

BANGLADESH CEREBRAL PALSY REGISTER (BCPR)

INFORMATION SHEET FOR PARTICIPANTS AND FAMILIES/CARERS

What is the CP Register?

The CP Register is a database of clinical information about cerebral palsy (CP). Information collected about each person with CP includes birth details, type and severity of cerebral palsy, other associated impairments and parent demographics. Bangladesh Cerebral Palsy Register (BCPR) is a pilot project which has been commenced in collaboration with the Child Sight Foundation (CSF), Bangladesh, the University of Sydney and Cerebral Palsy Alliance, Australia.

Why is the CP Register needed?

CP is a disorder of movement and posture resulting from damage to the developing brain. It is the most common cause of physical disability in childhood. There is no known cure for CP and rates have remained unchanged despite many recent advances in medicine. It is now recognised that most CP occurs as a result of factors present prior to birth, however little is known about such factors. For 80% of people, the cause of CP will be unclear.

The CP Register will provide a coordinated data collection system for CP in Bangladesh, and will increase the scope of research into CP. It will improve research quality by providing access to a large population sample.

What are the aims of the register?

The main aims of the register are to:

- Monitor trends of CP
- Gain further understanding about the causes of CP
- Develop and evaluate preventative strategies
- Assist in planning services for people who have CP

The Bangladesh CP Register will provide a national framework for research. The information contained on the register will assist with research projects that focus on causes, prevention and management of cerebral palsy. In addition, the register will generate reports on demographics, frequency, distribution and severity for government and service providers. This will enable better planning for the present and future service provision needs of people with cerebral palsy.

How can I participate?

People with CP and their families can register in a number of ways:

- Contact the Bangladesh CP Register Project officer/Physiotherapist directly by phone or email (phone: **+88 01829 407881** or email: **mphysio2002@yahoo.com**).
- Give permission to your local health practitioner, physiotherapist or occupational therapist to register your details.

Children under the age of 5 years will be contacted again after their fifth birthday, for final confirmation of details. Please notify the register if your personal details change.

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What about consent and withdrawal of consent?

Registration is voluntary. If you would like to have your details included on the CP Register you will be asked to provide written consent. Your details cannot be included on the register until a signed consent form (paper) is received by the BCPR staff.

You can download the consent form from BCPR website or contact BCPR project office and they will send one to you.

There are different levels of consent on the CP Register. You will be asked to consent to:

1. The collection, recording and storage of information on your state or territory register. This may involve consulting birth and current medical records
2. The transfer of de-identified information to the Australian Cerebral Palsy Register
3. Receiving invitations from register staff to participate in research projects
4. Health professionals that you nominate being contacted to assist in completing and verifying the register information

You can choose your contribution to the register by selecting your level of consent. You can change your level of consent at any time by submitting a revised consent form to the BCPR project office. If, in the future, you change your mind about participating in the register, you can withdraw consent and your name will be removed from the register. This will not disadvantage you in any way or affect services you are receiving.

What about privacy and confidentiality?

We respect your privacy. The information you provide to the CP Register is strictly confidential and will only be seen by the BCPR staff. Only your de-identified data will be shared with the Australian CP Register. Any research or reports generated from the register or information provided to other researchers and members of the public will be free of personal identifying information.

If you consent, from time to time CP Register staff may contact you with the option of participating in a research study. Register staff will forward you study information and you can then contact the researchers directly if you would like to participate or if you require more information. It is your decision to agree to or decline these offers. The CP Register will never provide your personal or contact details to researchers or anyone else.

This information sheet is for you to keep. If you have any questions or would like to know more about this project, please contact Bangladesh CP Register Project Officer.

Phone +88 01829 407881 email mphysio2002@yahoo.com