Government of **Western Australia**
Child and Adolescent Health Service

Perth
Children's
Hospital

Participant Information Sheet: Parents & Guardians

Short name of project	UCARE-Kids: Understanding Concussion healthcare And Recovery Experiences for children in WA
Full name of project	Understanding priorities and challenges in childhood concussion care from injury through to community: the perspectives of individuals, families, healthcare providers and educators.
Principal investigator	Dr Jemma Keeves
Project number	RGS0000007483
Site Name	Perth Children's Hospital

What am I being invited to do?

- You are being invited to take part in this research project because your child has recently had a concussion.
- Around 40 people from around Western Australia will take part in this project.
- This project is being conducted by researchers at Curtin University and the Perron Institute, in conjunction with Perth Children's Hospital (PCH).
- This study is being funded by a Perron Institute for Neurological and Translational Science research grant.

What is the purpose of this study?

- The project aims to better understand the healthcare and recovery experiences of children and young people who have had a recent concussion in WA. This includes gathering information about the care they have received, starting from the time of injury through to returning to school, sport and social activities.
- We also want to know more about what children/young people with concussion and their families would change about the care they received.
- If possible, we will also speak to healthcare providers involved in your child's care, and teachers who have helped with their return to school, to get their perspective on the concussion recovery process.
- We hope that the knowledge gained through this study will help to improve the recovery process for children and young people who sustain a concussion in future.

What do I have to do to take part?

- You and your child will be asked to participate in a short interview with a member of the research team, focusing on *your child's* experience of recovery after a concussion.
- You will also be asked to participate in a second interview *without your child present,* to focus on *your* experiences as a parent. Prior to commencing the interviews, you will be asked to complete a brief online survey (~ 5 minutes) which will also ask for your consent to participate in this project.
- All interviews will be conducted online using Zoom video-conferencing. We will make sure that the interviews are conducted at a time that suits you and your family. Each interview will take about 30-45 minutes.
- Each interview will be audio-recorded so that the researchers can go over the interview in detail to make meaning of your experiences.
- You can ask to provide more information related to the interview for up to one week after the interview. This can be done by contacting the study team via telephone or email. If you speak to a member of the study team over the phone, the conversation will be audio-recorded. This information will be added to the answers that you provided during your interview.

Do I have to take part and can I change my mind?

- Participation in any research project is voluntary. You and your child can say no. If you decide to take part and later change your mind, you are free to withdraw from the project at any stage. You do not need to tell us the reason why. If you leave the project, we will use any information already collected unless you tell us not to.
- Your decision to take part or not, or to take part and then withdraw, will not affect your child's healthcare or relationship with their teachers or sporting coaches.

What are the benefits of taking part?

- You and your child will each receive a $50 gift card for your involvement in the interviews. If you participate in more than one interview (i.e.an individual interview and alongside your child) you will receive an additional $30 gift voucher.
- There is no other direct benefit to you in participating. However, by taking part, you will help researchers understand more about concussion care and recovery. This knowledge

may help other children in the future and support the development of more concussion services for children in WA.

What are the risks and discomforts of taking part?

- We don't anticipate any risk to you in participating. However, if you find that the questions asked in the interview bring up difficult feelings or you are becoming distressed, you will be given the option to skip questions, take a break or stop the interview immediately.
- If necessary, the research team will provide you with information about how to access appropriate counselling support.

How will my information be used for this study?

- Data collected during the interviews or focus groups will be stored securely on a password protected computer located at Curtin University and only the researchers will have access to this information during the project.
- The audio recordings will be stored on a secure server at Curtin University and any identifying information about you and your family will be removed. The recordings will be sent to an external transcription service (Sonix) for transcription but will not include any of your personal details.
- Once the study is completed, the data collected from your child will be stored securely at Curtin University for a period of at least 7 years or until the youngest participant turns 25 years, whichever is later.
- It is anticipated that the results of this research project will be published and presented in a variety of forums. In any publication or presentation, information will be provided in such a way that your child cannot be identified, except with your permission.
- Once we have analysed the data for this study, we will email you a summary of our findings. This will be of the whole group of participants, not individual results of you and/or your child.

Who has reviewed and approved this study?

The Child & Adolescent Health Service HREC has approved this study. This is an independent committee that makes sure that this project meets Australian ethical standards for research that involves people.

Comments or complaints about how this study is being run:

If you have any comments or complaints about this project, please contact the following:

Reviewing HREC approving this research:

Reviewing HREC name	Child & Adolescent Health Service (CAHS)
Position	HREC Chair
Telephone	(08) 6456 8639
Email	CAHS.Ethics@health.wa.gov.au

Where can I find more information?

Thank you for taking the time to read this information about our project. You can contact a member of the project team at any time to ask questions.

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