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

Work Package 1 Protocol

Version 1.0

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Background

Complex Regional Pain Syndrome (CRPS) is a highly distressing and severely disabling chronic pain condition that occurs following injury or surgery to a limb. As well as severe, persistent pain, CRPS is associated with other changes in the limb including swelling, dramatic changes in hair and nail growth, skin temperature and skin colour (Harden *et al*., 2010). European population studies of CRPS equate to approximately 40,000 people living with CRPS in the UK (de Mos *et al.,* 2007). Although this is a relatively small number of people, CRPS causes significant burden to individuals and the NHS. People with CRPS often request amputation of their limb due to pain severity, dislike of the limb and loss of function. Amputation is not recommended by best practice guidelines and may lead to increased personal and societal burden (Goebel *et al.,* 2018).

There is no cure for chronic CRPS and the majority of CRPS cases resolve spontaneously in the first few months, however, retrospective studies report symptoms persist for between 22% and 64% of patients ≥3 years after diagnosis (Bean *et al.,* 2014). UK guidelines recommend prompt diagnosis and early referral for therapies that encourage normal movement and use of the limb from the outset (Goebel *et al.,* 2018). Diagnosis of CRPS may be the reason for the referral, or commonly this diagnosis is made by therapists during this episode of care. Once diagnosed, management of the condition will typically remain under the care of the therapy team. Expert clinical opinion states this approach gives patients the best chance of a good health outcome, and there is some evidence to support this Gillespie *et al,* 2016; Goebel *et al.,* 2018). However, due to the relative rarity of CRPS, clinicians lack confidence and competence in diagnosing and treating CRPS.

A 2017 Freedom of Information request revealed no care pathway or agreed initial management exists for CRPS in 82% of English NHS Trusts with CRPS-relevant services (Gillespie et al., 2018). A recent survey of clinicians working in the field of CRPS, identified that over half of UK respondents reported difficulty in recognising the signs and symptoms of CRPS, highlighting a lack of awareness of CRPS by healthcare professionals (Grieve *et al.,* 2019).

NHS specialist centres for CRPS do exist in England, and there are three such centres (Bath, Liverpool, London). There are also a limited number of clinicians with expertise in CRPS in the UK. However, there is often considerable delay from symptom onset to referral to a specialist centre or clinician, meaning that only a very limited number of people with CRPS are able to benefit from this specialist care because:

- therapists in non-specialist settings lack the confidence and competence to deliver similar care due to the limited number of people they see per annum, and the lack of a standardised treatment framework to work within
- resource issues of time and personnel outside of specialist services
- travel to specialist centres is expensive for patients and can be physically challenging, making it problematic for some patients to attend
- inappropriate beliefs by potential referring clinicians that CRPS is a lifelong condition for which nothing can be done
- capacity is limited, by the nature of the specialist referral system.

Despite the success of the specialist therapy delivery, there has been little opportunity to fully explore the mechanisms underlying the positive outcomes it achieves for patients, or to see how these could be applied more extensively across the clinical pathway. To address this knowledge gap, we need to:

- better understand the needs and concerns of practitioners across the care pathway and outside of specialist care
- more clearly understand how specialist therapy interventions bring about the clinical improvements observed
- explore the nature of the patient and clinician experiences.

Through a series of four work packages, the aim of the overall programme is to develop a package of care that will expedite patient access to evidence-based treatments for CRPS across the care pathway. This package of care will provide a stratified approach to rehabilitation based on the level of severity/complexity of the presenting patient, and the skills and resources available to the treating therapist.

Aim:

The current work package (work package 1) aims to gain a better understanding of the needs of therapists, working in non-specialist settings, in order for them to successfully treat people with CRPS, and the resource capacity available to support this.

Objectives:

1. Design and distribute an e-survey for completion by physiotherapists, occupational therapists and hand therapists.
2. Create a project-specific website to provide information about the research, support dialogue between non-specialist therapists with an interest in CRPS, and which provide a mechanism for ongoing consultation/receipt of opinion by the research team.

Research Questions:

1. What treatments are therapists in non-specialist settings in the UK currently providing for people with CRPS
2. To what extent are the current UK guidelines for CRPS being used by therapists in non-specialist settings?
3. What treatments would therapists like to provide to patients with CRPS?
4. What are the barriers and facilitators to treating people with CRPS?

Design:

Using the Qualtrics platform, we will conduct an E-survey of physiotherapists, occupational therapists and hand therapists across the UK to determine current provision, understanding of CRPS and treatments, the need for a specialist care package, organisational capacity and any other barriers or facilitators. The research team, consisting of different healthcare professionals and academics, will design a survey tool to ensure that it is accessible to respondents. The tool includes receipt of informed consent prior to presentation of open and closed questions to collect data including clinical role, training details, experience of treating CRPS, current provisions and organisational capacity to potentially deliver a specialist care package. Respondents will be asked whether they may be willing to be involved in future work packages, and to provide their email address if they agree to be contacted again. Respondents will also be signposted to the project-specific website, which includes a forum to support dialogue between non-specialist therapists.

Sample:

The survey will be distributed through several appropriate organisations, including but not restricted to the Chartered Society of Physiotherapists, the Royal College of

Occupational Therapists and the British Association of Hand Therapists. We will also advertise the survey via social media and relevant special interest groups, including UK based members of the International Association for the Study of Pain Complex Regional Pain Syndrome (CRPS) Special Interest Group and the CRPS International Research Consortium. We anticipate a response rate in the range of 100-150, based on previous survey work by members of the team and our knowledge of availability of service provision and expertise of this area.

Process:

A link to the survey will be included in social media posts and any correspondence to the appropriate organisations or special interest groups. The anonymized responses option will be enabled to ensure IP addresses or location data is not collected. The respondents will not be asked to submit any personal data unless they wish to input their email address to take part in future work packages. This data will be transferred from Qualtrics into a password protected database within a secure UWE OneDrive folder. Only members of the research team will have access to this information. The online survey will include links to the participant information sheet and the UWE Privacy Policy. We anticipate that the survey will take up to 15 minutes to complete. The survey will be active for four weeks and after this time, the survey will be closed and a courtesy message displayed.

Data analysis:

The free text responses will be analysed using thematic and content analysis. Quantitative responses will be entered into an Excel spreadsheet and analysed using descriptive statistics.

Data management:

Please refer to the separate data management plan.

Dissemination:

Data from this work package will be primarily used to inform future work packages within the wider NIHR Research for Patient Benefit project. The findings from this survey will contribute to a publication.

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