

NORTHERN IRELAND CEREBRAL PALSY REGISTER PRIVACY NOTICE

The Northern Ireland Cerebral Register (NICPR) and Queen’s University Belfast (“we”, “us” and “our”) are committed to protecting your personal data. The notice is addressed to people who have been notified to the NICPR and their parents/guardians (“you” and “your”). This Privacy Notice tells you why we need to collect personal information about you, what we will do with it, and how we will look after it. It also tells you about your legal rights in relation to your Personal Data. If you have any questions about this privacy notice, please contact us. Contact details are provided below.

WHO WE ARE

1. The Northern Ireland Cerebral Palsy Register (NICPR) is a confidential record of children with cerebral palsy (CP) in Northern Ireland since 1977. It is held at Queen’s University Belfast and is funded by the Public Health Agency (PHA).

HOW YOUR PERSONAL DATA IS COLLECTED

2. **Information you may provide:** When providing public health services we will ask for information about you, such as your name, address, DOB, health and care number, etc. This is known as your “Personal Data”. We may also ask you for some other information (for example details about your birth, your walking, hearing, speech, as well as other health related data). This is known as your “Sensitive Personal Data”.
3. **Data from other sources:** We also collect information about you from other sources such as from healthcare professionals that know you. This information also forms part of your “Personal Data” and “Sensitive Personal Data”.

HOW WE USE YOUR PERSONAL DATA

4. We use your Personal Data and Sensitive Personal Data in the following ways:

We use only use your personal data in special circumstances such as at the request of your (child’s) consultant/healthcare professional. Your personal data is linked to your sensitive personal data using a confidential code. The sensitive personal data is stored using the confidential code and is only used for research, reports, and resource planning. The data we collect will also be used to help provide information for local services, such as parent support groups and voluntary agencies.

We do not retain your address and so will not contact you directly. If we are asked to contact you about an ethically approved research project that you may be eligible to participate in, we will contact your healthcare professional and ask them to pass the information to you.

LEGAL BASIS FOR COLLECTING AND USING YOUR PERSONAL DATA

5. We will only use your Personal Data if we have valid reasons for doing so. These reasons are known as our “legal basis for processing”. There are circumstances where we have a legitimate interest to process your personal data. The lawful basis for processing your Personal Data is known as ‘public task’. That means we are using personal information to carry out tasks in the public interest. Our lawful basis for processing your sensitive data (including health information) is for ‘archiving purposes in the public interest, scientific or historical research purposes or statistical purposes. These tasks include making sure the NICPR is accurate and

monitoring how CP changes over time to help inform service development and delivery in Northern Ireland.

WHO WE SHARE YOUR DATA WITH

6. In line with our Data Protection Policy and Procedures we can share your information, including Personal Data and Sensitive Personal Data as follows:
 1. Personal information is only released to your (child's) medical clinician or the professional who notified your child to the NICPR, and only if they request it.
 2. Occasionally we receive information requests from clinicians and consumers for service improvement and research purposes. Requests for access to information for research purposes must be approved by the Research Subgroup of the NICPR's Advisory Committee and must obtain appropriate ethical and governance approvals.
 3. On an annual basis we transfer data to the Surveillance of Cerebral Palsy in Europe network to enable participation in programmes of work funded by the European Union. All information is anonymised and securely transferred using a password protected online system. The Surveillance of Cerebral Palsy in Europe privacy notice can be found here: <https://ec.europa.eu/dpo-register/detail/DPR-EC-01972>

7. DATA PROCESSING OUTSIDE EUROPE

We will not transfer your Personal Data and Sensitive Personal Data outside of the European Economic Area.

HOW LONG YOUR INFORMATION WILL BE KEPT

8. We will keep your Personal Data and Sensitive Personal Data for up to 5 years from the end of existence of the register. We will only keep your information for one of the reasons described above.

We place great importance on the security of the Personal Data that we hold. We use physical, technological and organisational measures to ensure your information is protected. These measures include secure, restricted access computer files, regular back-up of files to a separate secure location, offices within a secure facility that has 24 hour camera surveillance and restricted access.

YOUR RIGHTS

9. The Data Protection Act 2018 provides you with a number of legal rights in relation to your Personal Data, including the right:
 - to request access to your Personal Data;
 - to request correction of your Personal Data that is wrong or incomplete;
 - to request erasure or the restriction of processing of your Personal Data;
 - to request the transfer of your Personal Data in a structured; commonly used machine-readable format;
 - not to be subject to automated decision making; and
 - to withdraw your consent.

10. If you wish to exercise any of the rights set out above, or require further information about any of the rights, please contact us.
11. Where we need to collect your Personal Data, whether for the purposes of providing a service you have requested or under the terms of a contract we have with you, and you fail to provide that information when requested, we may not be able to provide the service or perform the contract. We may, therefore, have to cancel the contract or the service we provide to you but we will notify you if this is the case at the time.
12. There may also be times where we cannot stop using your Personal Data when you ask us to, but we will tell you about this if you make a request.

CONTACTING US

13. If you have any questions or comments about this privacy notice, the University's Data Protection Officer can be contacted at:

Derek Weir
Data Protection Officer
Registrar's Office
Lanyon South
Queen's University Belfast
University Road
BT7 1NN
info.compliance@qub.ac.uk

COMPLAINTS

14. You have the right to complain about how we treat your Personal Data and Sensitive Personal Data to the Information Commissioner's Office (ICO). The ICO can be contacted at:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

CHANGES TO THIS NOTICE

15. We may update this Privacy Notice from time to time. Any changes will be posted on our website