

**Establishing evidence –based management of Complex Regional Pain Syndrome to improve clinical outcomes throughout the care pathway (ENACT-CRPS)**

# Participant Information Sheet

You are invited to take part in research taking place at the University of the West of England, Bristol. Before you decide whether to take part, it is important for you to understand why the study is being done and what it will involve. Please read the following information carefully.

## Who is organising and funding the research?

The project has received funding from the National Institute for Health Research as part of the Research for Patient Benefit programme. The Chief Investigator is Dr Alison Llewellyn, Associate Professor - Clinical Research.

## What is the aim of the research?

This research is looking at a future treatment pathway for Complex Regional Pain Syndrome (CRPS) in non-specialist settings. We are interested in the views of physiotherapists, occupational therapists and hand therapists regarding current treatment provisions for CRPS, their perception of the need for therapy-led care for CRPS outside of specialist centres, the organisational capacity to deliver care for people with CRPS, and any other barriers or enablers. To help us answer these questions, we will be circulating an e-survey which will also include the option for therapists to give permission to be involved in future interviews. The results of the e-survey will be analysed and used to inform the design of an evidence-based stratified CRPS therapy care package for use in non-specialist settings.

# Why have I been invited to take part?

You have been invited to take part as you are a physiotherapist, occupational therapist or hand therapist working in a non-specialist setting.

## Do I have to take part?

You do not have to take part in this research. It is up to you to decide whether you want to be involved. If you do decide to take part, you will be asked to complete an online consent form before completing the e-survey. Participation is voluntary and you may withdraw from the survey at any point before final submission without giving any specific reason. However, once you have submitted the questionnaire, it will not be possible to have your results excluded from the analysis as responses will be anonymous. You will have the opportunity to provide your email address and give permission to be contacted about involvement in future interviews, however, you can decide whether you wish to take part in an interview at a later date. Your email address will be the only personal data that we collect from you.

## What will happen to me if I take part and what do I have to do?

If you agree to take part you will be asked to complete an online survey, which will take approximately 15 minutes. The survey can be accessed through the invitation link on any computer, tablet computer or smart phone with internet access.

At the end of the survey, information will be provided about the project website. The project website gives further details about the research team and progress to date. It also hosts a forum to support dialogue between non-specialist therapists. It is entirely your choice whether or not you choose to access the website or to participate in the forum.

## What are the benefits of taking part?

If you take part, you will be helping us to gain a better understanding of the current provision of CRPS treatments and contribute to the development of a stratified care package of therapies for use in non-specialist settings. The information will also be used to inform future research.

## What are the possible risks of taking part?

We do not foresee or anticipate any risk to you in taking part in this study.

## What will happen to your information?

All responses are anonymised unless you agree to provide your email address and give permission to be contacted about future interviews. The University of the West of England has a data processing agreement in place with the electronic consent form and survey provider: Qualtrics. All data transfer is fully encrypted and secure. Electronic data will be transferred and held in a secure, password protected folder on One Drive for Business. All data will be inputted into a database to be analysed, and we will ensure that there is no possibility of identification or re-identification from this point.

Anonymised results may be published and will be used to inform future work packages. The email addresses of those who provided permission to be contacted for interview, will be stored separately, and held in a secure, password protected folder on OneDrive for Business. We anticipate the project to last 18 months. Once the project is completed we will delete your email address and not use it for any other purpose.

All data will be managed in accordance with the University’s and the Data Protection Act 2018 and General Data Protection Regulation requirements. Please see our Research Privacy Notice for further information on how your data will be stored.

## Who has ethically approved this research?

The project has been reviewed and approved by the University of the West of England Faculty Research Ethics Committee (HAS.21.07.173). Any comments, questions, or complaints about the ethical conduct of this study can be addressed to the Research Ethics Committee at the University of the West of England at: Researchethics@uwe.ac.uk

## What if something goes wrong?

This is a very low risk study. However, if you have any concerns, please contact a member of the research team or UWE Bristol’s Research Governance Manager.

Dr Alison Llewellyn, Chief Investigator: Alison.Llewellyn@uwe.ac.uk; 0117 32 87495

Jessica Coggins, Research Associate: Jessica.Coggins@uwe.ac.uk; 0117 32 88427

Research Governance Manager at the University of the West of England: researchgovernance@uwe.ac.uk

## What if I have more questions or do not understand something?

If you would like any further information about the research, please contact Dr Alison Lewellyn, Alison.Llewellyn@uwe.ac.uk.

Thank you for considering taking part in this study.