



The Lives of People with Profound and Multiple Learning Disabilities in the UK

Short Information Sheet

Thank you for your interest in taking part in the 'Lives of People with Profound and Multiple Learning Disabilities in the UK' study.

Who are we?

We are a team of researchers from the University of Birmingham, Manchester Metropolitan University, the University of South Wales, the University of Glasgow, and Queens University Belfast and we have partner with PAMIS, the All Wales Forum, Positive Futures and Learning Disability England. This research is funded by the Baily Thomas Charitable Fund.

What is this survey about?

This survey is designed to help us understand the unique needs of people with profound and multiple learning disabilities (PMLD) aged 14 or older, and the needs of their carers. Carers must be 18 years of age, or older, to take part. The survey may take up to 45 minutes to complete, and you can stop for breaks at any time and return, using the same link, to where you left off. If you change your mind about taking part, you can stop and exit the survey. Everyone who completes the survey will be offered a chance to be included in a prize draw, and ten winners will each receive a £50 gift voucher. The draw will be held when the survey is finished.

How will your information be stored and how will we look after it?

Your data will be managed at the University of Birmingham and stored on a secure password protected server for 10 years. The University never sells personal data to third parties.

The only instance in which we may have to breach confidentiality is if you were to disclose that you or somebody else was at risk of harm. In this circumstance, we would have a legal responsibility to pass this information on to appropriate services. Where possible, we would endeavor to discuss this with you first and ensure you are aware of available support services.

Who can I contact about this study?

If you have any questions about the research, please contact

Dr Peter Mulhall, pmld-survey@contacts.bham.ac.uk

If you have any comments or concerns about the research you can talk to the Principal Investigator:

Professor Jill Bradshaw (j.bradshaw.2@bham.ac.uk).

If you want to complain about the research, you can contact:

The Ethics Team (uobstudyoversight@contacts.bham.ac.uk).

