COVID-19 Recovery Committee
6th Meeting, 2022 (Session 6), Thursday 9 March 2023
Long COVID inquiry

Introduction

We are pleased to share some of our key findings and expertise with the Long COVID inquiry. We jointly lead an ongoing Chief Scientist Office funded study (LOCO-RISE), which is examining Long COVID rehabilitation in four Health Boards across Scotland. LOCO-RISE is a collaboration of researchers (Robert Gordon University, University of Stirling, University of Dundee), people with lived experience of Long COVID, and NHS clinicians. Below are our responses to the inquiry's key topic areas. We will happily expand upon this statement when we meet with the committee.

Awareness and recognition

At a societal level it seems that there is a general level of awareness of Long COVID, though there is most likely varied understanding of what it is, its presentation and its impact on people's lives. In LOCO-RISE, people with Long COVID reported having varied experiences of presenting to primary care services. Some General Practitioners appear to take the condition very seriously and arrange for a range of different tests to be undertaken, while others are perceived to take Long COVID much less seriously, with patients reporting their concerns have been dismissed or not taken sufficiently seriously. People with Long COVID in our study also expressed frustration that health professionals more generally are often reluctant to diagnose Long COVID.

Our LOCO-RISE study found that rehabilitation practitioners who work in isolation or in remote/rural settings have less confidence in recognising Long COVID and less confidence in understanding what their role in supporting these patients could be. These practitioners reported that having access to others with specialist knowledge and opportunities to share experiences and learning helps their recognition of Long COVID and knowledge of how to intervene.

One of healthcare practitioners' challenges in recognising Long COVID and what should be undertaken to support patients is in keeping updated of current research, evidence and best practice. As Long COVID research findings are becoming increasingly more available, a centralised resource, such as dedicated health website on the NES Knowledge Network for the health professionals, with a repository of research findings and evidence summaries could provide a one stop location to develop professional's understanding and recognition of Long COVID.

Therapy and rehabilitation

To date, LOCO-RISE has found the following key points relating to rehabilitation and Long COVID:

Rehabilitation for Long COVID needs to be understood holistically and in its full breadth in terms of helping people to live well as well as to recover from ill health. Service models for

Long COVID rehabilitation vary across the country. To date many of these have been dependent on short-term funding and staff availability. This has resulted in considerable variation in professional availability and skill mix. A clear patient need for many in this population relates to mental health support. Yet very few services for Long COVID include mental health professionals or have an easy route to access these services.

Clinical staffing for rehabilitation teams as significantly stretched across Scotland pre-COVID. Challenges have therefore been experienced in responding to Long COVID service developments while restarting and maintaining existing rehabilitation services. Creating teams that focus on Long COVID rehabilitation develops staff's confidence, knowledge and expertise in working with this patient group with complex needs. Where a critical mass of staff cannot be resourced due to remoteness or rural settings such staff would greatly benefit from joining a knowledge network where they could benefit from the experience of their peers.

Clear and well publicised (to both the general public and Primary Care) pathways to access Long COVID rehabilitation result in significant numbers of people being referred and treated. In contrast, where such pathways have not been actively promoted referral numbers are very low. This highlights that patient need for Long COVID rehabilitation is considerable, but many members of the public are likely to be unable to access such services due to the lack of clearly publicised pathways and General Practitioners do not know where to refer patients to when they present. There is some evidence that staff in some Health Boards are unwilling to publicise such pathways as they are aware that their current funding and staffing capacity would make them unable to meet service demand and their current services would also suffer.

Study and research

Further research is required to understand the effectiveness of specific therapeutic interventions and rehabilitation services and for this population and specifically for sub-populations such as children and young people and individuals who have had Long COVID and wish to return to work.

The Scottish Government support the use of self-management strategies for Long COVID. The evidence-base for self-management interventions for people with Long COVID is limited. Our LOCO-RISE study has found that many people who present for assessment for Long COVID rehabilitation are considered unsuitable for self-management and require heath professional led and often lengthy and complex interventions. Further research into the suitability and effectiveness of self-management for Long COVID is therefore urgently required. Public and patient involvement should be sought in prioritising all future Long COVID research questions and PPI involvement should be central to all research teams throughout the research process.

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