

# **Cerebral Palsy Register: a preliminary study towards developing a hospital based national surveillance mechanism for Sri Lanka**

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## **Sri Lankan Cerebral Palsy Register Information sheet**

I am Dr. Samanmali Sumanasenaworking at Department of Disability Studies, Faculty of Medicine, University of Kelaniya. As principle investigator of this project I would like to invite you to take part in a research study titled: **“Cerebral Palsy Register: a preliminary study towards developing a hospital based national surveillance mechanism for Sri Lanka”**

### **1. Purpose of the study**

- There is little known about cerebral palsy (CP) in Sri Lanka. Here we aim to develop the Sri Lankan Cerebral Palsy Register to capture information about CP. The long-term aims of the CP register are to:
  - Monitor trends of CP
  - Gain further understanding about the causes of CP
  - Develop and evaluate preventative strategies
  - Assist in planning rehabilitative services for people who have CP

### **2. How can I participate?**

Your participation in this study is voluntary.

You are free to not participate at all or to withdraw from the study at any time.

If you would like to participate in the study, we will ask you to provide your consent and will then arrange to complete a brief 15-20 minute interview with you.

We will ask you to about your child’s details including, birth and medical history, family history and other relevant details. If you decide you do not wish to participate you can stop the interview at any time.

After the interview, we may seek any missing information from your or your child’s doctor/therapist and/or through access to your health record.

Information on your child will be kept in the Sri Lankan CP Register, a secure web-based database. A deidentified copy of CP register data will be shared with the Australian CP Register for future research.

### **3. Potential benefits or risks of participating**

There are no immediate direct benefits resulting from participation in this study. Joining the CP register will however provide you with opportunity to be contacted regarding research trials for new interventions that may be developed in the future. .

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The data you provide will form part of a large dataset that will help researchers learn more about CP in Sri Lanka. This data will be used to raise awareness about CP and to identify causes and prevention strategies for CP.

Beyond providing your valuable time for the interview, there are no significant risks involved with participating in this study.

### **4. Reimbursements**

There will not be any payment for participation in the study.

### **5. Confidentiality**

The interview will be held in a convenient separate meeting space or by telephone to ensure your privacy. Your child's information will be stored securely and no information by which you or your child can be identified will be released, published or presented.

### **6. How do I withdraw from the study?**

You may withdraw your consent to participate in this study at any time, with no penalty or loss of benefits. Please notify Dr. Samanmali .if you decide to withdraw.

Contact – Dr. Samanmali Sumanasena

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