – 10:50	Welcome and Introduction	Dr Simon Woods and Professor Jackie Leach Scully
10:50 – 12:00	<b>Session 1: Peals: Foundation and Early Progress</b>	<i>Chair: Professor Tom Shakespeare</i>
10:55 – 11:20	PEALS: The early years. À la recherche du temps perdu?	Professor Erica Haimes
11:20 – 11:45	Cultural contexts: How they matter ethically	Professor Christoph Rehmann-Sutter
11:45 – 12:00	Discussion	All
12:00 – 12:15	<b>Symposium Photograph</b>	
12:15 – 12:30	<b>Stemistry Project</b>	Marilyn Longstaff
12:30 – 13:25	<b>Lunch</b>	
13:25 – 14:30	<b>Session 2: Peals into the Second Decade: Collaborative Ventures</b>	<i>Chair: Professor Janice McLaughlin</i>
13:30 – 13:55	Heritable Human Genome Editing: And What about the Women?	Professor Françoise Baylis
13:55 – 14:20	Is Enhancement the Price of Prevention for Human Gene Editing?	Professor Eric Juengst
14:20 – 14:30	Discussion	All
14:30 – 14:45	<b>Canon Rachel Mann</b>	
14:45 – 15:00	Refreshments Break	
15:00 – 16:05	<b>Session 3: Peals in the Present: Expanding Horizons</b>	<i>Chair: Hugh Whittall</i>
15:05 – 15:30	Why data ethics? Or not...	Professor Madeleine Murtagh
15:30 – 15:55	Version 2.0: what we might achieve if we consciously disrupt bioethics	Dr Agomoni Ganguli-Mitra
15:55 – 16:05	Discussion	All
16:05 – 17:00	<b>Session 4: Peals and a Future Bioethics Agenda</b>	<i>Chair: Dr Simon Woods</i>
16:10 – 16:30	Bioethics in Court: Public Values and Voices of Faith	Sir Jonathan Montgomery
16:30 – 16:50	The end of bioethics as we know it?	Professor Søren Holm
16:50 – 17:00	Discussion	All
17:00 – 17:30	<b>Session 5: Panel Discussion and Closing Remarks</b>	<i>Chair: Dr Pauline McCormack</i>
	<b>Issues on the Horizon for Medical Sociology and Bioethics</b>	Panel: Dr Ed Coleman-Fountain Dr Lorraine Cowley Dr Alexis Paton Dr Sarah Skyrme
<b>PEALS 20th Anniversary Celebration Evening Reception 6.30pm-9:00pm</b>		

## Welcome Address

### **Professor Jackie Leach Scully**

Jackie Leach Scully has been Professor of Bioethics and the director of the Disability Innovation Institute at the University of New South Wales (DIU), Australia since August 2019. Prior to that she had a long association with PEALS, and was Director of Research before becoming Executive Director in 2016. Her research interests cover a broad range of bioethical areas, including disability and embodiment; new reproductive and genetic technologies; artificial intelligence in health and social care; humanitarian responses to global health emergencies; feminist bioethics; and public engagement in bioethical evaluation and policy making. She is a Fellow of the Academy of Social Sciences and of the Royal Society of Arts, a member of the South Eastern Sydney Clinical Ethics Committee and of the Australian Alliance for Artificial Intelligence in Healthcare, and Editor in Chief of the *International Journal of Feminist Approaches to Bioethics*.

## Session Speakers

### Session 1: Peals: Foundation and Early Progress

#### **Chair: Professor Tom Shakespeare**

*Tom Shakespeare is Professor of Disability Research at London School of Hygiene and Tropical Hygiene. He was the research development officer at PEALS from 1999, and subsequently Director of Outreach at PEALS and then a Research Fellow at University of Newcastle. He left PEALS in 2008, when he joined the World Health Organisation, and later UEA. His books include Disability Rights and Wrongs (2006).*

#### **Professor Erica Haines**

##### **PEALS: The early years. À la recherche du temps perdu?**

In this presentation I shall explore the foundation and early years of PEALS and evaluate their legacy for our future developments. In outlining the challenges for PEALS in our early days I shall also make various claims for our achievements and for our contributions as the UK's first interdisciplinary research centre to address the socio-ethical positioning of international developments in the life sciences. The emergence of the 'PEALS model', the close integration of (i) original research with (ii) policy and public engagement, and (iii) teaching and learning, was crucial in establishing an ongoing agenda for the rigorous scrutiny of scientific ambitions. As with most 'origins' stories/creation myths, this account will necessarily be partial, situated and perspectival - other versions are doubtless available!

*Erica Haines was the Founding Executive Director of PEALS from 1998-2008 (when she became Professorial Fellow) and again from 2013-2016, when she retired. She is now Emeritus Professor of Sociology. Her research interests include: interdisciplinary research on social, ethical and legal aspects of the life sciences, particularly reproductive and genetic technologies; 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. Erica has been a member of various policy and practice advisory bodies including: the Interim Advisory Group (Ethics and Governance) for UK Biobank (2003-4); the Ethics and Governance Council for UK Biobank (2007-2009); the UK's Medical Research Council's International DNA Banking Advisory Committee (2003-6); the Nuffield Council on Bioethics Working Party on the care of premature babies (2004-6); the Ethics and Public Policy Committee of the*

*International Society for Stem Cell Research (2009-14). She was a co-opted member of the Ethics and Law Advisory Committee of the UK's Human Fertilisation and Embryology Authority (2009-10). She was a member of the Ethics Advisory Board of the Royal College of Obstetricians and Gynaecologists, between 2011-2019, and she was appointed as a full council member of the UK's Nuffield Council on Bioethics between 2013-2019.*

## **Professor Christoph Rehmann-Sutter**

### **Cultural contexts: How they matter ethically**

My talk is a late response to Erica Haimes' 2002 *Bioethics* paper "What can the social sciences contribute to the study of ethics?" - which has become one of the classical references on interdisciplinarity in bioethics. In my research collaboration with PEALS that extends over the last 18 years, there was an underlying joint interest in contextually understanding both bioethical problems and the social practice of bioethics itself. But how do contexts matter? Can some of the methodological and epistemological issues of empirical ethics be solved from a hermeneutic and phenomenological point of view?

*Christoph Rehmann-Sutter is Professor of Theory and Ethics in the Biosciences at the Institute for History of Medicine and Science Studies of the University of Lübeck, Germany (since 2009) and Visiting Professor at the Department of Global Health & Social Medicine, King's College London. He holds a diploma degree in molecular biology from the Biozentrum of the University of Basel (1984) and studied philosophy and sociology at the Universities of Basel and Freiburg i. Brsg. Doctoral degree in philosophy 1995 from the Technical University of Darmstadt and Habilitation thesis in philosophy at the University of Basel 2000 on philosophical foundations of bioethics. Between 1996 and 2008 he was head of the Unit for Ethics in the Biosciences at the University of Basel and conducted various research projects on bioethical issues, including the risks of biotechnologies, the philosophy of genomics, ethics of gene therapies, genetic testing, stem cell research and end-of-life issues, always interested in integrating insights from qualitative research with philosophical analysis. 1999-2002 he was President of the Swiss Society of Biomedical Ethics, 2016-2019 President of the European Society of Philosophy, Medicine and Healthcare. From 2001 to 2009 he chaired the Swiss National Advisory Commission on Biomedical Ethics, advising the Swiss parliament and government. With interdisciplinary bioethics research teams in Basel and Lübeck he has tackled a broad range of topics including wishes to die of palliative care patients, bone marrow transplantation between siblings as children, new developments in prenatal diagnosis such as non-invasive-tests and precision medicine.*

## Session 2: Peals into the Second Decade: Collaborative Ventures

### **Chair: Professor Janice McLaughlin**

*Janice McLaughlin is a Professor of Sociology at Newcastle University where she is currently Director of Research and UOA REF coordinator in the Sociology Subject Area. She was Executive Director of PEALS between 2008 and 2013. Her own research is focused on childhood disability, examining how different medical and social institutions that disabled children move through, influence and shape their lives. While in PEALS she worked on a number of areas within this focus, for example exploring the diagnostic processes involved in paediatric genetics and researching embodied transitions into adulthood.*

### **Professor Françoise Baylis**

#### **Heritable Human Genome Editing: And What about the Women?**

In late November 2018, on the eve of the second international Summit *On Human Genome Editing II*, the world learned that twin girls Lulu and Nana (pseudonyms) had been created from embryos that had been genetically modified to provide them with resistance to HIV. The birth announcement was greeted with swift and near uniform condemnation: “the procedure was irresponsible and failed to conform with international norms. Its flaws include an inadequate medical indication, a poorly designed study protocol, a failure to meet ethical standards for protecting the welfare of research subjects, and a lack of transparency in the development, review, and conduct of the clinical procedures.” At the time, many were concerned about potential short- and long-term harms to the gene-edited babies. By comparison there was little to no concern for the women research participants, save some posturing around the quality of the informed consent process. In discussions of heritable human genome editing, as with most discussions of reproductive and genetic technologies, the potential harms to women are all too often overlooked. This is outrageous when one considers the essential role of women in reproduction, unless and until humans routinely reproduce using artificial gametes (synthetic eggs and sperm) and an artificial uterus. This presentation will highlight some of the potential harms of heritable human genome editing for the women research participants.

*Françoise Baylis is University Research Professor at Dalhousie University. She is a member of the Order of Canada and the Order of Nova Scotia, as well as a fellow of the Royal Society of Canada and of the Canadian Academy of Health Sciences. Baylis was one of the organizers of, and a key participant in, the 2015 International Summit on Human Gene Editing. She is a member of the WHO expert advisory committee on Developing global standards for governance and oversight of Human Genome editing. She is the author of *Altered Inheritance: CRISPR and the Ethics of Human Genome Editing*.*

### **Professor Eric Juengst**

#### **Is Enhancement the Price of Prevention for Human Gene Editing?**

In 2017 the U.S. National Academy of Sciences, like over 80 other organizations around the world, released a policy report on the boundaries of responsible human gene editing research. One of the major recommendations of that report is that clinical gene editing research should be conducted “only for indications related to the treatment or prevention of disease or disability.” This position reaffirms the traditional science policy rejection of genetic “enhancement” research aimed at improving human

traits beyond what is necessary to restore or preserve normal functioning. On the other hand, the NAS report also explicitly endorses research aimed at “resistance and resilience” in the face of health risks, in the name of prevention. This creates a problem within the report’s ethical framework, because there is a spectrum of ways to strengthen the body to resist disease, some of which raise the same concerns that stand behind the traditional proscription of genetic enhancement. Until now the problem that “preventive strengthening” brings to policy-making about human genetic modification research has been largely a philosopher’s line-drawing problem, since we have had neither the editing tools nor the genomic targets required to make it a live option. Now, however, the trajectory of gene editing technologies is converging with other genomic research efforts to identify DNA variants associated with traits that provide just that kind of benefit. In addition to human studies, of particular interest in this regard are studies aimed at modifying animals (as model organisms or for agricultural/commercial purposes) that might translate into homologous interventions in humans but would fall outside the jurisdiction of any policies restricted to human gene editing research. As this research matures, the possibility of using its discoveries in preventive gene editing interventions will make the problems of “incidental” and “off-label” human enhancement a practical science policy challenge.

*Eric Juengst is Professor in the Department of Social Medicine and the Department of Genetics at the University of North Carolina, Chapel Hill, where he directs the UNC Center for Bioethics. Dr. Juengst’s research interests and publications focus on the conceptual and ethical issues raised by new advances in human genetics and biotechnology. Juengst received his B.S. in Biology from the University of the South in 1978, and his Ph.D. in Philosophy from Georgetown University in 1985. He has taught medical ethics and the philosophy of science on the faculties of the medical schools of the University of California, San Francisco Penn State University, and Case Western Reserve University (CWRU). From 1990 to 1994, he served as the first Chief of the Ethical, Legal and Social Implications (ELSI) Branch of the National Center for Human Genome Research at the U.S. National Institutes of Health, and from 2005-2010 he directed the Center for Genetic Research Ethics and Law at CWRU, on whose advisory board Prof. Erica Haimes served. In 2007 he was honoured to be a HaSS Fellow at the PEALS program. In 2010 he moved to North Carolina to help build the bioethics center at the University of North Carolina, Chapel Hill, which now supports 8 core research faculty and the University Hospital’s Clinical Ethics Consultation Service.*

## Session 3: Peals in the Present: Expanding Horizons

### **Chair: Hugh Whittall**

*Hugh Whittall is the Director of the Nuffield Council on Bioethics, whose task is to identify and report on ethical questions raised by new developments in biological and medical research. Recent reports have covered areas including neurotechnology, emerging biotechnologies, children and clinical research, biodata and genome editing. Hugh was previously at the Department of Health, where he was involved with the preparation of the Human Tissue Act 2004 and the setting up of the Human Tissue Authority. He was also involved in end-of-life issues and transplantation policy. Prior to that Hugh spent three years at the European Commission in Brussels, involved in the funding and promotion of bioethics research, and he was for several years Deputy Chief Executive of the Human Fertilisation and Embryology Authority.*

### **Professor Madeleine Murtagh**

#### **Why data ethics? Or not...**

It now seems almost trite to note the datafication of contemporary life. Data is produced in our every action and reaction, used to monitor and audit, predict and persuade. In the biosciences these data-uses have multiple material impacts. In step, or in response, new instantiations of ethics are emerging. Or perhaps not? Using examples from work being undertaken in the PEALS Health Data and Society team, I outline (and problematise) several ways in which data ethics is '*becoming*' and explore the contested epistemic terrain in which these practices are situated.

*Madeleine Murtagh took up her post as Professor of Sociology and Bioethics in PEALS in 2017. Madeleine began her academic career in Australia, studying and teaching sociology, anthropology, public health and bioethics, before moving to the UK in 2000. Her earlier research examined how people interact with and make decisions about using new health treatments and technologies, and later expanded to consider practices of (open) data science in health (particularly in longitudinal cohort studies and biobanks) and health data ethics. Madeleine conducts social studies of sociotechnical and normative practices in health research data sharing and governance as well as developing new forms of governance which centrally involve citizens and research participants in ethical and governance decision-making. This work is carried out in the context of transdisciplinary and intersectoral research teams, often in interventionist, collaborative ethnographic studies.*

### **Dr Agomoni Ganguli-Mitra**

#### **Version 2.0: what we might achieve if we consciously disrupt bioethics**

While teaching bioethics over the last few years, I have faced a particular challenge: the concepts, tools and texts I seem to have at my disposal do not appear to do justice to the complexity and injustice of the world in which we are teaching and undertaking research. While we have come a long way from the days of simplistically applying principles or theory to applied contexts, I would argue that we are not pushing hard enough at the boundaries of the discipline, particularly with respect to questions of justice. Using illustrations from my current work on various aspects of reproduction, I suggest that we face, a great opportunity: that is to train future physicians, policy-makers, scientists and lawyers with a keen awareness of historical and current social and structural injustices and inequalities. Such fruitful disruptions can be achieved by learning from scholarship in social sciences which focuses on

inequality, power and intersectionality for example, as well as feminist philosophical approaches which focus on structural and epistemic injustice.

*Agomoni Ganguli-Mitra is Chancellor's Fellow in the Legal and Ethical Aspects of Biomedicine, and Co-director of the JK Mason Institute for Medicine, Life Sciences and the Law. She is also a member of the Wellcome Trust-funded Centre for Biomedicine, Self and Society. Agomoni's background is in bioethics, with a special interest in global bioethics, structural and gender justice. She has written on ethical issues related to global surrogacy, sex-selection, biomedical research in low-income countries, social value in research governance and the concepts of exploitation and vulnerability in bioethics. She is currently PI on a Wellcome Trust funded project entitled, Vulnerability and Justice in Global Health Emergency Regulation: Developing Future Ethical Models (2018-19).*

## Session 4: Peals and a Future Bioethics Agenda

### **Chair: Dr Simon Woods**

*Simon Woods is Reader and Executive Director of PEALS. Simon has a longstanding interest in developments within the life sciences, 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 16 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 NHS Health Research Authority's National Ethics Advisors' Panel.*

### **Sir Jonathan Montgomery, Professor of Health Care Law, University College London**

#### **Bioethics in Court: Public Values and Voices of Faith**

Recent UK court cases have seen intense conflict between secularised public bioethics and religious campaigners. Judicial neutrality has been questioned. Courts are being politicised and drawn into 'culture wars'. This paper examines the application of the 'welfare principle' and considers the claims of faith activists that it oversteps the proper role of the state. It also explores how the courts should respond to 'interventions', in which those not personally involved seek a voice in proceedings. It seeks to distinguish interference with due process from interventions that promote more fully informed decisions on public values in a pluralist democracy.

*Sir Jonathan Montgomery is Professor of Health Care Law at University College London. His research concerns good governance of bioethical issues. His public service roles have included chairing the Health Research Authority (2012-19), the Nuffield Council on Bioethics (2012-17) and the Human Genetics Commission (2009-12). He chaired the boards of a range of NHS organisations in Hampshire and the Isle of Wight between 1998 and 2013 and since April 2019, he has been Chair of Oxford University Hospitals NHSFT. He was knighted in the 2019 New Years' Honours for services to bioethics and health care law.*

### **Professor Søren Holm**

#### **The end of bioethics as we know it?**

Will bioethics be around when PEALS celebrates 40 successful years in 2039? The first part of the talk will briefly outline a number of existential threats to bioethics as a coherent field of study. Some of these threats are internal, e.g. speciation and hyper-specialisation, academic insularity and uncertainty about the purpose of bioethics; whereas others are external, e.g. the displacement of bioethics as a relevant mode of discourse by 'professionalism' in the health care professions or more action oriented discourses in relation to the environment. It will be argued that these threats are real and that bioethics may disappear as a field. The second part of the talk will then argue that even if bioethics disappears as a field, some of the core concerns and activities will not disappear. It will identify some of these persistent concerns and activities and will on the basis of this identification provide a prognosis for the next 20 years of PEALS.

*Søren Holm is Professor of Bioethics at the University of Manchester and part-time Professor of Medical Ethics at the University of Oslo. He is a (lapsed) medical doctor and philosopher with wide ranging interests in bioethics, bioethics policy, and philosophy of medicine.*

## The Panel

### **Chair: Dr Pauline McCormack**

Pauline McCormack is a Senior Lecturer in Sociology of Health at PEALS where she has worked since 2008. Pauline has a background in education, social policy and participatory methods. Her research encompasses: patient experiences of medical technologies, translational research and clinical trials; patient participation; and bioethics, with particular interests in notions of power and the patient voice.

### **Dr Edmund Coleman-Fountain**

Edmund Coleman-Fountain is a lecturer in Sociology at Northumbria University, and also worked at the Social Policy Research Unit, University of York. He was a research associate in PEALS between 2011 and 2013, working with Professor Janice McLaughlin on the ESRC funded Embodied Selves in Transition project. His research – largely influenced by his time at PEALS – centres on embodied identity-making in disabled young people. He has two books, 'Understanding Narrative Identity through Lesbian and Gay Youth' (Palgrave Macmillan, 2014), and 'Disabled Childhoods: Monitoring Differences and Emerging Identities' with Janice McLaughlin and Emma Clavering (Routledge, 2016).

### **Dr Lorraine Cowley**

Lorraine Cowley 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 and Visiting Scholar in PEALS (Policy, Ethics and Life Sciences), at Newcastle University. Her research interests are around the social implications of genetic testing for cancer susceptibility which was the subject of her PhD. She is supervisor and Principal Investigator on two projects, one exploring healthcare professionals' views of prenatal testing for cancer susceptibility and the other looking at the experiences of women who have not inherited their familial cancer susceptibility mutation. Lorraine currently has a bridging award from the National Institute for Health Research (NIHR) and Health Education England (HEE) to develop her research to explore how mainstreaming genomic testing affects patients and their families.

### **Dr Alexis Paton**

Alexis Paton joined the SAPPHERE group in December 2017. Prior to this, she was a Research Fellow at the Health Services Management Centre, University of Birmingham. She has held previous posts as a Postdoctoral Researcher at the Policy, Ethics and Life Sciences Research Centre at Newcastle University, as a lecturer for Yale University's Summer Institute in Bioethics, and as a Research Assistant at the University of British Columbia. She has also been a periodic lecturer for the University of Birmingham and Birmingham City University. Alexis' PhD (Sociology, Newcastle University, 2015) research examined how female cancer patients make difficult decisions about preserving their fertility during cancer treatment. She also holds an MA in Philosophy from the University of British Columbia (2010), and a BSc in Biology from the University of King's College (2007).

**Dr Sarah Skyrme**

Sarah Skyrme is a freelance and contract researcher with an interest in health, wellbeing, disability and marginalised identities. Currently, with animator Jeremy Richard, she is developing a short, animated film, 'In spate', which is partly based on her own experience of becoming ill with Hepatitis C. It depicts her experience of the gaps in health and social care provision, and joining a buyer's club to purchase her cure from abroad. These issues intersect with her interests and commitment to represent the voices of those who are marginalised and/or stigmatised through disability or illness. Sarah's experience of developing the screenplay and planning for their next project are deeply insightful and creative for her, as she enters a new field of research possibilities that merge imagery with more conventional forms of social research. Their next film will explore stigma and feelings of difference using verbatim text from interviews with ill and disabled individuals, merged with animation.

## The Exhibition

To celebrate the 20th anniversary of the Policy Ethics and Life Sciences Research Centre (PEALS) at Newcastle University an exhibition showcasing highlights from the last two decades will be on view in the Galleria space at the Great North Museum from 16th to 30th November 2019. PEALS was founded at a time of rapid developments in human genetics and embryo research. These advances pushed the boundaries of the life sciences, promising great benefits but also bringing new challenges for society. In addition to scholarly research PEALS has developed models of public engagement, from Café Scientifique and other kinds of public events to work with teachers and schools. Creative approaches to fostering engagement include working and collaborating with artists, writers, musicians and poets. This 20th anniversary exhibition showcases some of the creative highlights from the last two decades.

Many people have contributed to PEALS' success, and this exhibition celebrates them all. PEALS' original purpose was to promote "research and debate on the social and ethical aspects of the life sciences", through academic enquiry and public outreach and policy engagement. This combination of activities continues to be a distinctive feature of PEALS and is represented in this exhibition.

## The Artist

### **Dr Marianne Wilde**

Dr Marianne Wilde is a visual artist and academic whose work focuses on the relationship between art and science and with collaborative and interactive contemporary arts projects between the artist's studio and the scientific laboratory. In particular her work considers the methods and materials that are used to visualise the medicalised and diseased human body and the ways in which, in particular, genetic diseases are visually, linguistically and culturally represented. Since the 'genetic revolution' visualisations of disease and illness have become increasingly microscopic and as the 'invisible' world of disease emerges through advanced technology questions arise as to how we can articulate a discourse between how we see and how we say disease - how can we read the story that the body is writing?

## The Performers

### *Performance 1*

#### **Marilyn Longstaff**

Marilyn Longstaff lives in Darlington and is a member of Vane Women ([www.vanewomen.co.uk](http://www.vanewomen.co.uk)). She has an MA in Creative Writing from the University of Newcastle. Her third poetry book, *Raiment* ([Smokestack Books](http://SmokestackBooks.com) 2011), was selected by New Writing North's Read Regional in 2012. Her last full collection, *Articles of War* was published by Smokestack books in February 2017. From 2007, Marilyn was a member of a group of writers, invited by Lisa Matthews to be part of a PEALS project, *Stemistry*, which Lisa devised and ran over a number of years. Through meeting scientists involved in modern genomics, writing workshops, engaging with the general public, attending residential sessions – both with girls from the Angelou centre and people involved in public engagement projects from other universities, the group produced a wide range of quality writing, much of which can be seen on <https://research.ncl.ac.uk/stemistry/project.html>. Marilyn's latest pamphlet, *The Museum of Spare Parts*, (Mudfog Press 2018) contains a selection of her writing from this project.

### *Performance 2*

#### **Canon Rachel Mann**

Canon Rachel Mann is an Anglican priest, theologian and poet. The author of seven books, her debut full poetry collection, 'A Kingdom of Love' was recently published by Carcanet. Her study of Ritual, Memory and the Great War, 'Fierce Imaginings' was shortlisted for the Michael Ramsey Prize for theology, and she is a regular broadcaster on BBC Radio Four and Radio Two.

## Delegates

Ms	Samantha	Aceto	Newcastle University
Professor	Sarah	Banks	Durham University
Dr	James	Cummings	Newcastle University
Professor	Lilian	Edwards	Newcastle Law School
Professor	Catherine	Exley	Newcastle University
Dr	Gill	Haddow	University of Edinburgh
Professor	Julian	Hughes	University of Bristol
Dr	Neil	Jenkings	Newcastle University
Dr	Thomas	King	Royal Statistical Society
Dr	Christopher	Lawless	Durham University
Dr	David	Lawrence	Newcastle University
Dr	Mabel	Lie	Newcastle University
Professor	Susan	Lindsay	Newcastle University
Dr	Mavis	Machirori	Newcastle University
Dr	Joel	Minion	Newcastle University
Dr	Stephanie	Mulrine	Newcastle University
Dr	Daniel	O'Connor	Wellcome Trust
Professor	Michael	Parker	University of Oxford
Professor	Shaun	Pattinson	Durham University
Dr	Tim	Peel	Newcastle University
Dr	Gethin	Rees	Newcastle University
Dr	Stephanie	Roberts	Newcastle University
Ms	Katrina	Rose	Newcastle University
Dr	Peter	Selman	Newcastle University
Professor	Tracy	Shildrick	Newcastle University
Professor	Robert	Simpson	Durham University
Professor	Robert	Song	Durham University
Dr	Kenneth	Taylor	Newcastle University
Dr	Ilke	Turkمندag	Newcastle University
Dr	Matthias	Wienroth	Newcastle University

Policy  
Ethics  
And  
Life  
Sciences

