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

Submission date
25/08/2021

Recruitment status
No longer recruiting

Registration date
10/09/2021

Overall study status
Completed

Last Edited
05/11/2025

Condition category
Musculoskeletal Diseases

[X] Prospectively registered

[X] Protocol

[_] Statistical analysis plan

[X] Results

[_] Individual participant data

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

Contact information

Type(s)
Scientific

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Additional identifiers

National Institute for Health and Care Research (NIHR)
200753

Protocol serial number
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

Primary study design
Other

Study design
Electronic survey

Study type(s)
Other

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(s)
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

Key secondary outcome(s)
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.

Completion date
31/07/2023

Eligibility

Key inclusion criteria
Physiotherapists, occupational therapists, and hand therapists in England

Participant type(s)
Mixed

Healthy volunteers allowed
No

Age group
Adult

Sex
All

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
United Kingdom

England

Study participating centre
University of the West of England
School of Health and Social Wellbeing
Faculty of Health and Applied Sciences
Glenside Campus
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Sponsor information

Organisation
University of the West of England

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

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?
Results article		25/10/2025	05/11/2025	Yes	No
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
Study website	Study website	11/11/2025	11/11/2025	No	Yes