

University of Birmingham Privacy Policy for a study “The lives of people with Profound and Multiple Learning Disabilities (PMLD) in the UK.”

This Privacy Notice outlines how the University of Birmingham will collect, use and manage your personal information in accordance with data protection law.

The University of Birmingham is registered as a ‘Data Controller’ under registration number **Z6195856**

You may contact the University’s Data Protection Officer at:

Legal Services
The University of Birmingham
Edgbaston
Birmingham
B15 2TT

dataprotection@contacts.bham.ac.uk

The type of personal information we collect:

The University will collect and process the following information:

- *Name*
- *E-mail address*
- *Gender, Age, Employment status*
- *Postcode, Type of area- rural or urban*
- *Relationship to person with learning disabilities, Who the person with learning disabilities lives with, Postcode of where the person with learning disabilities lives, their age and gender, information about their disabilities.*
- *Ethnicity*
- *Views and experiences regarding various aspects of life for people with Profound and Multiple Learning Disabilities in the UK (including life since COVID, service provision, and social and emotional wellbeing)*

How we get your personal information and why we collect it

Most of the personal information we process will be provided to us directly by you for one of the following reasons:

- **Name, Email Address,** - We will use these data points to identify and contact you during the research study.
- **Demographic information:** (Gender, Age, Employment status, Postcode, Type of area- rural or urban, Relationship to person with learning disabilities, Who the person with learning disabilities lives with, Postcode of where the person with

learning disabilities lives), *their age and gender, information about their disabilities*. We will use this to ensure that we have a representative sample of people taking part in the study .

- **Role and ethnicity** – We will use this to ensure that we have a representative sample of people taking part in the study. For example, we would specifically like to hear from people with PMLD from racially minoritised groups.
- Under the General Data Protection Regulation (GDPR), the lawful basis we rely on for processing this information is the performance of a public task and the legal basis for processing special category health and ethnicity data is for research and statistics under Article 9(j) of UK GDPR.

What is our legal basis for processing your data?

The legal justification we have under data protection law for processing your personal data is that it is necessary for our research, which is a task we carry out in the public interest. The legal basis for processing special category health and ethnicity data is for research and statistics under Article 9(j) of UK GDPR. These data will not be used to make decisions about you.

This condition is met as the research:

- (a) is necessary for archiving purposes, scientific or historical research purposes or statistical purposes,
- (b) is carried out in accordance with Article 89(1) of the GDPR (as supplemented by section 19), and
- (c) is in the public interest.

How we store your personal information

The University takes great care to ensure that personal data is handled, stored and disposed of confidentially and securely. Our staff receive regular data protection training, and the University has put in place organisational and technical measures so that personal data is processed in accordance with the data protection principles set out in data protection law.

The University has an Information Security Management System based on ISO27001 with a range of controls covering the protection of personal information. Annual security awareness training is mandatory for staff and the University is accredited under the NHS Information Governance Toolkit, the Payment Card Industry Data Security Standard and is in the process of gaining Cyber Essentials Plus for defined services.

Your information will be securely stored at the University of Birmingham on an electronic data server. We will store your personal data (name and contact details) separately to your survey response data.

How long will my personal data be kept?

Your data will be retained for will be stored and archived for 10 years following the closure of the study in accordance with the University's research data retention period. If you withdraw from the project, we will keep the information we have already obtained but, to safeguard your rights, we will delete your personally identifiable data if requested.

We will not transfer your personal data outside the UK.

Who will my personal data be shared with?

Your personal data will only be accessible to the study team at Birmingham University. We will not share your data with other universities or third parties.

Sometimes, external organisations assist us with processing your information, for example, in providing IT support. These organisations act on our behalf in accordance with our instructions and do not process your data for any purpose over and above what we have asked them to do. We make sure we have appropriate contracts in place with them to protect and safeguard your data.

Your rights in relation to your data:

Under data protection law, you have rights including:

Your right of access - You have the right to ask us for copies of your personal information.

Your right to rectification - You have the right to ask us to rectify personal information you think is inaccurate. You also have the right to ask us to complete information you think is incomplete.

Your right to erasure - You have the right to ask us to erase your personal information in certain circumstances.

Your right to restriction of processing - You have the right to ask us to restrict the processing of your personal information in certain circumstances.

Your right to object to processing - You have the the right to object to the processing of your personal information in certain circumstances.

Your right to data portability - You have the right to ask that we transfer the personal information you gave us to another organisation, or to you, in certain circumstances.

Your right to withdraw consent- You have the right to withdraw your consent to be part of the research in line with the information provided in the PIS and consent form.

You are not required to pay any charge for exercising your rights. If you make a request, we have one month to respond to you.

Please contact the University's Data Protection Officer if you wish to make a request at:

Legal Services, The University of Birmingham
Edgbaston
Birmingham
B15 2TT

dataprotection@contacts.bham.ac.uk

If you would like more information on your rights, would like to exercise any right or have any queries relating to our processing of your personal data, please contact:

The Information Compliance Manager

Legal Services, The University of Birmingham
Edgbaston
Birmingham B15 2TT

Email: dataprotection@contacts.bham.ac.uk

Telephone: +44 (0)121 414 3916

If you wish to make a complaint about how your data is being or has been processed, please contact our Data Protection Officer.

Dr Nicola Cárdenas Blanco

The Data Protection Officer
Legal Services, The University of Birmingham
Edgbaston
Birmingham B15 2TT

Email: dataprotection@contacts.bham.ac.uk

Telephone: +44 (0)121 414 3916

You also have a right to complain to the Information Commissioner's Office (ICO) about the way in which we process your personal data. You can make a complaint using the ICO's website.

You can also complain to the ICO if you are unhappy with how we have used your data.

The ICO's address:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire

SK9 5AF

Helpline number: 0303 123 1113

ICO website: <https://www.ico.org.uk>