

PARTICIPANT INFORMATION SHEET

BE WHAT YOU WANT TO BE

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Meeting the needs of people living with complex regional pain syndrome: Defining the problem

CQUniversity, with CRPS Awareness – The Purple Bucket Foundation and the Australian Pain Management Association are conducting a research project. You are invited to participate because you have been diagnosed with Complex Regional Pain Syndrome (CRPS).

Project Overview

This research seeks to find out the information needs of people with a new or existing diagnosis of CRPS. The results of this project will be used to develop a thorough collection of information to suit the specific needs for people with a confirmed or suspected diagnosis of CRPS. This information will help people with CRPS to cope with the changes to their daily life and includes support to assist their recovery whilst waiting for specialist appointments.

Participation Procedure

You are invited to take part in an interview which consists of questions regarding the information needs of people with CRPS. For example, you will be asked what do/did you want to know about your condition and how do/did you want to receive the information, and how have your information needs changed across time and during the course of your condition?

The interview will be audio recorded with your consent. Completion of the interview will take around 30 minutes. The interview will be held at a location of your choosing, on-line via Zoom or face-to-face, at a time organised with the researcher. You will be given the opportunity to read through your written responses to the questions in the interview (transcript) to make sure you are happy with the information you provided.

Benefits and Risks

There may be no direct benefit to you for participating in this project. However, it is expected that this project may help people diagnosed with CRPS, health professionals, and the wider community in the future. It is expected that this project will contribute to the CRPS knowledge base of pain clinicians and pain researchers also.

You may experience inconvenience in giving up your time to attend and complete this interview. We do not anticipate that participation in this research will cause you any undue discomfort beyond that experienced in normal day-to-day living. However, if you are concerned, please consider viewing the support available at Australian Pain Management Association <https://www.painmanagement.org.au/> or calling their helpline on 1300 340 357. You may also wish to access the information at CRPS Awareness - The Purple Bucket Foundation <https://www.tpbf.org.au/> or phone +61.411147367. Support is also available through Lifeline 13 11 14 (www.lifeline.org.au), your General Practitioner or preferred healthcare provider.

Confidentiality

The interview will not collect any identifying information; your responses will be confidential. At the start of the interview, you will be asked to choose a pseudonym which will be used to speak with you from that time forward.

The data will be securely stored as outlined in CQ University policy. It is anticipated that the data may be useful to future research, as such your responses as collected in the interviews (data) is not intended to be disposed of.

Outcome

The results of this research will be presented in an academic form in journal articles and at conferences. A simpler written version of the results will be posted on the websites of CRPS Awareness – The Purple Bucket Foundation and the Australian Pain Management Association.

Consent

Your verbal permission to participate in this project will be obtained before recording the interview.

Right to Withdraw

Your participation is voluntary. You are free to end the interview whilst it is underway at any time, without any penalty, by asking the interviewer to stop. Any of your responses will then be removed from the research project. If you finish the interview, and once you have read the written account of your responses (transcript), it will not be possible to withdraw your information (data).

Feedback

A short and simple summary of the project's findings will be available in about 12 months. You will be sent a copy of this at this time.

Questions/ Further Information

If you have any questions about this project, please contact the Chief Investigator Dr Colleen Johnston-Devin via c.johnston-devin@cqu.edu.au Phone 07 5440 7081.

To book an interview

Please email the Research Assistant Danielle Bywaters, d.bywaters@cqu.edu.au who will work with you to book your interview.

This project has been approved by the CQUniversity Human Research Ethics Committee, approval number 0000024026.

Please contact Central Queensland University's Research Division (Tel: 07 4923 2603; E-mail: ethics@cqu.edu.au) should there be any concerns about the nature and/or conduct of this research project.