



Bioethicists as Advocates and Activists: Professional Boundaries and Commitments

PEALS 18th Annual International Symposium

19th – 20th September 2017

Great North Museum, Newcastle upon Tyne



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Introduction

Welcome!



Welcome to the 2017 PEALS International Symposium. We are very happy to be able to welcome you to Newcastle and to PEALS for what is our 18th annual symposium.

The 'PEALS tradition' aims to facilitate processes of exchange and dialogue, sharing diverse perspectives and bringing a critical and creative approach policy and practice. Each year, our symposia form an important part of that process. We aim to provide an open and friendly space in which to explore an ethical topic or theme, together with an invited group of speakers and participants from across

academic disciplines and a range of interests in (bio)ethics, policy making and professional practice within the life sciences.

This year's symposium will consider an increasingly topical question: **Is there a role for bioethicists in advocacy or activism in controversial areas of the life sciences?** Some recent cases have seen bioethics severely criticised both for *involvement* and *lack of involvement* in social and political activism, in contentious areas such as organ trafficking, surgical 'rectification' of intersex, or the role of healthcare professionals in torture and interrogation. Individual bioethicists can find themselves torn between demands for academic objectivity (and there is debate over what exactly that means), and political or personal commitments. The symposium aims to address questions such as:

- Can bioethical research be done at all without adopting defined ethical positions?
- To what extent does activism/advocacy blur the boundaries between personal, political and professional viewpoints?
- How should bioethics deal with perceptions of bias and/or conflicts of interest?
- Do bioethicists have a duty to engage more actively with social issues and problems, and if so what are its limits?
- What is the relationship between activism/advocacy and whistle-blowing?
- Do attitudes to bioethical advocacy have implications for opinions on conscientious objection?
- Are there risks for the academic who becomes an activist or advocate, for their institution, or for the field as a whole?

How can bioethicists and activists most effectively work together?

We are delighted to be able to bring together colleagues to engage with these important questions. We thank you for taking the time to join us in Newcastle as speakers, chairs and participants.

We are grateful to colleagues in the Policy, Ethics and Life Sciences Research Centre (www.peals.ncl.ac.uk) and the School of Geography, Politics and Sociology for their ongoing collegiality and general support. Special thanks to Tom Martin, Penny Kelly, Leeann Bewick for their patience, efficiency and professionalism. We would also like to thank Newcastle University for financial support to the symposium.

Bioethicists as Advocates and Activists: Professional Boundaries and Commitments

19 September 2017

Time	Theme	Speaker
12:00 – 13:00	Registration and buffet lunch	
13:00 – 13:15	Welcome and introduction	Jackie Leach Scully
13:15 – 14:45	Session 1: Inside academia	Chair: Erica Haines
13:15 – 13:45	The accidental activist	Wendy Rogers
13:45 – 14:15	Supporting families in court hearings concerning withdrawal of life-prolonging treatments	Celia Kitzinger
14:15 – 14:45	Discussion	All
14:45 – 15:15	Tea and coffee break	
15:15 – 16:45	Session 2: Costs and benefits of activism	Chair: Pauline McCormack
15:15 – 15:45	Taking on the Taliban: ethics of academia on the frontline	Ayesha Ahmad
15:45 – 16:15	Should junior academics be activists?	Greg Moorlock
16:15 – 16:45	Discussion	All
16:45 – 16:55	Concluding comments and organisation	Jackie Leach Scully
<i>Must leave venue by 17:00!</i>		
18:15 for 18:30	Dinner at Blackfriars Restaurant http://www.blackfriarsrestaurant.co.uk/	All

20 September 2017

Time	Theme	Speaker
09:00 – 09:30	Coffee on arrival and registration.	
09:30 – 11:00	Session 3: Activism in theory and practice	Chair: Madeleine Murtagh
09:30 – 10:00	Is there a place for activism in bioethics?	Simon Woods
10:00 – 10:30	Bioethics to the barricades!	Hilde Lindemann
10:30 – 11:00	Discussion	All
11:00 – 11:15	Tea and coffee break	
11:15 – 11:30	Symposium photograph	All
11:30 – 13:00	Session 4: Is input into governance and policy activism?	Chair: Matthias Wienroth
11:30 – 12:00	Reinventing the wheel all over again	Michaela Mayrhofer
12:00 – 12:30	<i>TBC</i>	Jonathan Montgomery
12:30 – 13:00	Discussion	All
13:00 – 13:45	Buffet lunch	
13:45 – 15:00	Session 5: Disability and activism	Chair: Joel Minion
13:45 – 14:15	Disability rights and wrongs: academic balancing acts (video)	Tom Shakespeare followed by reflections by Jackie Leach Scully
14:15 – 14:45	Disturbing the academic-activist relationship or working from 'inbetween' spaces? Reflections on the #JusticeforLB campaign	Sara Ryan
14:45 – 15:15	Discussion	All
15:15 – 15:30	Tea and coffee break	
15:30 – 16:15	Session 6: Final discussion and concluding comments	Heather Draper
16:15 – 16:45	Planning for the future	All who can stay

Presentation Abstracts

Session 1: Inside academia

Wendy Rodgers

The accidental activist

In academic bioethics, scholarship involves reflection, rigour and the embrace of complexity and uncertainty. Ethical nuances are identified and explored through elegantly crafted arguments that seek to elucidate morally compelling reasons to support particular positions. These values of scholarship seem to be in tension with being an activist which requires pragmatism, simplicity, certainty and above all, action. In this paper I explore this apparent dichotomy, using the case example of my own involvement in international efforts to end forced organ harvesting from prisoners of conscience in China. This experience has thoroughly blurred the lines between my academic work and activism, in both constructive and potentially concerning ways. It has also led me to a broader consideration of the responsibilities, risks and rewards of being an academic activist.

Celia Kitinger

Supporting families in court Hearings Concerning Withdrawal of Life-Prolonging Treatments

My research (jointly with sister/colleague Professor Jenny Kitinger, Cardiff University) on coma and disorders of consciousness arose out of our family experience after our sister, Polly Kitinger, was catastrophically brain-damaged in a car accident in 2009. We have now carried out around 100 interviews with family members of people in vegetative or minimally conscious states and used our research to inform and underwrite our very active engagements in activism/advocacy in this area. We used video-clips from our interviews to create an online multi-media resource (<http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/topics>), as a result of which more than a dozen families have contacted us support in bringing a case through the courts. We've treated our support for families as a form of 'ethnographic' research: it includes conversations with families before, during and after the hearing (a period of a year or more), visiting the patient, attending best interests meetings, reading minutes, medical documents, family statements and court position papers and attending the court hearing (and sometimes the subsequent funeral). We have fed back this experience (with permission from families and other participants) into the medical ethics literature as case studies. For two such cases (both open access in JME) see: (1) *Re S* case: <http://jme.bmj.com/content/early/2016/09/22/medethics-2016-103853.short?rss=1> (2) *Paul Briggs* case: <http://jme.bmj.com/content/early/2017/06/22/medethics-2016-104118?papetoc>

Issues I'll discuss include: our role as insider/outsider researchers; how we engage with notions of 'objectivity'; co-production with families and practitioners; strategies for social change in clinical and legal contexts; the difference between REF notions of 'impact' and our version of 'making a difference'.

Session 2: Costs and benefits of activism

Ayesha Ahmad

Taking on the Taliban: Ethics of academia on the frontline

In this presentation, I argue that academics working in areas of health and human rights are inherently engaging with structural and epistemic forms of inequality and injustice. I shall critically consider the absence of activism and advocacy is an ethical challenge. To illustrate my argument, I will discuss several reflections resulting from recent fieldwork and research in Afghanistan investigating gender-based violence and mental health.

My research is situated in a political discourse that fundamentally opposes and challenges ideologies such as those implemented on a governmental level during the Taliban regime in Afghanistan. My positionality as a woman of Muslim origin and an academic in the United Kingdom resulted in escapable juxtapositions and the necessary blurring of the boundaries between personal and professional viewpoints.

I will critically discuss the development of the research, with a view to the ethical challenges I faced in working with a local non-governmental organisation (NGO) and the risks and threats that I have experienced due to the nature of my work. I will argue that I have a moral obligation as an ethicist working in global health, with resources and expertise, to systematically develop my research questions and objectives in accordance with an end goal to tackle and deconstruct harmful ideologies and practices, in this case, towards girls and women in a society marred by the complexities of a conflict context.

Gregory Moorlock

Should junior academics be activists?

In this talk I will argue that there are good reasons for junior academics to restrict their involvement in activism during the early stages of their careers. I will suggest that there are several advantages to postponing one's involvement in activism until one has fully established one's academic career, and that there are both self- and other-regarding reasons for doing this. That many junior academics are on short, fixed-term contracts means that their current employment, and career more generally, is often precarious. I will argue that, although one may accept that bioethicists have a duty to be activists, it is permissible, and moreover prudent, for junior academics to prioritise those activities most likely to assist in obtaining employment security and reputation-building (and that this may exclude activism). I will then argue that engaging in activism before one has gained the reputation and credibility that comes with a more established academic career may risk undermining one's later attempts at effective activism. I will conclude that although my arguments may not provide reasons for junior academics to avoid activism completely, they suggest that junior academics should carefully consider the how focussing too much effort on activism may reduce their ability to be more effective activists later in their careers.

Session 3: Activism in theory and practice

Simon Woods

Is there a place for activism in bioethics?

The issue of activism has been prevalent in philosophy for millennia. Socrates went to his death charged with the corruption of Athenian youth by enabling them to think critically (surely a species of philosophical activism) and his devotee Plato believed that we would all be better off with a philosopher king. John Stuart Mill, one of the founders of utilitarianism, was also a noted social reformer and activist, arrested for his distribution of literature about contraception. Those who have visited the memorial to Karl Marx in Highgate cemetery will remember his claim that "Philosophers have only interpreted the world in various ways - The point however is to change it". What we now call bioethics itself emerged in that crucible of protest and activism for racial equality, women's health, disability rights, and HIV/AIDS activism that characterised the 60s, 70s and 80s. Peter Singer's book 'Animal Liberation: A New Ethics for Our Treatment of Animals' (1975) was a spur to the animal rights/ welfare movements and is credited with changing the thinking (and behaviour) of many people with regard to non-human animals. There is no question that moral deliberation ought to lead to better moral judgments and better action-guiding principles, and this is surely a form of activism.

However 'activism' as it is commonly understood usually requires campaigning, political lobbying, and even outright protest. So is there a potential conflict for academic bioethics scholars in terms of the virtues and values inherent in that role? Is there a moral obligation for academics to avoid commitments that might prevent them from performing their role as well as possible? For example, partisanship can bias one's thinking, and biased thinking may be in conflict with the role of academics to be impartial in their teaching and research. There is a genuine puzzle here: should bioethics scholars (such as academics with teaching and research roles within public universities) consider themselves obliged to remain neutral in their professional role or, on the contrary, are they actually obliged to become 'activists' as a consequence of performing their role?

Hilde Lindemann

Bioethics to the Barricades!

In this talk I begin with an anecdote about Frances Kamm as a way of exploring just exactly what activism entails. Are we talking about the kind of activism every citizen ought to engage in? Should we confine our topic to activism in health care settings? Just what is activism anyway, and how much and what kind ought bioethicists to engage in? Finally, I'll consider the possibility that it's perfectly permissible for bioethicists not to be activists of any kind.

Session 4: Is input into governance and policy, activism?

Michaela Mayrhofer

Reinventing the wheel all over again?

BBMRI-ERIC is a member state owned research infrastructure for biobanks and biomolecular resources which currently comprises of 20 members and growing. Its mission is to facilitate access to samples and data, which have been entrusted by patients, donors, research participants and citizens across Europe to advance biomedical research and ultimately clinical care. It collaborates with stakeholders from academia, industry and patient advocacy. It is interested to promote and achieve high standards in the quality of samples and data, cross-border research, public-private partnerships while implementing appropriate safeguards in data management and protection. The founding statutes of BBMRI-ERIC specify that it shall operate on a non-economic basis, be politically neutral and guided by the following principles: "pan-European in scope, combined with scientific excellence, transparency, openness, responsiveness, ethical awareness, legal compliance and human values." To address the ethical, legal and societal aspects of such a goal appropriately, a Common Service ELSI has been established and was operative over the last years. This presentation will provide an overview on the achievements and challenges of BBMRI-ERIC and its Common Service in the light of a transdisciplinary initiative where activism and policy setting are intertwined and require a high portion of reflection to remain true to its values.

Jonathan Montgomery

Governance as an activist response to terrorist bioethics

Session 5: Disability and activism

Tom Shakespeare

Disability rights and wrongs: academic balancing acts

Tom's contribution is by video: a short, personal piece about the experience of being a disability scholar and activist. **Jackie Leach Scully** will offer some reflections in response.

Sara Ryan

Disturbing the academic-activist relationship or working from 'inbetween' spaces?

Reflections on the #JusticeforLB campaign

The social media based #JusticeforLB campaign set out to gain accountability for the death of my son, Connor Sparrowhawk, in an NHS hospital in 2013. It cut across typical boundaries and silos, drawing together a diverse range of people and groups who do not necessarily have common interests. This included academic networks, self-advocacy groups, disability and human rights activists, learning disabled people, carers and families, journalists, patient safety campaigners and information specialists. Cross-cutting themes were generated including law,

Participant Biographies

Ayesha Ahmad is a philosopher with a PhD in medical ethics who is working in global health. She is a lecturer at St Georges University of London in Medical Ethics and Law, and an Honorary Lecturer at the Institute for Global Health, University College London. She specializes in the mental health and the humanities in the context of gender-based violence in conflict developing trauma therapeutic interventions using traditional storytelling in extreme situations such as Afghanistan. She is also a writer of poetry.

Heather Draper joined the University of Warwick in January 2017 to take up the newly established chair in Bioethics in Warwick Medical School. She has a broad portfolio of research interests ranging from the development of social robotics to humanitarian disasters and emergencies, through research ethics, ethics of parenting, military medicine and tissue and organ donation. She is a member of three local clinical ethics committees and also the Defence Medical Services Ethics Committee. For more information, see:

http://www2.warwick.ac.uk/fac/med/staff/h_draper

Erica Haimes is Emeritus Professor of Sociology, based in PEALS. 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 has also provided policy and practice guidance in the above fields through her memberships of: the Ethics and Governance Council for UK Biobank; 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- present) and through her appointment to the Nuffield Council on Bioethics (2013 - present). Erica was awarded the OBE in June 2017 for services to the social sciences.

Celia Kitzinger is a Professor and scholar-activist, for whom academic research and social change are inextricably linked. She has also had a long-standing interest in qualitative methodologies and has explored the ways in which the researcher's own 'insider' or 'outsider' status influences theory, data and analysis; different perspectives on data analysis and 'objectivity'; and the role of the 'personal' in understanding the social world.

Hilde Lindemann is Emerita Professor of Philosophy and Associate in the Center for Ethics Humanities in the Life Sciences at Michigan State University. A Fellow of the Hastings Center and a past president of the American Society for Bioethics and Humanities, her ongoing research interests are in feminist bioethics, feminist ethics, the ethics of families, and the social construction of persons and their identities. Her most recent book is *Holding and Letting Go: The Social Practice of Personal Identities*. Earlier books include *An Invitation to Feminist Ethics* and *Damaged Identities, Narrative Repair*. With James Lindemann Nelson, she also wrote *The Patient in the Family: An Ethics of Medicine and Families*. She is the former editor of *The Hastings Center Report* as well as of *Hypatia: A Journal of Feminist Philosophy*. She was the coeditor of Rowman & Littlefield's Feminist Constructions series and the general coeditor (with James Lindemann Nelson) of the Reflective Bioethics series at Routledge.

Michaela Th. Mayrhofer is a political scientist and historian educated in Vienna, Louvain-la-Neuve, Essex and Paris. In 2010, she has earned her PhD from both the Ecole des Hautes Etudes en Sciences Sociales and the University of Vienna. Furthermore, she is a Research Fellow at the IFZ and Member of the Editorial Board of the Austrian Journal of Political Science (ÖZP). She served as investigator in several national and international research projects focusing on the politics of biotechnology and the life sciences. Her current role within BBMRI-ERIC is Chief Coordination Officer/Chief Policy Officer of the Common Service ELSI.

Pauline McCormack is a Senior Lecturer 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. 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.

Joel Minion initially completed postgraduate degrees in both anthropology and information science before working for many years as a librarian in Canada. He then moved to the UK to complete a PhD in qualitative health informatics at the University of Sheffield in 2010. After this, Joel worked at the University of Leicester on a study into patient safety and quality of care in the NHS, before joining the Data to Knowledge group to focus on sociotechnical aspects of health data and knowledge translation. His current research involves use of ethnographic methods to study data sharing, governance and participant engagement in longitudinal cohort studies.

Agomoni Ganguli Mitra is Chancellor's Fellow in Legal and Ethical Aspects of Biomedicine and Co-director of the JK Mason Institute for Medicine, Life Sciences and the Law. She is a bioethicist with an interest in issues related to global justice, gender justice and global health. Most recently, she has been working on global surrogacy, global health emergencies, and the concepts of exploitation and vulnerability in bioethics.

Jonathan Montgomery is Professor of Health Care Law at University College London, and Chair of the Health Research Authority. A former Chair of the Nuffield Council on Bioethics, he was appointed as a member of the new European Group on Ethics in Science and New Technologies in 2017.

Greg Moorlock is a bioethicist based at the University of Warwick. His research to-date has focused primarily on organ donation and transplantation ethics. He is also interested in activism, particularly in relation to obesity/fat acceptance, and transplantation.

Madeleine Murtagh is newly appointed Professor in Sociology at PEALS. Madeleine began her academic career in Australia studying sociology, anthropology and public health and examining how people interact with and make decisions about using new health treatments and technologies. She leads ethnographic research examining (and interfering in) practices of (open) data science in health (particularly in longitudinal cohort studies and biobanks). She conducts social studies of sociotechnical and normative practices in data sharing and data governance as well as taking part in developing new practices in the context of transdisciplinary research teams.

Christoph Rehmann-Sutter is Professor of Theory and Ethics in the Biosciences at the University of Lübeck / Germany. His first training was in molecular biology and he subsequently studied philosophy and sociology, specialising in bioethics. Together with Jackie Leach Scully he established the Unit of Ethics in the Biosciences at the University of Basel/Switzerland and led a series of funded research projects that combined philosophical analysis with qualitative empirical methodology. From 1997-1998 he was Research Fellow at the Department of Environmental Science, Policy and Management, University of California at Berkeley, and from 2001-2009 he was president of the Swiss National Advisory Commission on Biomedical Ethics, elected by the Swiss government. He is currently president of the European Society of Philosophy, Medicine and Healthcare ESPMH and visiting professor at King's College, London. Research interests include phenomenology and hermeneutics in ethics, philosophical issues of genomics and prenatal genetics, and end-of-life issues, in particular palliative care patients' wishes to die.

Wendy Rogers is Professor of Clinical Ethics at Macquarie University, Sydney. Her current research, funded by the Australian Research Council, investigates conceptual and practical issues to do with overdiagnosis. More broadly, her research interests include feminist bioethics, governance of research ethics, vulnerability, and ethics of surgical research and practice. Over the past two years, she has become an activist seeking to end forced organ harvesting from prisoners of conscience in China. She is the inaugural chair of the International Advisory Committee of the International Coalition to End Organ Pillaging in China.

Sara Ryan is a senior research lead in the Health Experiences Research Group, Nuffield Department of Primary Care Health Sciences, University of Oxford. A sociologist by background, her work focuses on disability, autism and, more recently, pets and health.

Ted Schrecker is Professor of Global Health Policy in the Institute of Health and Society, Newcastle University. He is a political scientist by background, and moved from Canada to take up a position at Durham University in June 2013 before transferring to Newcastle University. His research interests focus on the political economy of health inequalities, neoliberal globalisation, and issues at the interface of science, ethics, law and public policy. Earlier in his working life, he spent many years involved with environmental policy and law as a legislative researcher, academic and consultant.

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, the Netherlands Institute of Human Rights at Utrecht University, and Humboldt University, Berlin. Her research interests are in disability bioethics, feminist bioethics, new reproductive and genetic technologies, forensics, humanitarian bioethics, public bioethics, and identity. She is Editor in Chief of the *International Journal of Feminist Approaches to Bioethics (IJFAB)*.

Tom Shakespeare is a sociologist and bioethicist, currently Professor of Disability Research at the University of East Anglia. His books include *Genetic Politics: from Eugenics to Genome* and *Disability Rights and Wrongs*. He has been involved with the disability movement for 30 years.

Ellen Stewart is a social scientist working at the intersection of medical sociology, health policy and public administration. She studies how health systems accommodate and negotiate different forms of 'lay' and 'expert' knowledge, including demands for public engagement and for evidence-based policy. She currently holds a CSO Chancellor's Fellowship in the Usher Institute at the University of Edinburgh and her monograph, *Publics and their Health Systems: Rethinking Participation* was published in 2016.

Matthias Wienroth is RIF Researcher at PEALS. In my work I attend to science and technology as social practices. I am particularly interested in studying disciplinary, cross-disciplinary and cross-boundary knowledge production and organisation, their social and ethical aspects, and issues of governance. In current projects I focus on innovations in genetics and genomics, study debates about the social compatibility of novel genetic/genomic technologies and data, and engage in ethical deliberation with scientific practitioners and decision-makers.

Simon Woods is Reader in Bioethics and Deputy Director of the Policy, Ethics and Life Sciences Research Institute (PEALS www.ncl.ac.uk) at Newcastle University. Simon holds bachelor and doctoral degrees in philosophy, and over the past 17 years he has pursued a career of teaching and research within bioethics with a strong trend towards empirically informed bioethics. Simon's longstanding interest in medical ethics and bioethics more broadly developed from his earlier career as a cancer nurse. His earlier research focused upon palliative and end of life care but went on to develop a research portfolio exploring the social and ethical aspects of new and emerging biotechnologies. Simon has been involved in several major international research projects that have posed important questions about research ethics and patient representation. Several projects had a specific focus on rare disease genomics in which issues related to research governance and data sharing as well as the participation of children (and families) have been central. Simon has a strong interest in the ethics and regulation of bioscience research; he has been a member and vice-chair of NHS research ethics committees and is currently a member of the Health Research Authority's National Ethics Advisors' Panel.