

Participant Information Sheet – Minors (13-18 years)

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 you have 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 how children and young people recover after a concussion. We want to hear about the care you received for your injury and about getting back to school, sport and social activities.
- If possible, we will also speak to your parents, as well as doctors or other health professionals involved in your care, and teachers who have helped with your return to school, to get their thoughts on recovering after a concussion.
- We hope what we learn from this study will help make it easier for kids and young people to get back to normal after a concussion in future.



What do I have to do if I take part?

- We will ask you to take part in a short interview with a member of the research team. Prior to commencing the interview, we will get your permission to be included in the study using an online consent form.
- Next, you or your parents will complete a brief online questionnaire with some of your information and details about your concussion injury.
- Interviews will be conducted online and will be recorded to make it easier for researchers to go over the details afterwards. We will make sure that the interviews happen at a time that suits you and your family. Each interview will take about 30-45 minutes.
- If you are 16 years or older you can opt to be interviewed without a parent or guardian present, otherwise we will conduct the interview with your parent present as well.
- A separate interview will be completed for just your parent/guardian.
- If you think of anything else or would like to correct anything you said in the interview, you or your parent/guardian can contact us by telephone or email for up to one week after the interview. 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 can say no if you don't want to take part. If you decide to take part and later change your mind, you can 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 the healthcare you receive, or your relationship with your teachers or sporting coaches.



What are the benefits of taking part?

- You will receive a \$50 gift card for your involvement in the interviews.
- There is no other direct benefit to you for participating. However, by taking part, you will help the researchers understand more about concussion care. This knowledge may help other children and young people who have a concussion in future.



What are the risks and discomforts of taking part?

- We don't believe there are any risks to you if you take part in this study. However, if you find that the questions asked in the interview make you feel upset or 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 and your parents/guardian with information about how to access appropriate counselling support.



How will my information be used for this study?

- Any information we collect from you during this study will be **confidential** – that means, what you tell us is private and we will not tell anyone else. The only exception to this is if you share any information during the research about harm to yourself or others, or any concerns regarding your safety or well-being, as we are required to share this with your parent or your doctor.
- We will keep any information about you on a secure, password protected computer located at Curtin University, and only the researchers will have access to this information.
- The information we keep from your interview will not include your name or any other personal details so that anyone else would not know it's about you. Once the study is completed, the information we collected will be stored securely at Curtin University for a period of at least 7 years or until the youngest participant in the study turns 25 years, whichever is later.
- We plan to present the results of this research project either by writing and publishing it or speaking about it at conferences. In any publication or presentation, information will be provided in such a way that you cannot be identified, unless you tell us that we can.
- Once we have analysed the information for this study, we will email you and/or your parent/guardian a summary of our findings. This will be of the whole group of participants involved in the study, not individual results just about you.



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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