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Participant Information Sheet

Project Title: Resource for Individuals Recently Diagnosed with Concussion
Approval Number: 2022-03941-TURNER
Lead Investigator: Mrs. Karyn West
Other Investigators: Dr. Mitchell Turner, Mrs. Manja Laws, Ms. Leah Dempsey, Associate Professor Mandy Stanley and Dr Travis Cruickshank.

An invitation to participate

You are invited to participate in workshops that aim to develop a consumer informed resource for individuals recently diagnosed with concussion.

Please read this information carefully. Ask questions about anything that you do not understand or want to know more about. If you decide to take part, you might want to talk about it with a relative or friend.

If you want to take part in the research project, you will be asked to sign a consent form. By signing the attached consent form, you are telling us that you:

- Understand what you have read;
- Consent to take part in the research project;
- Consent to be involved in the research described;
- Consent to the use of your personal information as described;
- Understand that you can withdraw at any time.

What is this project about?

The project aims to develop a resource together with people diagnosed with concussion. This resource will aid individuals with concussion by providing information and guidance to optimise their clinician consultation time. It will include a collection of questions that individuals recently diagnosed with concussion will find helpful in their first interactions with their clinician after diagnosis. This project has been funded by MSWA.

What does my participation involve?

Your participation in this research project will involve attending two in-person consumer-centric workshops. Before the first workshop, you will be asked to reflect on questions you wished you could have asked or forgot to ask your clinician when first diagnosed and bring them with you to the workshop. These questions will be the basis of a three-hour workshop. During this workshop, you will be asked to participate in small and large group conversations about the questions you previously created. By the end of the workshop, we will have a list of the most important questions to ask clinician when first diagnosed with concussion. We will also ask you some short, simple questions such as your age, gender, years of lived experience, and postcode. You will then be invited to attend an optional second three-hour workshop several weeks after the first workshop. During the second workshop, you will be asked to participate in small and large group conversations about the best presentation

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format for the questions developed in workshop one. Attendance and contribution to the workshops does not imply any commitment to further research participation.

The conversations within this workshop will be recorded by note takers and on paper to allow for the analysis of data at a later date. Only the individuals named as investigators on this research project will have access to those notes. As a token of gratitude for participating in these workshops, you will receive a $50 honorarium for each workshop attended. Light refreshments and breaks will be provided.

Do I have to take part?

No, your participation in this study is completely voluntary. If you do not wish to take part, you do not have to. If you do decide to take part and later change your mind, you are able to withdraw (exit) at any time. Please note that if you do withdraw, it will not be possible to retract the data you provided during the workshop, as no information allowing you to be identified will be collected during the workshop to maintain anonymity.

If you do decide to take part, you will be given a consent form to sign, and you will be given a copy of this information letter to keep. Your decision to take part, or to take part and later withdraw, will not affect your relationship with the research team, any health professionals or community organisations.

Your privacy

By signing the consent form, you consent to the research team collecting and using information about your personal views on your health condition for the research project. As no personally identifying information will be collected, your responses during the workshop will remain anonymous. Your information will only be used for the purpose of this research project, and it will only be disclosed with your permission, except as required by law.

It is anticipated that the results of this workshop will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified, except where requested for specific reasons, and then you will be asked to provide written consent.

All data collected will be stored in an anonymous manner on a secure server for a minimum of seven years. Following this period, all data will be permanently deleted. Likewise, any hard-copy data generated from this project will be stored in a locked filing cabinet in the chief investigator's office for a period of seven years, after which the data will be destroyed via a paper shredder.

Possible Benefits

These workshops will not lead to any direct personal benefits. However, by providing information on the most important questions to ask your clinician when recently diagnosed, you will benefit individuals, such as yourself, who are diagnosed with concussion.

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Possible Risks and Risk Management Plan

There is a very low level of risk involved with participation. It is unlikely, but if you feel that some of the questions make you feel uncomfortable, you do not need to respond.

What happens after the workshop?

If you wish to receive a copy of the outcomes of the workshop, please speak to one of the team members on the day. We also intend to publish our results in research journals and present them at research conferences locally, nationally and internationally. No identifying information will be included in any of the publications or presentations.

Has this research been approved?

This project has received the approval of Edith Cowan University's Human Research Ethics Committee in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research (2007)*. The approval number is 2022-03941-TURNER.

Contacts

If you would like to discuss any aspect of this project, please contact the following people.

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Approval to conduct this research has been provided by the Edith Cowan University's Human Research Ethics Committee, approval number 2022-03941-TURNER, in accordance with its ethics review and approval procedures. If at any time you are not satisfied the research or wish to make a complaint about the research process, you may contact the Human Research Ethics team on 6304 2170 or by emailing them at research.ethics@ecu.edu.au.