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# What constitutes ‘ethical’ research for people with PMLD? A call for reader responses

Ben Simmons, Stuart Read, Anne Parfitt, and Tanvir Bush

In this paper we discuss what constitutes ethical research for people with profound and multiple learning disabilities (PMLD) We describe the work of university ethics committees and suggest that people with PMLD and those involved in their care and support have not been given due consideration in mainstream research ethics regulations. Readers are invited to share their thoughts about what an ethical research project looks like for people with PMLD.

## What is research?

Whilst the meaning of ‘research’ has been debated, it is commonly defined as the process by which we develop and share new insights of relevance to society (HEFCE et al., 2011, OECD, 2015). These insights are vast in range and might include discoveries such as about how the brain works, the development of pharmaceutical treatments to improve mental health, and the advancement of technology in neonatal incubators. Such medical research is high-profile in the UK, and the public imagination is captured through calls for donations (e.g. through cancer research TV adverts) and celebrations of drug trials in the media (e.g. the Guardian’s 2022 article describing the latest Alzheimer’s drug hailed as ‘historic moment’).

Medical research is important, but it is just one field of inquiry, and universities serve to develop insights into a range of topics that can benefit society. For example, social science research can evaluate approaches to improving how hospital staff communicate with patients who cannot use speech, or develop insights into parental opinions on controversial topics such as sex education in special schools. Humanities research can uncover the historical reasons why people with learning disabilities were placed in institutions, while arts research can produce artefacts that tell stories about disability activism. Regardless of the topic being explored, all research is bound by principles of ethics. But, what does it mean for a project to be ethical?

## What are research ethics?

The word ‘ethical’ is sometimes used in our society to indicate whether or not something is morally right. For example, businesses such as shops and restaurants sometimes claim to ethically source their products. This can mean a number of things. It can mean that the products are not tested on animals, that the people who

make products have fair working conditions and are not victims of modern slavery, and that the creation and transportation of products are environmentally friendly. The reputation of some high street businesses revolves around the extent to which they are ethical – ethics are the core of their ‘brand value’.

UK universities pride themselves on conducting ethical research, and each project has to be approved by a Research Ethics Committee before data collection begins. Whilst the process can vary from project to project, it typically involves a researcher writing an ethics report that outlines the design of the study (e.g. who will be involved, how the data will be collected, analysed and stored, how risks to participants will be mitigated, etc). The job of a Research Ethics Committee is to decide whether a project can go ahead, or whether it should be modified to satisfy research regulations. This is an important process as it serves to ensure that all projects minimise risk of harm to both participants and the researcher.

The need for research ethics approval emerged against a backdrop of – quite frankly – dreadful studies that showed little care for the lives of participants. Textbook examples of unethical research include the Tuskegee Study which investigated the long-term effects of untreated syphilis on 600 African American patients. During the Tuskegee Study, diagnosis and treatment was deliberately withheld from the patients so that researchers could study the progression of syphilis over time (CDC, 2021). Examples such as this led to the creation of formal scientific ethical guidelines such as the Belmont Report (1978), and over the last forty years a plethora of regulations and guidelines have been published to minimise harm during the research process.

### How are research ethics contested?

On the surface, research ethics appear straightforward. The principle of minimising harm to research participants intuitively feels like the right thing to do. However, when we scratch beneath the surface to examine real world examples, we realise that ethical decisions are complex and problematic. For example, informed consent is often seen as a benchmark of an ethical project. Informed consent means that the participants know exactly what they are signing up for, that they can read and understand a research project information sheet (which may consist of technical or legal jargon), and consent to participate by signing a form. Whilst some participants are very capable of reading and signing such documents, it is not altogether clear how people with PMLD can participate in this process. For people with PMLD under the age of 16, a parent or guardian can sign a consent form. Even though this may satisfy a university's Research Ethics Committee, it completely overlooks the wishes of people with PMLD. For researchers who deny that people with PMLD have any perspective on participating in projects, this may not be an issue, but for others who seek to honour the agency and experiences of people with PMLD this is simply not good enough and dehumanises the 'participants' of research. An alternative model is to seek what is known as 'assent', that is, to honour the expressions of approval and agreement provided by people with PMLD during the research process, even though they cannot legally consent to participate. However, whilst informed consent is almost universally acknowledged as a benchmark of ethical research, the processes by which we seek assent is neither regulated nor universally acknowledged, resulting in inconsistent ethical practices.

What the example above demonstrates is that a cornerstone of ethical research – seeking informed written consent – is not a process which all groups can participate in. Does this mean that research should only include participants who are literate? Should research focus only upon those who have the privilege of being fluent in written language? We argue that this would result in a narrow body of knowledge that only reflects privileged groups. As readers may recognise, this problem extends beyond people with PMLD. It might, for example, exclude people whose first language is not English, or parents without a university degree who are less familiar with the jargon of higher education. One solution to the problem is to simplify the language used in project information sheets and consent forms, such as through use of 'easy read', accessible materials. While simplifying language may go some way to redressing barriers, it still leaves unaddressed how people with PMLD can participate in the process.

Research ethics become even more complex when we take into account the different philosophical positions that inform debate. One branch of ethics is 'deontological ethics', which means that there are universal ethical principles or rules for everyone about what is right and wrong. Informed written consent is currently one of these rules - everyone should be able to read information and decide whether or not they want to participate in research. A contrasting position is consequentialist ethics. Consequentialism holds that we should not follow general rules (an ethical code of conduct), but instead design studies based on whether or not they will result in good outcomes for the groups under investigation. If people with PMLD were participating in research then the research should benefit the participants directly, or people with PMLD more generally. A third ethical position is relational ethics. According to Ellis (2007) relational ethics requires that researchers are not objective in their research but act from their 'hearts and minds' (p. 3), that they acknowledge interpersonal bonds and take responsibility for actions and their social consequences. Research informed by relational ethics 'recognizes and values mutual respect, dignity, and connectedness between researcher and researched, and between researchers and the communities in which they live and work' (Ibid, p. 4). This kind of research has been influential where participants are judged to be vulnerable, or in contexts where the responsibility of caring is already prioritised, such as nursing research (Hammersley and Traianou 2012). Instead of prioritising informed consent, which is an agreement that takes place before the research takes place, relational ethics suggests that researchers maintain a good relationship with participants during and after the research. What these different philosophical positions on ethics ultimately demonstrate is the complexity of ethical decisions, and how researchers should be mindful of a range of issues that cannot always be prescribed in advance. For people with PMLD, it means we have to consider not simply formal rules, but the perceived benefits of the research as well as the relationships that develop during the course of a project. Given the lack of research about what constitutes an ethical project for people with PMLD, we invite readers to get in touch and help shape ethical debates.

### Call for reader responses

As a research group, we agree that all research projects should obtain research ethics approval and minimise risk of harm to participants and society at large. However, research ethics guidelines are typically created by universities and professional bodies rather than the research participants themselves. In other words, academic organisations decide what constitutes an ethically or morally right research project, at the expense of listening to people who are the actual subjects of research (i.e. the people being researched). Modern

research ethics takes the non-disabled experience to be the norm, and by doing this, devalues the interests of the people who are the subjects of research, including people with PMLD. We wish to flip the narrative here. We call on readers to think about what would constitute an ethical research project for people with PMLD and those involved in their care. As a research team, we cannot abandon university ethics, but we can enrich it by creating a code of practice that reflects the values of the communities we engage with, such as people with PMLD. We invite readers to engage in this debate and we welcome emails on the topic. What do you think an ethical PMLD research project involves? What should we do to make a project more ethical, and what should we avoid? Is it enough to simply minimise risk, or does all research involve an element of risk? If you have any questions, suggestions, disagreements and comments, please get in touch with us - we welcome all opinions on this controversial topic.

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### References

- CDC (2021) *The Tuskegee Timeline*. Retrieved from <https://www.cdc.gov/tuskegee/timeline.htm#print> 07/10/2022
- DoHEW (1979) *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. Retrieved from <https://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/read-the-belmont-report/index.html> 07/10/2022
- Ellis, C. (2007) Telling Secrets, Revealing Lives: Relational Ethics in Research With Intimate Others. *Qualitative Inquiry*, 13(1), 3–29.
- Guardian (2022) Success of experimental Alzheimer's drug hailed as 'historic moment'. Retrieved from <https://www.theguardian.com/society/2022/sep/28/alzheimers-disease-progression-slowed-by-new-drug-lecanemab> 07/10/2022
- Hammersley, M. and Traianou, A. (2012) *Ethics in Qualitative Research: Controversies and Context*. London: Sage.
- HEFCE (2011) REF 2014: *Assessment framework and guidance on submissions*. HEFCE, Stoke Gifford
- OECD (2015) *Frascati Manual 2015: Guidelines for Collecting and Reporting Data on Research and Experimental Development, The Measurement of Scientific, Technological and Innovation Activities*, OECD Publishing, Paris

## Get Involved

All contributions to our journal PMLD Link are welcomed. Share your ideas about future topics for the journal or make suggestions of authors we might approach. If you want to write for us yourself, it's easier to get your experiences and thoughts into print than you might think. We also welcome shorter items about new resources, books, websites, events, courses or news in general.

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