# A survey of healthcare professionals for evidence-based management of Complex Regional Pain Syndrome to improve clinical outcomes throughout the care pathway

Submission date	<b>Recruitment status</b> No longer recruiting	[X] Prospectively registered		
25/08/2021		[X] Protocol		
Registration date	Overall study status	Statistical analysis plan		
10/09/2021	Completed	☐ Results		
Last Edited	Condition category	☐ Individual participant data		
04/06/2024	Musculoskeletal Diseases	<ul><li>Record updated in last year</li></ul>		

#### Plain English summary of protocol

Background and study aims

Complex Regional Pain Syndrome (CRPS) is a severe pain condition that affects a limb, usually following injury or surgery. The limb is highly sensitive to touch. Other limb symptoms include swelling and altered temperature, colour, sweating, hair and nail growth. CRPS is rare, poorly understood and incurable.

CRPS significantly impacts patients' physical and psychological well-being. People with CRPS tell us they "struggle to come to terms with something they just don't understand".

To improve limb movement, people are referred to local therapy services. Early treatment gives the best chance for good outcomes but the rarity of CRPS means therapists often know little about, and lack confidence and knowledge in, how best to manage it. This further adds to patients' distress and delays appropriate care.

NHS CRPS specialist centres exist and provide a range of rehabilitation therapies, but patients can only access these specialist services if local services have "failed" to improve their symptoms. Patients tell us how life-impacting CRPS can be and that they would like to be able to have timely access to therapies provided locally by knowledgeable clinicians.

Our overall aim is to develop a package of therapies for CRPS that can be offered by therapists in local non-specialist clinics. Providing the right therapies early on will improve care for the majority, and enable those with more complex needs to have quicker access to specialist centres.

In the first stage of this work we will conduct an electronic survey of physiotherapists, occupational therapists, and hand therapists working with people with CRPS in non-specialist settings in England. Our aim is to gain a better understanding of their needs and current practices. Together with data from later phases of the research, this will inform the draft package of therapies that we will develop for use by therapists in non-specialist settings.

Who can participate?

This study aims to collect data from Physiotherapists, Occupational Therapists and Hand Therapists working in a non-specialist setting with people with Complex Regional Pain Syndrome.

#### What does the study involve?

Study participants 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. Participation is voluntary and participants may withdraw from the survey at any point before final submission without giving any specific reason. Participants will also have the opportunity to provide an email address and give permission to be contacted about involvement in future interviews if they wish.

What are the possible benefits and risks of participating?

Participating in this study will help us to gain a better understanding of the current provision of CRPS treatments and will contribute to the development of a future stratified care package of therapies for use in non-specialist settings. We do not foresee any risks to participants arising from taking part in this study

Where is the study run from?
University of the West of England (UK)

When is the study starting and how long is it expected to run for? May 2021 to July 2023

Who is funding the study? National Institute for Health Research (NIHR) (UK).

Who is the main contact?

Dr Alison Llewellyn, alison.llewellyn@uwe.ac.uk

#### Study website

https://enact-crps.co.uk/

# **Contact information**

# Type(s)

Scientific

#### Contact name

Dr Alison Llewellyn

#### **ORCID ID**

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#### Type(s)

**Public** 

#### Contact name

Ms Jessica Coggins

#### Contact details

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# Additional identifiers

#### **EudraCT/CTIS** number

Nil known

#### **IRAS** number

# ClinicalTrials.gov number

Nil known

# Secondary identifying numbers

NIHR200753 Phase 1 - survey

# Study information

#### Scientific Title

Establishing evidence-based management of Complex Regional Pain Syndrome to improve clinical outcomes throughout the care pathway. Phase 1: a survey of healthcare professionals

#### Acronym

**ENACT-CRPS** 

#### **Study objectives**

Complex Regional Pain Syndrome (CRPS) is a severe chronic pain condition which usually occurs following limb trauma. Associated with limb oedema, sensitivity to touch, colour and temperature changes, it causes significant burden to individuals and society. NHS UK guidelines recommend early referral for therapies that encourage limb movement and use. However, due to its rarity, clinicians in non-specialist settings can lack confidence and competence in diagnosing and treating CRPS.

Specialist evidence-based CRPS rehabilitation therapies are available in a small number of centres but access to these services can be limited. Patients report how life-impacting CRPS is, and their need for timely access to therapies closer to home.

The overall aim of the programme of research is to develop a draft stratified package of care for use by therapists in non-specialist settings and which will expedite patient access to evidence-based treatments for CRPS across the care pathway.

The current study aims to gain a better understanding of the current practices of therapists working in non-specialist settings, and of their needs in order to successfully treat people with CRPS.

#### Ethics approval required

Old ethics approval format

#### Ethics approval(s)

Approved 13/08/2021, University of the West of England Faculty of Health and Applied Sciences Faculty Research Ethics Committee (Glenside Campus, Blackberry Hill, Stapleton, Bristol, BS16 1DD, UK; no telephone number provided; researchethics@uwe.ac.uk), ref: HAS.21.07.173

#### Study design

Electronic survey

#### Primary study design

Other

#### Secondary study design

#### Study setting(s)

Internet/virtual

#### Study type(s)

Other

# Participant information sheet

See study outputs table

# Health condition(s) or problem(s) studied

Complex Regional Pain Syndrome

#### **Interventions**

The study consists of an electronic survey of primary, community and secondary care physiotherapists, occupational therapists and hand therapists in relation to the provision of therapy care for Complex Regional Pain Syndrome (CRPS). The survey includes open and closed questions to collect data around clinical roles and current practice. Respondents will also be asked if they will be willing to participate in future interviews in a later phase of the overall research programme.

#### **Intervention Type**

Other

#### Primary outcome measure

Current practices of physiotherapists, occupational therapists and hand therapists working in non-specialist settings with people with Complex Regional Pain, reported via questionnaire survey at a single time point

#### Secondary outcome measures

Current perceptions of therapists physiotherapists, occupational therapists and hand therapists working in non-specialist settings regarding the barriers and facilitators to providing services for people with Complex Regional Pain Syndrome, reported via questionnaire survey at a single time point.

#### Overall study start date

01/05/2021

#### Completion date

31/07/2023

# **Eligibility**

#### Key inclusion criteria

Physiotherapists, occupational therapists, and hand therapists in England

#### Participant type(s)

Mixed

#### Age group

Adult

#### Sex

Both

#### Target number of participants

Survey respondents (physio/occupational/hand therapists): n=100-150

#### Total final enrolment

77

#### Key exclusion criteria

1. Therapists and other clinicians not working/having worked with people with Complex Regional Pain Syndrome

#### Date of first enrolment

20/09/2021

#### Date of final enrolment

30/11/2021

# Locations

#### Countries of recruitment

#### England

# **United Kingdom**

# Study participating centre University of the West of England

School of Health and Social Wellbeing Faculty of Health and Applied Sciences Glenside Campus Bristol United Kingdom BS16 1DD

# Sponsor information

### Organisation

University of the West of England

# Sponsor details

Frenchay Campus
Coldharbour Lane
Bristol
England
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BS16 1QY
+44 (0)11732 87928
Res.Admin@uwe.ac.uk

# Sponsor type

University/education

#### Website

http://www.uwe.ac.uk/

#### **ROR**

https://ror.org/02nwg5t34

# Funder(s)

# Funder type

Government

#### **Funder Name**

#### National Institute for Health Research

#### Alternative Name(s)

National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

#### **Funding Body Type**

Government organisation

#### **Funding Body Subtype**

National government

#### Location

United Kingdom

# **Results and Publications**

# Publication and dissemination plan

Planned publication in a high-impact peer-reviewed journal.

#### Intention to publish date

31/08/2024

#### Individual participant data (IPD) sharing plan

The datasets generated during and/or analysed during the current study are not expected to be made available as the researchers have no provision for this within their ethical approval or data management plan.

#### IPD sharing plan summary

Not expected to be made available

# **Study outputs**

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Participant information sheet	version 1	14/06/2021	08/09/2021	No	Yes
Protocol file	version 1	14/06/2021	17/10/2022	No	No