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## Information Sheet: Queensland Cerebral Palsy Register

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## What is the Queensland Cerebral Palsy Register?

The Queensland Cerebral Palsy Register (QCPR) is a secure, web-based database of information about the population of people with cerebral palsy in Queensland. Population databases such as the QCPR are vital for important public health and related research. Information collected includes birth details, type and severity of cerebral palsy, other associated impairments, and family details. By joining the QCPR, you will assist us to find better interventions, identify the causes and prevention of cerebral palsy, and achieve better services.

## What is the Australian Cerebral Palsy Register?

The Australian Cerebral Palsy Register (ACPR) is a central database of information uploaded (every two years) from the CP Registers in each state and territory from which names and contact details have been removed. The ACPR is managed and hosted by Cerebral Palsy Alliance in Sydney. It provides a national overview of cerebral palsy and generates reports to compare trends between states and across the country as a whole.

## What do you need to do?

We are asking parents of children with cerebral palsy who live in or access services in Queensland, to agree to their child's information being included on the QCPR. Cerebral palsy affects everyone differently and it is therefore our aim to include as many people as possible on the QCPR.

## What will happen to the information about my child?

If you consent to participate, this will create a confidential registration for your child on the QCPR database. The type of information being collected includes:

- Name, gender, date of birth, address, and birth details (e.g., birthweight, gestational age at birth, admission to intensive care at birth or not)
- Type (e.g., hemiplegia) and severity of cerebral palsy
- Findings of any MRI investigations, cause of cerebral palsy if known
- Other associated problems (e.g., vision, hearing impairments) and
- Parent demographics (e.g., date of birth and country of birth) and person responsible contact details (e.g., email address) if available.

## **What do I have to do for my child's information to be included on the QCPR and the ACPR?**

Agreeing for your child's information to be included on the Registers is completely voluntary, and if you decide not to participate, this will not affect you or your child's relationship with any of the affiliated organisations.

If you agree to participate, you can provide consent and then share information about your child by completing and returning the questionnaire either: 1) online (<http://www.qcpr.org.au>); 2) via email ([cpregister@cpl.org.au](mailto:cpregister@cpl.org.au)); 3) via a phone call with QCPR staff, (07) 3358 8026; or 4) via mail (CP Register PO BOX 387 Fortitude Valley QLD 4006). Additionally, you can allow QCPR staff to access information from hospital medical records as relevant.

## **What are the possible benefits?**

There will be no instant benefit to you or your child from taking part in the Register.

The Register is expected to provide key insights into the rate, severity, and characteristics of people living with cerebral palsy in Australia, which may benefit people with cerebral palsy more broadly in the future.

## **What are the possible risks?**

Participation in the Register is *not* expected to place you at any risk.

## **What if I change my mind and decide to withdraw?**

If you change your mind at any time, contact QCPR staff to have your child's registration made inactive. You can do this by telephoning (07) 3358 8026, emailing [cpregister@cpl.org.au](mailto:cpregister@cpl.org.au), or in writing to CP Register PO BOX 387 Fortitude Valley QLD 4006.

## **How will privacy and confidentiality be maintained?**

The QCPR is committed to maintaining the highest level of privacy and confidentiality for our stakeholders. Any personal information collected about your child for inclusion on the QCPR is strictly confidential and will only be seen by QCPR staff or unless required by law. Any research or reports that are generated from the QCPR will be published in such a way that you and/or your child are not identifiable in any way.

## **Who can I contact about the project?**

If you have any further questions regarding this project, please feel free to contact:

- QCPR Staff on [cpregister@cpl.org.au](mailto:cpregister@cpl.org.au) or (07) 3358 8026
- Dr Megan Auld on [mauld@cpl.org.au](mailto:mauld@cpl.org.au)

If you would like to speak to someone not involved in the study, you may contact the CPL Ethics Committee contact officer, Mel Stephen on (07) 3358 8000.

This study is conducted in accordance with the National Health and Medical Research Council's guidelines for research. Approval has been received from the Choice, Passion, Life (CPL) ethics committee (EC00417).

You may also find out further information about the QCPR on our website, <http://www.qcpr.org.au/>