

PARTICIPANT INFORMATION STATEMENT

HREC Project Number:	HRE2019-0298
Project Title:	Exploring the lived experience of people with Complex Regional Pain Syndrome (CRPS) in Western Australia.
Chief Investigator:	Dr Darren Beales, Level 1 Curtin research supervisor and Specialist Physiotherapist
Student researchers:	David Carolan, Joshua Chuah Choong, Sarah Hammond, Eimear O'Brien
Version Number:	1.2
Version Date:	13/04/2019

What is the Project About?

The advice that people with complex regional pain syndrome (CRPS) are given in regard to management of their condition is highly variable. We would like to better understand what it is like living with CRPS, and the impact it has on different aspects of life. This qualitative study will investigate the experiences of people with CRPS and aim to guide the management of health care professionals in the future.

The outcomes from this research will be used to help improve the advice and care provided by health professionals to people with CRPS.

Who is doing the Research?

This study is being conducted as part of Curtin University Clinical Masters of Physiotherapy programme, under the supervision of Dr Darren Beales, Professor Helen Slater, Dr Sonia Ranelli, Dr Tim Mitchell and Mrs Eileen Boyle, with postgraduate student researchers, David Carolan, Joshua Chuah Choong, Sarah Hammond and Eimear O'Brien. The results of this research project will be used by these research students to obtain a Masters of Clinical Physiotherapy at Curtin University. There will be no costs to you and you will not be paid for participating in this project.

Why am I being asked to take part and what will I have to do?

- You have been asked to participate because you have a diagnosis of CRPS. We are interested to learn about your experience of CRPS and the advice you have been given by health professionals.
- Your participation will involve a brief survey (to provide some personal information about your condition) to be answered via an iPad provided (or via an emailed link), followed by a 30 – 45 minute in-depth interview about your experience as a person with CRPS.



Lived experience of CRPS

- The study will take place at a Private Physiotherapy Clinic in South Perth (Pain Options) or via telephone/Skype if you are unable to travel to South Perth.
- We will ask you questions about your CRPS such how it impacts your life, and your general wellbeing (physical and emotional).
- The questionnaire and interview will be conducted only once. Completed questionnaires will be collected prior to the interview in the clinic, or can be submitted electronically via the email link (if you are unable to attend the clinic for the interview)
- We request that participants arrive 30 minutes prior to their interview, to complete the personal information sheet and questionnaires. The interview will take approximately 30-45 minutes.
- There will be no cost to you for taking part in this research and you will not be paid for participating.
- We will make a digital audio recording so we can concentrate on what you have to say and not distract ourselves with taking notes. After the interview we will provide a full written copy of the recording for you to check as an accurate record of our conversation. You will not be identified in this transcript and your recording will be identifiable only through a code. Your name will not be used.

Are there any benefits' to being in the research project?

There may be no direct benefit to you from participating in this research. Our project will give you an opportunity to express your experience, in regard to living with CRPS, and the care you have received. The results of this research will help people understand this disorder, and this assist in improving the care and management of people with CRPS.

Are there any risks, side-effects, discomforts or inconveniences from being in the research project?

- There are no foreseeable risks from this research project.
- We have been careful to make sure that the questions in the survey do not cause you any distress. If you feel anxious about any of the questions, you do not need to answer them. If the questions cause any concerns or upset you, you are advised to let us know during the interview and we can take the appropriate action.
- In this project we will use a questionnaire asking about your mental health (PROMIS- 29 Profile v2.0). If we identify a very high score in any of the subscales (e.g.; depression or anxiety), we will advise you to contact your GP to address any possible concerns.
- Sometimes just thinking about CRPS and the impact it has on your life or relationships can be upsetting. If you chose not to be in this research but feel distressed from considering it then please contact your GP or Lifeline 13 11 14.

Who will have access to my information?

- The information collected in this research will be re-identifiable (coded). This means that we will collect data that can identify you, but we will then remove identifying information on any data or sample and replace it with a code when we analyse the data. Only the research team have access to the code to match your name if it is necessary to do so. Any information we collect will be treated as confidential and used only in this project unless

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otherwise specified. The following people will have access to the information we collect in this research: the research team as named above and, in the event of an audit or investigation, staff from the Curtin University Office of Research and Development.

- Electronic data will be password-protected and hard copy data will be in locked storage.
- The information we collect in this study will be kept under secure conditions at Curtin University for 7 years after the research is published and then it will be destroyed, in compliance with Curtin University data management policy
- The results of this research may be presented at conferences or published in professional journals. You will not be identified in any results that are published or presented.

Will you tell me the results of the research?

- A summary of the project's overall results will be sent to participants upon request. Results will not be individual but based on all the information we collect and review as part of the research.
- If you are interested in obtaining a summary of the results please contact the researchers after November 2019.

Do I have to take part in the research project?

- Taking part in this research project is voluntary. You do not have to agree if you do not want to. If you decide to take part and then change your mind, you can withdraw from the project at any time. If you choose not to take part, or start and then stop the study, it will not affect your relationship with the University, staff or colleagues.
- Choosing to participate or withdrawing from the study at any point will not impact any treatment you may be receiving or your relationship with the treating physiotherapist or pain specialist.
- You can withdraw your participation prior to submitting your online questionnaire responses by simply closing the browser.
- You are free to withdraw from the study at anytime during the interview or prior to approving your transcript

With your permission, if you chose to leave the study we will use any information collected unless you tell us not to.

What happens next and who can I contact about the research?

- For further information or any questions, you can contact Dr Darren Beales via email: d.beales@curtin.edu.au
- At the start of the questionnaire, available via the link provided, there is a checkbox to indicate you have understood the information provided here in the information sheet.
- Please take your time and ask any questions you have before you decide what to do. You will be given a copy of this information and the consent form to keep.

Curtin University Human Research Ethics Committee (HREC) has approved this study (HREC number HRE2019-0298). Should you wish to discuss the study with someone not directly involved, in particular, any matters concerning the conduct of the study or your rights as a participant, or you wish to make a confidential complaint, you may contact the Ethics Officer on (08) 9266 9223 or the Manager, Research Integrity on (08) 9266 7093 or email hrec@curtin.edu.au.