## CHILDREN'S HEALTH QUEENSLAND HEADS UP FOR KIDS CONCUSSION PRIVACY POLICY



**Project Title** Caring for Children after a Concussion: Uptake, Outcomes,

and Health Care Impacts of a Patient-Driven Technology

Assisted Clinical Care Pathway

HREC Number LNR/19/QCHQ/52434

**Investigator** Professor Karen M. Barlow

We are doing a study to assess how best to help children recover from a concussion or head injury. We use a mobile phone app and related website to provide information about concussion recovery and use surveys to track recovery. This will help us plan how best to care for children with concussion in the future.

You have been asked to take part in this study because your child had a concussion or head injury and has been to the Emergency Department at the Queensland Children's Hospital.

Most children recover quickly after a head injury, but 25% can take more than a month to get better. Parents tell us that they would like more information about what they can do to help recovery, and when they should go and get extra help for their child. We are trying to do this using a mobile app on your phone.

If you decide to take part you will be asked to;

- 1. Download a secure mobile phone app
- 2. Answer some questions about your child and their injury.
- 3. Use the helpful information, videos, and resources on the app to help your child recover
- 4. Complete questionnaires every week to tell us how your child is recovering so we can track their progress with you. These will take 5-10 minutes to complete and we would like you to do them for a total of 3 months.

We will send regular notifications (or reminders) to your phone to ask how your child is doing. You can share the results of your child's progress with your GP.

## We take security and privacy very seriously

All information will be stored securely as per <u>University of Queensland</u>, <u>Children's Health Queensland</u> and <u>Commonwealth Scientific and Industrial Research Organization</u> (CSIRO) **privacy policies**.

• we will store your telephone number, and your child's <u>if</u> you give it to us. These will be encrypted and password-protected. No other identifying information will be collected.

- we will store your first name, your child's first name, and their sex and age, . You and your child will be recognized by an ID number only. non-identifiable information about your child's recovery will be collected. All information will be stored securely as per University of Queensland and Children's Health Queensland policies.
- Only the research team or you will have access to any of this information.

Participation is optional and it is **ok to say no.** If you decide to participate you are free to withdraw consent and discontinue participation at any time.

There are no risks or direct benefits from participating in the study.

If you would like more information about the project or if you need to speak to a member of the research team please contact:

Ph: 3069 7605

Email: <u>uq\_ABiC@uq.edu.au</u>

This research is being led by Professor Karen Barlow, who is an expert in concussion and Chair of Paediatric Rehabilitation in Acquired Brain Injury at the University of Queensland Child Health Research Centre, in collaboration with the Commonwealth Scientific and Industrial Research Organization (CSIRO). The research is funded by The Financial Markets Foundation for Children and has been approved by The Children's Health Queensland Hospital and Health Service Human Research Ethics Committee (HREC). If you have any concerns and/or complaints about the project, the way it is being conducted, or your child's rights as a research participant, and would like to speak to someone independent of the project, you can contact the HREC Co-ordinator on:

Ph: 3069 7002

Email: CHQETHICS@health.qld.gov.au

If you agree to participate the following is assumed;

- you have read and understood the above information
- you understand the purposes, procedures and risks of the research described
- you freely agree to your child participating in this research project as described and understand that you are free to withdraw them at any time during the research project without affecting their future health care

To proceed, close this pop-up and let us know if you want to participate by pushing a button at the bottom of this screen.

Even if you don't want to participate you can still access the website <a href="https://www.kidsconcussion.com.au">www.kidsconcussion.com.au</a> to find more information.