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Assessing long-term rehabilitation needs in COVID-19 survivors using a telephone screening tool (C19-YRS tool)

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Abstract

The COVID-19 pandemic has caused more than 5 million infections and 300,000 deaths worldwide. Many survivors of the illness are likely to have long-term symptoms and disability that will pose a significant burden to the healthcare systems and economies all over the world. Given the scale of the burden and lockdown measures in most countries, there is a need for a pragmatic tele-assessment tool to screen for needs and target rehabilitation interventions in time. A comprehensive multi-system telephone screening tool called COVID-19 Yorkshire Rehabilitation Screening (C19-YRS) tool has been developed by multi-disciplinary-rehabilitation teams from Leeds, Airedale and Hull NHS Trusts to assess and capture symptoms and guide rehabilitation interventions for these individuals. The tool has been shown to cover all the components of the WHO ICF Framework.

Introduction

The first cases of Coronavirus disease 2019 (COVID-19) were reported in Wuhan in Dec 2019 rapidly spreading to other countries and was declared a pandemic by the World Health Organisation (WHO) on 11th March 2020. The United Kingdom is one of the worst affected countries with over 250,000 infected cases and more than 35,000 deaths at the time of writing this article. The condition is a respiratory illness caused by coronavirus SARS-CoV-2 and presents with a clinical spectrum that varies from asymptomatic or mildly symptomatic forms to life-threatening multi-organ failure and death. Wu et al (2020) reported that majority (81%) of cases have a mild presentation with either no symptoms or mild upper respiratory tract infection symptoms.[1] About 14% of cases have severe disease with dyspnoea, increased respiratory rate, hypoxia and/or lung infiltrates within 24-48 hours. A small but significant minority (5%) develop critical disease with respiratory failure, septic shock and/or multiple organ dysfunction/failure needing management in ITU. Case fatality

rate has been reported to range between 2% and 10% in different countries depending on extent of testing and reporting of deaths related to the infection.

COVID-19 is truly a multi-system illness with known common complications affecting the respiratory system (ARDS), cardiac (arrhythmias, myocardial injury), renal (acute kidney injury), gastrointestinal, nervous (neuropathy, encephalopathy), endocrine and musculoskeletal (weakness, pain, fatigue) systems.[2] The long-term problems in survivors is currently unknown but lessons can be learnt from previous major coronavirus outbreaks of Severe Acute Respiratory Syndrome (SARS) in 2002 and Middle East Respiratory Syndrome (MERS) in 2012. A meta-analysis of follow-up studies in SARS and MERS show reduced lung function and reduced exercise capacity in up to one-fourth of survivors at 6 months after discharge from hospital.[3] Mental health problems including post-traumatic stress disorder, anxiety and depression were observed in around one-third of survivors at 12 months after discharge. The quality of life was observed to be low even one year after discharge from the hospital. This research recommends rehabilitation clinicians and services to anticipate similar long-term health problems in survivors of COVID-19, investigate them accordingly and plan timely treatments to enable best possible recovery and quality of life for survivors.[3]

The NHS Long Term Plan (2019) pledges to improve outcomes for those with serious conditions by investing in out-of-hospital care and community services.[4] The emphasis is to provide personalised digitally-enhanced care that can be sustained long-term. Managing the aftermath of COVID-19 will require a holistic, multi-disciplinary team (MDT)-led integrated care in the community, whilst minimising face to face contact. Telemedicine is a well-established method of assessing, monitoring and providing interventions in a wide range of health conditions. Applying telemedicine to the current challenge of aftercare in the COVID-19 pandemic is an obvious choice for healthcare services across the globe.

Aims

We have developed a telephone screening tool (C19-YRS) for the rehabilitation clinician to capture the multi-system impairments and functioning in these individuals and use it as an intervention guide to provide needed support in the community.

Methods

The tool was developed by multidisciplinary teams of clinicians involved in providing COVID-19 rehabilitation care across the three regions of Yorkshire: West Yorkshire (Leeds Teaching Hospitals NHS Trust and Leeds Community Healthcare NHS Trust); North Yorkshire (Airedale NHS Foundation Trust) and East Yorkshire (Hull Hospitals NHS Trust). The teams comprised of physiotherapists, occupational therapists, speech and language therapists, psychologists, dietitians and physicians in Rehabilitation Medicine. Specialists from Respiratory Medicine and Intensive Care Medicine were also consulted.

These teams used virtual meeting methods to discuss and finalise a list of potential long-term problems after Covid-19 infection based on their clinical experience of managing these patients and also from reviewing the literature on SARS and MERS

follow-up studies. Through an iterative process they then decided on best pragmatic questions that would capture these domains concisely, without placing undue burden on the patient in the telephone screening process.

The final list of main problems identified by the specialists included breathlessness, voice, swallowing, nutrition, mobility, fatigue, personal care, usual activities, pain/discomfort, anxiety, depression, post-traumatic stress disorder, continence, cognition, perceived health status and family/carers views.

The C19-YRS screening tool

The tool is administered by a specialist clinician who is suitably trained to provide advice and suggestions to the patient during the telephone call (can also be done via video call). Consent of the patient is sought at the beginning of the interview. There are 19 questions capturing the main problems identified by the MDT, each with either yes/no response options and/or ordinal scale 0-10 grading response (Fig 1). The patient is also asked to provide a response for some symptom pre-illness (pre-COVID-19) if possible (this is not mandatory and will be difficult for those with cognitive impairment).

Two introductory questions address medical problems since discharge and utilisation of healthcare services including re-admission to acute care hospital. The structured questions follow, and the tool ends with the opportunity to capture any other new problems or consultation discussions in free text recording. The questionnaire can also be completed (even if not all questions) by family members or carers if the patient is unable to do the telephone consultation themselves due to cognitive or language impairments. The respondent is asked for consent to be called again for future follow-up telephone assessments. The clinician also provides specialist advice and directs the patient to local resources or services which are captured in the free text options of the tool. The tool took around 15 minutes to administer in some of our initial telephone consultations.

Fig 1. The C19-YRS tool

Covid 19 Yorkshire Rehab Screen (C19-YRS)

Patient name and NHS number:

Time and date of call:

Staff member making call:

We are getting in touch with people who have been discharged after having had a diagnosis of coronavirus disease (Covid-19). The purpose of this call is to find out if you are experiencing problems related to your recent illness with coronavirus. We will document this in your clinical notes. We will use this information to direct you to services you may need and inform the development of these services in the future.

This call will take around 15 minutes. If there's any topics you don't want to talk about you can stop the conversation at any point. Do you agree to talk to me about this today? **Yes** ☐ **No** ☐

Opening questions:

Have you had any further medical problems or needed to go back to hospital since your discharge? Re-admitted? **Yes** ☐ **No** ☐ Details:
Have you used any other health services since discharge (e.g. your GP?) **Yes** ☐ **No** ☐ Details:

I'll ask some questions about how you might have been affected since your illness. If there are other ways that you've been affected then there will be a chance to let me know these at the end.			
1. Breathlessness	On a scale of 0-10, with 0 being not breathless at all, and 10 being extremely breathless, how breathless are you: (n/a if does not perform this activity)	Now	Pre-Covid
	a) At rest?	0-10: ____	0-10: ____
	b) On dressing yourself?	0-10: ____ N/a ☐	0-10: ____ N/a ☐
	c) On walking up a flight of stairs?	0-10: ____ N/a ☐	0-10: ____ N/a ☐

2. Laryngeal/ airway complications	Have you developed any changes in the sensitivity of your throat such as troublesome cough or noisy breathing? **Yes** ☐ **No** ☐ If Yes: rate the significance of impact on a scale of 0-10 (0 being no impact, 10 being significant impact) **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐
3. Voice	Have you or your family noticed any changes to your voice such as difficulty being heard, altered quality of the voice, your voice tiring by the end of the day or an inability to alter the pitch of your voice? **Yes** ☐ **No** ☐ If Yes: rate the significance of impact on a scale of 0-10 (0 being no impact, 10 being significant impact) **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐
4. Swallowing	Are you having difficulties eating, drinking or swallowing such as coughing, choking or avoiding any food or drinks? **Yes** ☐ **No** ☐ *If Yes:* rate the significance of impact on a scale of 0-10 (0 being no impact, 10 being significant impact) **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐
5. Nutrition	Are you or your family concerned that you have ongoing weight loss or any ongoing nutritional concerns as a result of Covid-19? **Yes** ☐ **No** ☐ Please rank your appetite or interest in eating on a scale of 0-10 since Covid-19 (0 being same as usual/no problems, 10 being very severe problems/reduction) **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐
6. Mobility	On a 0-10 scale, how severe are any problems you have in walking about? *Or moving about if normally mobilises in another way* 0 means I have no problems, 10 means I am completely unable to walk about. Now: **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐ Pre-Covid: **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐
7. Fatigue	Do you become fatigued more easily compared to before your illness? **Yes** ☐ **No** ☐ *If yes:* how severely does this affect your mobility, personal cares, activities or enjoyment of life? (0 being not affecting, 10 being very severely impacting) Now: **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐ Pre-Covid: **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐
8. Personal-Care	On a 0-10 scale, how severe are any problems you have in personal cares such as washing and dressing yourself? 0 means I have no problems, 10 means I am completely unable to do my personal care. Now: **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐ Pre-Covid: **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐
9. Continence	Since your illness are you having any <u>new</u> problems with: • controlling your bowel **Yes** ☐ **No** ☐ • controlling your bladder **Yes** ☐ **No** ☐

10. Usual Activities	On a 0-10 scale, how severe are any problems you have in do your usual activities, such as your household role, leisure activities, work or study? 0 means I have no problems, 10 means I am completely unable to do my usual activities. Now: **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐ Pre-Covid: **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐
11. Pain/ discomfort	On a 0-10 scale, how severe is any pain or discomfort you have? 0 means I have no pain or discomfort, 10 means I have extremely severe pain Now: **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐ Pre-Covid: **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐
12. Cognition	Since your illness have you had new or worsened difficulty with: • concentrating? **Yes** ☐ **No** ☐ • short term memory? **Yes** ☐ **No** ☐
13. Cognitive-Communication	*Have you or your family noticed any change in the way you communicate with people, such as making sense of things people say to you, putting thoughts into words, difficulty reading or having a conversation?* **Yes** ☐ **No** ☐ If Yes: rate the significance of impact on a scale of 0-10 (0 being no impact, 10 being significant impact) **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐
14. Anxiety	On a 0-10 scale, how severe is the anxiety you are experiencing? 0 means I am not anxious, 10 means I have extreme anxious. Now: **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐ Pre-Covid: **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐
15. Depression	On a 0-10 scale, how severe is the depression you are experiencing? 0 means I am not depressed, 10 means I have extreme depression. Now: **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐ Pre-Covid: **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐
16. PTSD screen	a) Have you had any unwanted memories of your illness or hospital admission whilst you were awake, so not counting dreams? **Yes** ☐ **No** ☐ If yes, how much do these memories bother you? (is the distress: **mild** ☐ **/ moderate** ☐ **/ severe** ☐ **/ extreme** ☐) b) Have you had any unpleasant dreams about your illness or hospital admission? **Yes**☐ **No**☐ If yes, how much do these dreams bother you? (is the distress: **mild** ☐ **/ moderate** ☐ **/ severe** ☐ **/ extreme** ☐) c) Have you tried to avoid thoughts or feelings about your illness or hospital admission? **Yes** ☐ **No** ☐ If yes, how much effort do you make to avoid these thoughts or feelings? (**mild** ☐ **/ moderate** ☐ **/ severe** ☐ **/ extreme** ☐) d) Are you currently having thoughts about harming yourself in any way? **Yes** ☐ **No** ☐

17. Global Perceived Health	How good or bad is your health overall? 10 means the best health you can imagine. 0 means the worst health you can imagine. Now: **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐ Pre-Covid: **0** ☐ **1** ☐ **2** ☐ **3** ☐ **4** ☐ **5** ☐ **6** ☐ **7** ☐ **8** ☐ **9** ☐ **10** ☐
18. Vocation	What is your employment situation and has your illness affected your ability to do your usual work? Occupation: _____ Employment status before Covid-19 Lockdown: _____ Employment status before you became ill: _____ Employment status now: _____
19. Family/carers views	Do you think your family or carer would have anything to add from their perspective?

Closing questions:

Are you experiencing any other new problems since your illness we haven't mentioned? Any other discussion (clinical notes):

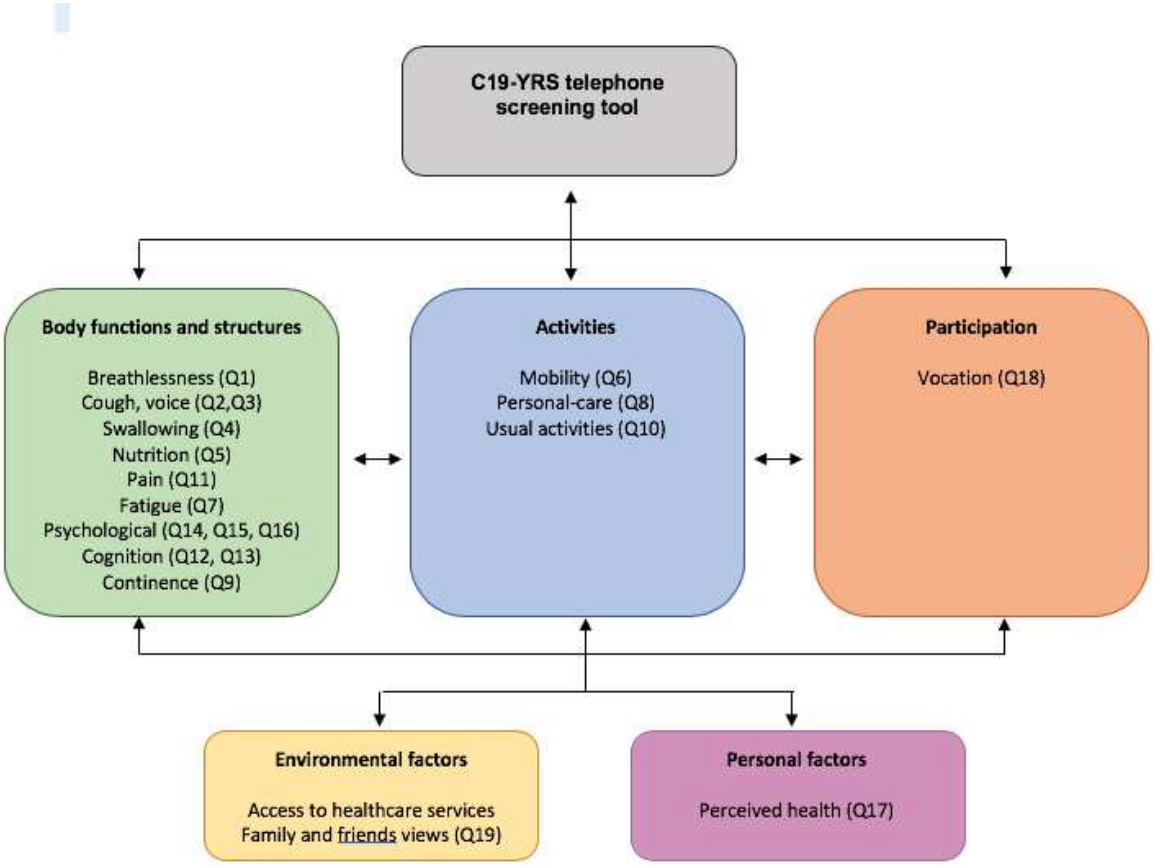
Discussion

The C19-YRS telephone screening tool captures the main potential long-term clinical problems COVID-19 survivors are likely to encounter after discharge from acute care services. It is a quick screening tool to be administered over a telephone (or video call) interview and not aimed at this stage to be a valid outcome measure on its own for this population. The tool is likely to be further developed in an iterative fashion based on clinicians' experiences during the consultations and suitable changes will be made to suit the needs and expectations of COVID-19 survivors.

Mapping of tool 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.[5] The domains covered by the C19-YRS tool when mapped to the components of ICF (Fig 2) 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.

Fig 2. Mapping of the C19-YRS tool onto ICF framework



Integration of services

The telephone screen can be administered by rehabilitation clinicians across the hospital and community Trusts. This promotes seamless care for these individuals after discharge from hospital. These work stream have been set up to support the survivors during the pandemic and in the long run will provide a model of integrated MDT follow-up for a wide range of other patient groups, in line with the NHS long-term plan.

COVID-19 MDT Rehabilitation Team

An ideal MDT Rehabilitation Team (Table 2) should have specialists trained in managing aspects of care of these individuals' and those with skills in managing chronic conditions. The team needs to have strong links with Respiratory Medicine and Intensive Care Unit teams and together develop network pathways for provision of appropriate care to these patients.

Table 2. COVID-19 MDT Rehab team

Staff	Roles
Physiotherapist	Pulmonary rehabilitation programme; improving mobility and stamina; fatigue management
Occupational therapist	Improving ability in ADLs, fatigue management, cognitive rehabilitation, vocational rehabilitation
Speech and Language therapist	Managing swallowing problems, voice and cognitive communication
Dietitian	Nutrition advice and intervention
Psychologist	Managing psychological problems
Physician (specialist in Rehabilitation Medicine/ GPwSI in chronic conditions/ other physicians)	Managing multimorbidity of Covid-19; Co-ordinating MDT care; mood and pain management; medication review

Information technology and data sharing

The completed tool can be uploaded to the patient's electronic records by the clinician conducting the telephone consultation. Both acute and community Trusts in Yorkshire have full integrated electronic medical records that are accessible to each other and also to patient's GP service. C19-YRS tool has also been programmed to automatically export responses into a Microsoft Excel file to avoid the need for manual data input. This allows rapid data analysis and generation of summary statistics.

Evaluation and next steps

C19-YRS is currently being used by at least 10 NHS Trusts in the UK to audit the long-term outcomes in Covid-19 discharged patients. Its use as a screening tool to

identify those requiring additional rehabilitation interventions can be tailored depending on local pathways, services and available resources. Interventions may include immediate advice from the administering clinician, directing to online resources for further information, signposting to Adult Social Care, or making referrals to community or specialist services. The findings of the audit in all the Trusts using it are likely to influence local policy, commissioning and service delivery that is needed to manage these individuals during the pandemic.

Conclusion

A pragmatic, comprehensive tele-assessment tool C19-YRS has been developed to screen for needs and target rehabilitation interventions in Covid-19 survivors after discharge from hospital care. The tool covers the multiple body systems affected in Covid-19 and covers all domains of the WHO ICF framework.

Using the tool

The C19-YRS tool is free to use and the MS Word/ PDF copy of the tool is available on ACNR website. The programmed version that can automatically export responses to MS Excel can be requested by contacting the corresponding author of this article.

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