

PAPER PROPOSAL FOR THE 5TH ANNUAL CONFERENCE FOR THE CENTRE FOR THE STUDY OF GLOBAL ETHICS: BODIES AND EMBODIMENT

ABSTRACT

Title: The embodied research participant: interests beyond interventions

Research topic

This paper proposes that the embodied interests and identities of participants in health research risk being overlooked where the research in question utilises data or stored tissues, rather than direct contact with participants' bodies. It argues that recognising the potential role of embodiment in the choices and experiences of participants is vital to ensuring ethical approaches to governing data- and tissue-based research, and to the protection of participants' interests in particular.

Method and context

The central conceptual and analytical framework on which this paper draws is one in which our self-conceptions are understood as constituted by our embodied narratives of who we are. From this foundation, the potential contribution, value and risks of research participation to our self-narratives is articulated. As such, this work is a bioethical inquiry, and contributes to wider debates about the changing nature of health research and what this means for the shifting roles, identities and responsibilities of participants and researchers.

Argument and implications

While it might be obvious how the embodied experiences of participants can be relevant to ethical research practices in studies that involve physical interventions or examination of participants' bodies – for example, taking tissue samples or administering drugs – it may be less obvious how or why they are pertinent to studies that do not. Yet, increasingly, health research involves analysis of vast datasets, biobanks and secondary uses of data collected for other purposes. The line between patient and participant is also increasingly becoming blurred, for example, where health services use genomic testing to aid diagnosis and care, while also seeking to use the results for research.

This paper identifies some of the ways that individuals' embodied experiences and conceptions of who they are may be implicated in, and impacted by, these kinds of 'research without intervention'. It further sets out what this could entail in terms of the expectations and interests of participants, the roles and ethical obligations of researchers, and the nature of the research relationship.

It is proposed that some of the ways in which research participants' embodied experiences and interests might be engaged by data- and tissue-based research include: the possibility that participation, especially in genomic research, could provide a means of enacting biological relationships and associated responsibilities; perceptions of the use of materials sourced from one's body in research as the implication of the self in (un)ethical projects; and instances in which the value of individual research findings to participants lies in their contribution to a self-conception that supports the individual in navigating their embodied existence.

This paper concludes by outlining some of the responsibilities that may accrue to researchers as a result. These include: recognition that several of the existing ethical norms of research practice, such as one-off consent, and reliance on anonymisation, may not be sufficient to protect embodied interests that follow tissues and data on their research journeys; and a possible role for researchers as 'interpretive partners', supporting participants in understanding how research findings may (or may not) provide useful tools for make sense of their embodied experiences.

KEYWORDS: health research; research participation; identity; narrative; data

AUTHOR INFORMATION

Dr Emily Postan

Early Career Fellow in Bioethics

Edinburgh School of Law & The Mason Institute for Medicine, Life Sciences and the Law, The University of Edinburgh

e.postan@ed.ac.uk

07970 963 610

BIOGRAPHY

Emily Postan is an Early Career Fellow in Bioethics at Edinburgh School of Law at the University of Edinburgh and a Deputy Director of the *JK Mason Institute for Medicine, Life Sciences and the Law*. She is a researcher on the Wellcome Trust project *Liminal Spaces in Health Research Regulation*. Her field of research is interdisciplinary bioethics and her background is in philosophy and policy management. She was awarded her PhD by The University of Edinburgh for her thesis '*Defining Ourselves: narrative identity and access to personal bioinformation*' in 2017. Prior to her doctoral research she worked in policy roles at the Scottish Government in the fields of public health and environmental policy. She was project leader and co-author of the Nuffield Council on Bioethics 2013 report '*Novel Neurotechnologies: intervening in the brain*'. Emily's main research interests are: the role of identity interests in bioethical debates; narrative identity theory; health research ethics, particularly the role of consent, the relationship between researchers and participants and the disclosure of research findings; neuroethics; the ethics of assisted reproductive technologies and personal genomics; conscientious objection in healthcare; and public health ethics.