

Manoj Sivan MD FRCP (Ed),

is an Associate Clinical Professor and Honorary Consultant in Rehabilitation Medicine (RM) with University of Leeds, Leeds Teaching Hospitals and Leeds Community Healthcare NHS Trusts. He led UK's first study on Covid-19 long term symptoms (Long Covid) published in July 2020 that led to the setting up of UK's first Covid rehabilitation service in Leeds in Sept 2020. He is also a WHO consultant for Covid rehabilitation in Europe.

**Stephen Halpin, MBChB, BSc, MRCP,**

is a Consultant in Rehabilitation Medicine in Leeds Teaching Hospitals and Leeds Community Healthcare Trusts, and Senior Clinical Research Fellow in Rehabilitation Medicine in University of Leeds. He is one of the lead clinicians of the Leeds Covid rehabilitation service.

**Jeremy Gee BSc MSc MCSP,**

qualified as a Physiotherapist in 2009 working rotationally across a wide variety of key areas within Airedale NHS Foundation Trust before focussing mainly on rehabilitation of older adults both in inpatient and community settings. After completing a Masters in Advanced Practice at the University of Leeds in 2019 Jeremy has expanded his holistic management of people within the community setting.

**Sophie Makower BA (Hons), Grad Dip Phys,**

qualified as a physiotherapist in 1989. After gaining broad experience she specialised in neurology. She has worked as a research physiotherapist within a multi-disciplinary research team at the University of Leeds developing and investigating therapeutic exercise devices for people with stroke. Since retiring from the NHS in 2018 she has continued to work in a research physiotherapist / research support role within a number of projects including the C19-YRS scale development project.

**Amy Parkin, MSc,**

is a senior neurological occupational therapist, currently on secondment with the Leeds Long Covid research team. She usually works at a specialist complex neurological rehabilitation unit, with a special interest in traumatic brain injury and motor processing. She is advancing her research skills in preparation for return to clinical practice and potential clinical academic career.

**Denise Ross, PhD,**

is a clinical academic specialist physiotherapist within the field of complex and neurological rehabilitation. She works at Leeds Teaching Hospitals NHS Trust, and leads R&I for the Physiotherapy Services.

**Mike Horton, PhD,**

is an academic Research Fellow at the University of Leeds, and the Director of Leeds Psychometric Laboratory for Health Sciences. He has over fifteen years of applied health research experience, and his research interests focus around measurement science, psychometrics, and implementing Rasch Measurement Theory to create measures of latent constructs.

**Rory O'Connor, MD FRCP,**

is the Charterhouse Professor of Rehabilitation Medicine, Chair of the Academic Department of Rehabilitation Medicine and a Pro-Dean for Research and Innovation at the University of Leeds. He is Lead Clinician and honorary consultant rehabilitation physician in Leeds Teaching Hospitals NHS Trust. He is also Deputy Clinical Director and Rehabilitation Technology theme lead for the National Institute for Health Research Devices for Dignity MedTech Co-operative (D4D).



The self-report version and digital format of the COVID-19 Yorkshire Rehabilitation Scale (C19-YRS) for Long Covid or Post-COVID syndrome assessment and monitoring

Abstract

The C19-YRS was the first scale reported in the literature for patient assessment and monitoring in Long Covid or Post-COVID syndrome. The scale has demonstrated content validity in a previous COVID-19 follow-up study. The growing number of patients with Post-COVID syndrome required the development of a self-report version (and a digital format) so that the scale can be completed by patients themselves. Individuals with Long Covid and clinicians providing care were involved in iterative changes to the scale. The self-report version of the scale captures symptom severity, functional disability and global health status. The C19-YRS digital format comprises a smartphone application for the patient and a web portal for the clinician to assess, triage and monitor patients remotely. The items have been shown to span all the components of the WHO ICF Framework for health condition.

Introduction

Long Covid (LC) refers to persistent symptoms four weeks after contracting COVID-19 illness and Post-COVID syndrome refers to symptoms 12 weeks after the illness.¹ There are an estimated more than 400,000 cases of Post-COVID syndrome in the UK alone and more than five million cases worldwide.¹ More than 200 symptoms across 10 organ systems have been reported with most common symptoms being breathlessness, fatigue, palpitations, dizziness, pain, brain fog (cognitive problems), anxiety, depression, post-traumatic stress, skin rash and allergic reactions.² It is a remitting and relapsing condition with a protracted course causing significant distress and disability to the individual.

A multidisciplinary team (MDT) of rehabilitation professionals quickly identified the need to address the essential issue of following up COVID-19 patients after hospital discharge during the first wave of the pandemic. As face-face appointments were deemed risky, the team recognised the requirement for virtual assessment of these patients.^{3,4} A telephone screening scale, the C19-YRS, was developed based on staff experience of managing these patients and knowledge from our systematic review of previous outbreaks.⁵ The final questions were decided using a consensus method and the scale was kept balanced in terms of questions spanning all aspects of the 2001 WHO International Classification of Functioning, Disability and Health (ICF) framework.⁶ The scale also allows directing patients to appropriate interventions based on severity of symptoms scored on the scale.⁷

We conducted the UK's first COVID-19 follow-up study investigating 100 patients discharged from hospital using a version of the C19-YRS scale to capture symptoms and rehabilitation needs.⁸ This study provided the content validity of the scale in that it captured and measured persistent symptoms reported in other studies.^{9,10} Fatigue, breathlessness, psychological symptoms, pain and cognitive problems were the

most common problems at seven weeks after hospital discharge. The findings of the above study prompted Leeds Clinical Commissioning Group (CCG) to invest in setting up a dedicated COVID rehabilitation service. This was the UK's first dedicated specialist service and is currently the benchmark service for other UK centres setting up their services. The central theme of this service is a comprehensive assessment of the individual, which is done using the C19-YRS scale. The scale guides person specific management and interventions based on severity of problems reported on the scale.

C-19 YRS is currently the only scale reported in the literature that can capture these symptoms and grade the severity of symptoms and no other outcome measures currently measures both the symptom severity and functional disability in LC. NHS England has recently invested £20 million in setting up 40 LC centres (clinics) to assess and manage patients with LC; recommending the use of C19-YRS at first assessment, six weeks and six months to monitor progress.¹¹ The use of the scale has been also been recommended in the NICE rapid guidelines.¹

With the growing number of cases of LC, there was a need for a patient self-report version of the scale that could be completed without clinician support. There was also a need for a digital format to reduce administrative burden and enable real time communication of findings to the LC MDT.

Aims

To describe the development of the self-report version and the digital version of the C19-YRS and to discuss the scale subsections of symptom severity, functional disability and overall health status.

Methods

A multidisciplinary team of physiotherapists, occupational therapists, rehabilitation physicians, researchers and a psychometrician has been involved in an iterative development of the self-report version of the C19-YRS. Important persistent symptoms (that define rehabilitation needs) reported in studies that have included non-hospitalised patients have also been considered.

The development of the self-report C19-YRS involved rephrasing some items of the original telephone C19-YRS to enable patients to respond to the questions on their own without needing a clinician to complete the responses. Items were reordered to separately group the items relating to symptoms, and the items relating to functional disability. Six additional items relating to symptoms were added based on emerging evidence reported by patients and clinical experience of authors.

Six individuals with Post-COVID syndrome completed the self-report C19-YRS and their feedback on content was incorporated in this new version of the C19-YRS. Specialists from Speech and Language therapy, dietitians, psychologists, Respiratory Medicine and



Figure 1: Digital display of C19-YRS scores on the application.

Intensive Care Medicine were also consulted during the scale development process. The emphasis remained on keeping the scale as brief and comprehensive as possible, without placing undue burden on the respondent (patient).

The final list of main problems included in the self-report or digital C19-YRS included breathlessness, cough/voice, swallowing/nutrition, fatigue, continence, cognition, pain/discomfort, anxiety, depression, post-traumatic stress disorder, communication, mobility, personal care, activities of daily living, social role, perceived health status and family/carers views.

The digital format of the self-report scale was developed by a private health company called ELAROS. The content of the digital format is the same as the self-report paper/electronic version difference only in the user interface and layout.

Self-report C19-YRS version

The scale can be completed independently by each individual or, if the individual prefers, by a clinician via telephone or face-face consultation, or with support from their family members or carers. It can be completed on paper or in electronic document format. There are 15 questions capturing the main problems, each with either yes/no response options and/or ordinal scale 0-10 severity grading. The respondents at first assessment are also asked to compare their symptoms before COVID if

applicable (Figure 1). Symptom severity can be considered mild if less than 3, moderate 3-5, severe 6 or more.

Questions 1-10 relate to the severity of the symptoms and questions 11-15 relate to the functional disability experienced by the individual. An additional six symptoms are placed towards the end of the scale, capturing severity of symptoms at the moment without pre-COVID severity. These symptoms will be tested in ongoing studies and will be incorporated into the core symptoms section if they are found to be clinically appropriate.

Digital format of C19-YRS

The digital C19-YRS uses a patient-facing app that captures symptoms and transfers this data safely, securely and in real-time to a web portal which can be remotely accessed by clinicians. The digital C19-YRS will also include extensive reporting tools to support health organisations to better deploy, gather evidence and account for the complex mix of resources utilised for these patients.

The app can be used by the patients and families to monitor progress in symptoms and provide reassurance on their progress (a radar splat graph of shrinking or expanding LC will be generated by the app) (Figures 1 and 2). This real time feedback is extremely important given the nature of symptoms and lack of professional contact during the lockdown measures. The patient can also be in the control of tracking daily and weekly fluctua-

Breakdown			
	Before COVID	Now	Total Score
Symptom severity			
1. Breathlessness	0	6	39/100
2. Cough / Voice Change / Noisy Breathing	0	0	
3. Swallowing / Nutrition	0	0	
4. Fatigue	0	9	
5. Continence	0	0	
6. Pain / Discomfort	2	5	
7. Cognition	0	6	
8. Anxiety	2	4	
9. Depression	1	7	
10. PTSD Screen	0	2	
Functional disability			
11. Communication	0	4	25/50
12. Mobility	0	3	
13. Personal-Care	0	4	
14. Other activities of daily living	0	6	
15. Social Role	0	8	
Overall health			
16. Overall Health	8	3	3/10
Other Symptoms			
Rate the severity of any Dizziness you've encountered	-	6	
Rate the severity of any Palpitations you've encountered	-	7	
Rate the severity of any Weakness you've encountered	-	2	
Rate the severity of any Sleep Problems you've encountered	-	7	
Rate the severity of any Fevers you've encountered	-	0	
Rate the severity of any Skin Rash you've encountered	-	0	
Overview			
	Before COVID	Now	
Symptom severity (out of 100)	5	39	
Functional disability (out of 50)	0	25	
Overall health (out of 10)	8	3	

Figure 2: Clinician web postal display of scores compared to before COVID.

tions of symptoms which can support planning of their daily routine (such as pacing for fatigue management).

Discussion

The self-report C19-YRS, and its digital format, captures the severity of the main persistent symptoms and functional disability in individuals with Long Covid or Post-COVID syndrome. The 0-10 likert scale of the items enables monitoring of problems across different time points of the condition, and can capture the impact of interventions used in the manage-

ment of the condition. The digital format of the scale allows users to track their condition in time and provides them with a quantitative assessment of improvement or deterioration of LC which is crucial in the management given lack of frequent human contact during the pandemic. Clinicians are able to monitor the patient's progress using the web-based clinical portal. Healthcare services can evaluate their treatment programmes using the digital system. National comparison of LC data can be undertaken while assessing the influence of individual demographics and illness characteristics

on LC symptoms. International standardisation of defining and quantifying the condition will also help towards developing clinical diagnostic criteria for the condition.

Mapping of scale to the ICF framework

The World Health Organisation (WHO)'s International Classification of Functioning, Disability and Health (ICF) provides us with a framework to understand the relationship between different aspects of any health condition.⁶ The domains covered by the self-report C19-YRS when mapped to the components of ICF (Figure 3) shows that there is satisfactory capture of all the components (body functions and structures, activities, participation, environmental factors and personal factors) making it suitable for a comprehensive biopsychosocial assessment.

Further research

Our future work with the scale will involve further validation of the use of the self-report version of C19-YRS (and its digital format) in the LC population. We will assess the construct validity of the scale, and whether the symptoms included in the self-report version adequately capture the burden in the individual. We will estimate whether the measure shows changes in the condition (responsiveness) and can be used by patients and clinicians to monitor effect of interventions, along with picking up the natural daily and weekly fluctuations of the condition. This can also estimate how effectively the measure captures differences between individuals, and changes over time within the individual. The floor and ceiling effects of the measure will be assessed to establish the active measurement range of the scale, and we will estimate how effectively the measure captures small differences between individuals at either end of the clinical spectrum of the condition. We will also evaluate the respondent burden of completing the measure within the population, and we will assess the use of digital tools, which can be challenging in certain cohorts (such as those with cognitive problems and those who do not use smartphones). The scale will undergo further gold-standard psychometric testing (through Rasch analysis) to further refine the scale and determine its validity as an outcome measure for monitoring the condition.

The C19-YRS self-report version/ digital format is currently being used by at least 20 UK NHS Trusts in their LC centres to assess and monitor the LC symptoms. This provides us with an opportunity to pool data and undertake big data analysis to undertake a robust analysis of psychometric properties. There is also an opportunity to explore whether it could be developed to a preference based measure and undertake an economic evaluation of resource use and QALY analysis. The findings of this further research is likely to influence local policy, commissioning and service delivery that is needed to manage the growing number of LC cases worldwide.

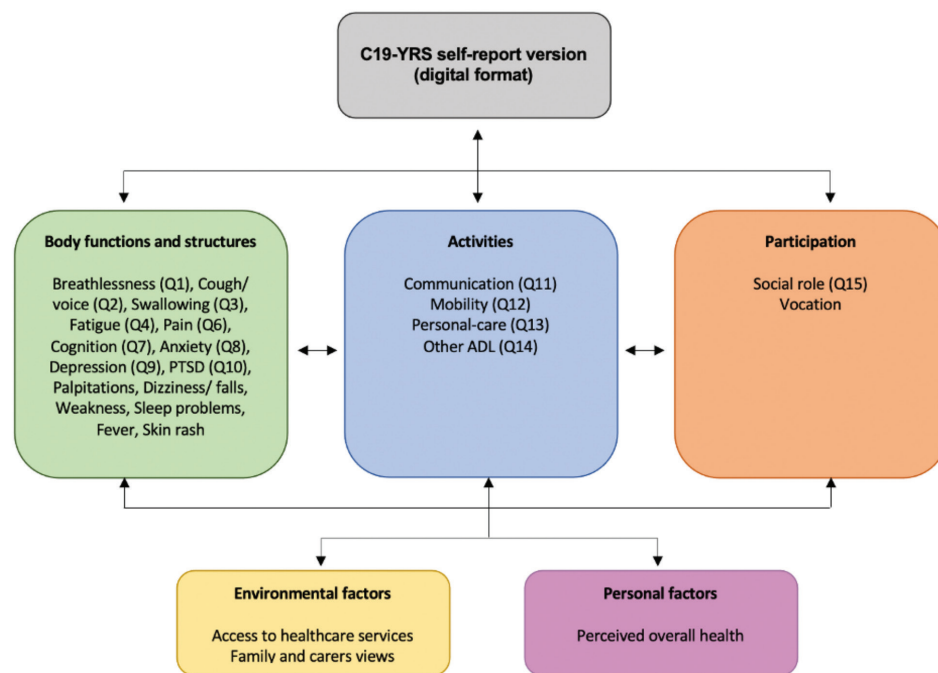


Figure 3: Mapping of the C19-YRS tool onto ICF framework.

Conclusion

A self-report C19-YRS has been developed to capture common symptoms, functional disability and overall health, assessing problems across the multiple body systems affected in LC and cover all aspects of the WHO ICF framework. The scale allows patients and health care staff to monitor these components over the course of the condition and assess the impact of rehabilitation interventions.

Using the scale

The C19-YRS self-report paper version is free to use, and the MS Word/ PDF copy of the tool is available on the ACNR website or University of Leeds website. The digital system for a clinical service can be acquired by contacting ELAROS who will provide a demonstration of the system and be involved in discussions with the institution's information governance department. The company might charge the service a fee for maintaining the web portal.

Correspondence to: M.Sivan@leeds.ac.uk

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Download the self-report C19-YRS

Appendix 1. The C19-YRS self-report version (for first assessment)

<https://acnr.co.uk/wp-content/uploads/2021/04/Appendix-I-Self-report-C19-YRS-first-assessment.docx>

Appendix 2. The C19-YRS self-report version (for subsequent assessments)

<https://acnr.co.uk/wp-content/uploads/2021/04/Appendix-II-Self-report-C19-YRS-subsequent-assessments.docx>

UoL weblink for the scale

<https://licensing.leeds.ac.uk/product/c19-yrs-covid-19-yorkshire-rehabilitation-scale>