

**National Institute for Health and
Care Excellence**

COVID-19 rapid guideline: managing the long-term effects of COVID-19

**[2] Supporting document: Expert
testimony for rehabilitation**

NICE guideline NG188

November 2021

Guideline version (Final)



COVID-19 supporting document: Expert testimony of rehabilitation services

Review date: November 2021

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Objective

This supporting document aims to present expert testimony that was heard by the expert panel in relation to gaps in the evidence around rehabilitation identified through review question in the scope for this guideline.

Review questions

The review questions that this supporting document aims to supplement are:

- What symptoms or signs indicate that referral to specialist care is needed for assessment or management of post-COVID-19 syndrome?
- What monitoring is helpful to assess deterioration or recovery in people with ongoing physical and mental health symptoms and problems of functioning and disability following acute COVID-19?
- What components should be included in a service model for the delivery of services to adults, children and young people with post-COVID-19 syndrome?

Methodology

The supporting document was developed using [NICE interim process and methods for guidelines developed in response to health and social care emergencies](#).

Where limited or no relevant studies are found on a key question, the panel can request expert testimony or expert evidence to be presented. This is to help them make recommendations on an identified evidence gap. A call for evidence was not appropriate because of the short development time, and very specific knowledge and expertise that was needed. Expert witnesses were needed for the areas of rehabilitation, vaccines and managing the long-term effects of COVID-19 in people under 18. The experts were chosen based on their knowledge, skills and experience in these areas, as well as their involvement with active research in this area. Expert witnesses were asked specific questions to answer in their testimony. A summary of each expert testimony was recorded in a standard form. When considering expert testimony, the panel consider the applicability, validity and consistency (when there is more than 1 testimony on a subject) of the testimonies. When recommendations are wholly or partly based on expert testimony, the evidence to decision or rationale sections of relevant recommendations

set out the panel considerations of the expert testimony. This supporting document covers the expert testimony presented for rehabilitation, in relation to the gaps in the evidence identified by the [review questions](#).

Summary of expert testimony

The expert panel were presented with testimonies presented by 3 different experts. This testimony covered the expert's experiences of interventions and rehabilitation for people with long term effects of COVID-19. A summary of the expert testimonies are provided in [Table 1](#).

Table 1: Summary of expert testimony

Expert(s)	Institution/Organisation	Intervention or programme	Focus of expert testimony
Gp Capt Edward Nicol QHS Defence Consultant Advisor in Medicine Consultant Cardiologist and General Physician	Defence Medical Services Royal Brompton Hospital	The Defence COVID-19 Recovery Service (DCRS) Defence Medical Rehabilitation Centre (DMRC) COVID-19 Rehabilitation service	Investigation and rehabilitation of those with ongoing symptoms of COVID-19 in the military
Dr Ben Kenny Director, Research Outcomes and Science Aidan Innes Research Associate & Outcomes Analyst Jodie Breach Senior Physiotherapist	Nuffield Health	COVID-19 rehabilitation programme	Referral, consultation and outcomes of the rehabilitation programme.
Bette Locke AHP Professional Advisor in Rehabilitation	Chief Nursing Officer's Directorate, Scottish Government	Long COVID services in Scotland	Results of a scoping survey of existing services for people with long COVID.

See [appendix](#) for full expert testimonies.

Expert panel discussion

Benefits and harms

Assessment and investigations

For people with ongoing symptomatic COVID-19 or post-COVID-19 syndrome, the panel heard evidence from expert testimony that an in-depth consultation between the individual and an appropriately skilled healthcare professional can be an informative part of the assessment process. Expert testimony (Nicol 2021 and Nuffield Health 2021) suggested that some practice is moving away from conducting lots of clinical tests towards a model where discussion is held with the individual to determine what matters to them and what their goals are, which was viewed as helpful for determining which are the most appropriate tests for that individual. One programme (Nicol 2021) progressively removed tests from its rehabilitation assessment, as it found that they did not inform whether a person was referred to rehabilitation, and what that rehabilitation looked like for them.

Expert witness testimony advised that many adults with new or ongoing symptoms after acute COVID-19 were experiencing anxiety caused by unnecessary investigations and referrals to different specialists. Members of the panel agreed that while clinical tests may still be indicated, particularly to identify the presence of other conditions, a conversation can be more reassuring and reduce anxiety by explaining what is known about ongoing COVID-19 and post-COVID-19 syndrome. Therefore, the panel advised that the NICE guideline on shared decision making should be signposted to. The panel agreed there should not be a recommendation cautioning against unnecessary investigations or referrals because there was already under-referral to dedicated clinics or MDTs. The panel also heard evidence from expert testimony (Locke 2021) that people value a range of formats for interactions with health services, with requests to use video formats which might allow the individual to watch the session back at a later date.

Rehabilitation

The panel heard evidence from expert testimony about various rehabilitation programmes (Nicol 2021 and Nuffield Health 2021). The length of these programmes varied: Nicol 2021 described a 2-week residential programme followed by monitoring and a gradual return to work. Nuffield Health 2021 described a 12-week programme (the first 6 weeks is completely virtual, the second 6 weeks has an in-person element) followed by continued access to support resources to use in the individual's own time.

The panel considered how long rehabilitation should last and agreed that it was dependent on the severity of symptoms at baseline; the change in these symptoms over time; and the goals set by the person (which might depend on the level of

support they had access to from other services, groups, or family members and friends). They agreed that, although it might be easiest not to set a timeline for discharge, this might result in a large increase to the resources needed by rehabilitation services and could divert resources from other parts of the health system, resulting in an opportunity cost. They therefore recommended that plans should be made, but that both the individual and the healthcare professional should take part in these decisions

The panel also heard evidence (Locke 2021) about the fluctuating nature of ongoing symptomatic COVID-19 and post-COVID-19 syndrome. Expert testimony put forward the importance of people being able to re-enter rehabilitation services after being discharged if their symptoms worsened. The panel recognised that symptoms may fluctuate and recur with patients needing to re-access support and services in the most efficient way possible. However, following shared decision making, local referral pathways would need to be followed due to variation in practice and funding.

The panel discussed, based on expert testimony (Locke 2021), that in some areas of the UK provision of an integrated multidisciplinary assessment service is not feasible and so added wording to take into account the other services that people may be referred to.

Certainty of the evidence

The panel acknowledged that the three testimonies all had limitations in terms of generalisability. People employed by the military may differ in characteristics from the rest of the population; the Nuffield model had fewer resource considerations than in the rest of the healthcare system; and the testimony from Scotland is in the context of the service model in NHS Scotland only. However, they noted that these findings were consistent with their own experiences, and were internally coherent. Despite the indirect elements of these models, the principles of shared decision making in discharge planning highlighted by the testimonies informed the panel decision making.

They discussed the fact that it is not possible to conduct randomised studies which actively withhold testing to investigate the effect on the referral pathway for ethical reasons, and therefore different types of evidence must be used.

Equity

The panel noted the possible under-representation of ethnic minorities and other groups with protected characteristics in the military (Nicol 2021) and accessing rehabilitation run by fee-paying organisations (even where the programme is free – Nuffield Health 2021). They felt that a reliance on an in-depth conversation about how symptoms impact on the individuals' health and well-being may be especially

important in these groups, and so did not expect the change to this current recommendation to result in equality issues.

Values and preferences

The panel also noted the expert testimony advising that many people with new or ongoing symptoms after acute COVID-19 were experiencing anxiety caused by unnecessary investigations and referrals to different specialists. Therefore, the panel agreed that for people who are concerned about new or ongoing symptoms 4 weeks or more after acute COVID-19, shared decision making should be used to discuss and agree with the person whether they need a further assessment.

Appendix: Expert testimony

Nicol 2021

Section A: Developer to complete	
Name:	Gp Capt Edward Nicol QHS
Role:	Expert Witness – practitioner Defence Consultant Advisor in Medicine Consultant Cardiologist and General Physician
Institution/Organisation (where applicable):	Defence Medical Services Royal Brompton Hospital
Guideline title:	Managing the long-term effects of COVID-19: update
Guideline Committee:	Expert Advisory Panel for the update of NG188
Subject of expert testimony:	Interventions and rehabilitation
Evidence gaps or uncertainties:	What monitoring is helpful to assess deterioration or recovery in people with ongoing physical and mental health symptoms and problems of functioning and disability following acute COVID-19? What symptoms or signs indicate that referral to specialist care is needed for assessment or management of post-COVID-19 syndrome? What components should be included in a service model for the delivery of services to adults, children and young people with post-COVID-19 syndrome?
<p>The following questions were agreed by the expert advisory panel as being most important for the expert testimony to address:</p> <ol style="list-style-type: none">1. What <u>assessments</u> (in primary care) and information on the referral form do you need to have before a person starts their rehabilitation?2. Who do you <u>accept referrals</u> from?3. What are the <u>barriers</u> to starting rehabilitation (e.g. blood tests not completed in primary care)?4. Do you <u>provide any advice</u> for management of people in primary care (for example, where waiting lists are long and there is a delay in accessing specialist management and rehabilitation?)5. How do you <u>identify people</u> who are appropriate for your rehab programme and how do you identify those who need to be referred to other care pathways for management of their symptoms?6. What <u>assessment</u> do you undertake prior to starting a rehabilitation programme (face to face or virtual)?7. What are the <u>components of the rehab programme</u> you offer (length of time, virtual or face to face, how many sessions), is it multimodality and what healthcare professionals are involved?	

8. What ranges of symptoms do you see, have you seen 'clusters' of symptoms (phenotypes) and what approaches have you used/ have worked well/ what were the outcomes with different symptom clusters?
9. How do you take account of fluctuating symptoms within the rehab programme (e.g. can the person re-access if they relapse, or does it require a new referral)?
10. What are the criteria for discharge from your programme and subsequent follow-up?
11. Are there any data about outcomes from your programme (number entered, completed, withdrawn [why?]) any improvement on QoL seen? Which outcome tools are you using (clinical tools and patient reported outcomes)?

Section B: Expert to complete

The Defence Medical Services perspective was presented for the investigation and rehabilitation of those with ongoing symptoms of COVID-19. Key points of the approach were highlighted:

- Questions with regards return to work after infection came very early on the pandemic.
- Due to the high-hazard, and demanding, roles of the military, there was a need to understand the prevalence of "hard" pathology, including myocarditis, pulmonary emboli, lung fibrosis. There transpired to be a low prevalence even in patients with severe initial disease.
- "Long COVID" emerged as a label but the preferred term remained "ongoing symptoms".
- Advice was provided early to the employer (Commanders) to highlight the "duty of care" to overcome misconceptions about the condition and potential underestimation of the impact of a novel disease on those working in an environment requiring high levels of fitness and motivation.
- In conjunction with occupational medicine, advice was provided by physicians and rehabilitation specialists to GPs that included screening, clinical advice, and referral pathways for those who remained symptomatic.
- 2 pathways were developed – The Defence COVID-19 Recovery Service (DCRS) which is a physician-led service, designed to confirm, or exclude, significant underlying "hard" pathology, and the Defence Medical Rehabilitation Centre (DMRC) COVID-19 Rehabilitation service, for post viral rehabilitation, with patients often following both pathways.
- A pragmatic approach to DCRS was developed, with regular iteration based on evidence from the population seen in the service.
- The ongoing Military COVID-19 (M-COVID) study; a longitudinal, observational cohort study, was initiated to allow assessment of residual effects of COVID-19 over time. The study involves baseline assessment (at a median 5 months since acute infection), 6-month and 12-month follow up of participants.

The DCRS programme was conceived in April 2020, the business case submitted in May 2020, and the programme was launched in August 2020.

The main internal challenges to setting up the service included remote working of GPs, and other administrative and support staff during the first lockdown and early stages of the pandemic, and the heavy demands on physician staffing resources, who were embedded in the NHS and supporting Host NHS Trust acute COVID-19 services.

The main external challenges included the lack of confirmatory tests for COVID-19 in the early stages of the pandemic, and issues with access to the NHS for secondary health care investigations during the peaks of the pandemic.

In the early iterations of the pathway, severity was defined clinically, at the earliest point of the pandemic, and patients with severe clinical disease, or ongoing symptoms >8 weeks, were progressed to further assessment. Whether a patient was symptomatic or asymptomatic

determined the timings with regards return to work and exercise, the need for primary care assessment, and occupational health clearance.

For patients recovering from severe acute COVID-19, a consensus-based 8-week follow up period was established, including appropriate tests. Chest pain was identified as a concern for myocarditis. POTS was not specifically identified as a major concern initially as it was unknown as a complication in the early phase, however pre-syncopal symptoms were a marker of significant concern, from the outset.

The cut-off point for further follow-up (in those with ongoing symptoms) was revised from 8 weeks to 12 weeks in the pathway to align with NG188 in January 2021. The pathway was further revised in March 2021, as more patients were admitted to hospital in the second wave, which led to the need to distinguish severe hospitalised patients, from those with less significant disease, who had been admitted.

Having 2 complimentary but distinct services (DCRS and the DMRC COVID-19 Rehabilitation service) led to some confusion among referring GPs, so the referral flowchart was revised into to highlight the pathways into both services. DCRS currently sees those who have received critical care admission (ITU/HDU or NIV) and those with a physiological deficit (O₂ Saturations <95%, chest pain and ECG changes).

The most common symptoms seen have been shortness of breath, fatigue, cognitive symptoms and poor concentration. However, mental health was considered important from the outset and patient reported outcome measures, including anxiety, depression, PTSD, mental wellbeing, fatigue, and alcohol misuse have been routinely collected from the outset.

Cardio-pulmonary exercise testing has been the key test, amongst others, and clinical investigation and assessment have been followed by a consultation with a physician and rehabilitation consultant and then discussion in a multidisciplinary team meeting to determine further investigations (if required) in Oxford.

The iterative development of the programme meant that tests that were found to be of limited value were ceased, including echocardiography, 6-minute walk test and dedicated spirometry (as this offered nothing above CPET spirometry). Cognitive testing is now done in the rehabilitation service, rather than in DCRS.

The DMRC Post COVID-19 service started in May 2020 and specific points regarding the rehabilitation programme includes:

- Rehabilitation starts at point of illness, supports a self-directed approach, and no blood tests are specifically needed to access the service.
- The pathway initially involves is a video consultation if patients' symptoms have not returned to baseline at 4-weeks or more.
- There is no specific recommendation for graded exercise, but exercise is encouraged and advice is tailored to patient needs.
- Goals are defined, using a booklet for information and education
- Physical deconditioning is assessed, and is prevalent following COVID-19 infection, however most individuals have been found to improve significantly (to near baseline) at 8-9 months
- Approximately 50% patients offered the 2-week residential programme attended, with numbers falling recently (this may be vaccine related).
- Safety netting (due to the concern over potential significant mental health effects) was built into the service from the outset, with access to appropriate specialist services.
- Graduated return to work is advised and over 90% of patients have returned to (some form of) work at 12 weeks

The DCRS service has recently scaled back due to lower numbers of patients, but prevalence is being monitored in preparation for a possible surge.

The provision of care has evolved into a more traditional post-viral rehabilitation model, with the physician-led service scaling back significantly, given the low prevalence of “hard” pathology found.

Summary of key findings of the physician led DCRS:

- There were very low levels of clinically significant cardiopulmonary pathology (<5% almost exclusively in hospitalised patients).
- Abnormal imaging findings are more prevalent, but usually associated with no physiological deficit, and clinically mild or asymptomatic patients in almost all cases.
- Cardio-pulmonary exercise testing has proven an excellent discriminator to identify those at risk of “hard” pathology.
- Meeting age predicted maximal exertion (which could be assessed at scale with Bruce Exercise ECG, or ramp bike protocols) excludes underlying pathology with high sensitivity and specificity.
- 25% of patients seen had dysautonomia (mainly seen in older age and a higher BMI)
- Importantly, there is no significant association between symptoms and dysautonomia.
- Dysautonomia does not explain shortness of breath, exertional intolerance or palpitations, but is associated with reduced functional capacity.

Questions:

Question: Blood tests in initial assessment provide important objective evidence e.g., CRP troponin, BNP etc., is this part of initial assessment?

Answer: At the initial consultation (at a median of 5 months after initial infection), all patients previous blood tests and imaging were sought prior to consultation, and all had additional blood tests and imaging, including BNP, full blood count, U&E, and CRP, but these have not been found to be of value for COVID-19 specifically. Blood tests are not considered helpful except for ruling out other diseases/causes of symptoms. Cardio-pulmonary exercise testing is seen as far more valuable, to ensure that patients are appropriately triaged. Exercise tests are likely to be better at scale, as access to CPET may be limited.

Question: How did you determine the appropriate rehab strategy for community-based patients who have had severe disease with ongoing symptoms?

Answer: Severity is clearly not directly linked to ongoing symptoms, as many who were not hospitalised and may not have had a serologically confirmed diagnosis still have long term effects. It is important to monitor these patients over 6-9 months. There is a low threshold for referral and DMRC COVID-19 rehabilitation, and supportive education. It is encouraging that these patients are starting to return to normal at this length of follow up.

Question: How was dysautonomia defined? Was it screened for, and, where present, did it alter the rehab approach?

Answer: A NEJM paper was used to diagnose dysautonomia based on the diagnostic criteria (Jouven, 2005). The finding of dysautonomia has not resulted in a significant change to rehabilitation, but certainly has interplayed with other symptoms such as anxiety and perception of breathlessness. It has informed advice and education for patients.

Question: Who should be admitted to inpatient care, and how many self-managed and how long was self-management process?

Answer: As a broad indication, around 75% patients were offered 2-week admission residential, but many didn't think they needed it and felt that the video consultation was enough with further self-management. As a proxy for the duration of self-management, the period of around 3 months appears to be the norm, as most people had returned to work in some capacity at that point. There is not a fixed period of intervention then an abrupt end, since it is patient led service, and tailored duration is needed. Access to rehabilitation services and specialist advice remains open, and patients may just need some further reassurance rather than a new consultation.

Question: Is the study population different to the general population and are the results generalisable?

Answer: Data is generalisable as the population characteristics are not dissimilar to the working aged general population. The data cannot be dismissed just because of the military setting – the population affected is not hugely different to the working-age general population (median age just under 40, BMI 30, high proportion of non-white and female attendees); and the data has relevance to the general population, since it concurs with other data outside the military setting.

Question: If diagnosis is confirmed is this self-fulfilling in improving symptoms?

Answer: Having confirmed serological diagnosis appears to be helpful, it allows triangulation of symptoms and may alleviate anxiety. Some people infected early in the pandemic had no formal serological diagnosis and waited for up to 6 months to get help when the service started, which in itself almost certainly caused anxiety and may have exacerbated symptoms.

Question: Was pharmacotherapy used in the cohort?

Answer: No pharmacological interventions have been advised. There is a need to manage symptoms and complications individually as necessary, which may involve established drug treatments. Steroids in acute phase have had a phenomenal impact and there is a need for research on anti-inflammatory agents in the context of long-term effects.

References to other work or publications to support your testimony' (if applicable):

Barker-Davies RM, O'Sullivan O, Senaratne KPP, Baker P, Cranley M, Dharm-Datta S, Ellis H, Goodall D, Gough M, Lewis S, Norman J, Papadopoulou T, Roscoe D, Sherwood D, Turner P, Walker T, Mistlin A, Phillip R, Nicol AM, Bennett AN, Bahadur S. The Stanford Hall consensus statement for post-COVID-19 rehabilitation. Br J Sports Med. 2020 Aug;54(16):949-959. doi: 10.1136/bjsports-2020-102596. Epub 2020 May 31. PMID: 32475821; PMCID: PMC7418628.

O'Sullivan O, Barker-Davies R, Chamley R, Sellon E, Jenkins D, Burley R, Holden L, Nicol AM, Phillip R, Bennett AN, Nicol E, Holdsworth DA. Defence Medical Rehabilitation Centre (DMRC) COVID-19 Recovery Service. BMJ Mil Health. 2021 Feb 5:e001681. doi: 10.1136/bmjilitary-2020-001681. Epub ahead of print. PMID: 33547188.

O'Sullivan O, Barker-Davies RM, Thompson K, et al Rehabilitation post-COVID-19: cross-sectional observations using the Stanford Hall remote assessment tool BMJ Mil Health Published Online First: 26 May 2021. doi: 10.1136/bmjilitary-2021-001856

Disclosure:

Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.

Nil

Declaration of interests: Please complete NICE's [declaration of interests \(DOI\) form](#) and return it with this form.

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Nuffield Health 2021

Section A: Developer to complete	
Name:	Ben Kenny Aidan Innes Jodie Breach
Role:	Expert Witness – Practitioner Director, Research Outcomes and Science Research Associate & Outcomes Analyst Senior Physiotherapist
Institution/Organisation (where applicable):	Nuffield Health
Guideline title:	Managing the long-term effects of COVID-19: update
Guideline Committee:	Expert Advisory Panel for the update of NG188
Subject of expert testimony:	Interventions and rehabilitation
Evidence gaps or uncertainties:	<p>What monitoring is helpful to assess deterioration or recovery in people with ongoing physical and mental health symptoms and problems of functioning and disability following acute COVID-19?</p> <p>What symptoms or signs indicate that referral to specialist care is needed for assessment or management of post-COVID-19 syndrome?</p> <p>What components should be included in a service model for the delivery of services to adults, children and young people with post-COVID-19 syndrome?</p>
<p>The following questions were agreed by the expert advisory panel as being most important for the expert testimony to address:</p> <ol style="list-style-type: none"> 12. What <u>assessments</u> (in primary care) and information on the referral form do you need to have before a person starts their rehabilitation? 13. Who do you <u>accept referrals</u> from? 14. What are the <u>barriers</u> to starting rehabilitation (e.g. blood tests not completed in primary care)? 15. Do you <u>provide any advice</u> for management of people in primary care (for example, where waiting lists are long and there is a delay in accessing specialist management and rehabilitation?) 16. How do you <u>identify people</u> who are appropriate for your rehab programme and how do you identify those who need to be referred to other care pathways for management of their symptoms? 17. What <u>assessment</u> do you undertake prior to starting a rehabilitation programme (face to face or virtual)? 18. What are the <u>components of the rehab programme</u> you offer (length of time, virtual or face to face, how many sessions), is it multimodality and what healthcare professionals are involved? 	

19. What ranges of symptoms do you see, have you seen 'clusters' of symptoms (phenotypes) and what approaches have you used/ have worked well/ what were the outcomes with different symptom clusters?
20. How do you take account of fluctuating symptoms within the rehab programme (e.g. can the person re-access if they relapse, or does it require a new referral)?
21. What are the criteria for discharge from your programme and subsequent follow-up?
22. Are there any data about outcomes from your programme (number entered, completed, withdrawn [why?]) any improvement on QoL seen? Which outcome tools are you using (clinical tools and patient reported outcomes)?

Section B: Expert to complete

Summary testimony:

The programme developed by Nuffield Health for the rehabilitation of ongoing symptoms of COVID-19 was presented.

There are four main steps to the rehabilitation service:

1. Referral: via GP, Consultant, Physiotherapy clinics, occupational health, and, recently, self-referral.

Inclusion/exclusion criteria apply: no uncontrolled medical conditions that would be exacerbated by exercise, have had either confirmed or suspected COVID, must not have active acute COVID symptoms, able to independently walk a minimum of 20 metres and climb a single flight of stairs, have the use of a smartphone, tablet or computer with a camera and internet access, are aged 18 or over.

2. Those referred complete a digital preassessment questionnaire on their clinical history and current health status and functional capacity.

3. Telephone triage consultation with a trained physiotherapist. This in-depth conversation on the patient's COVID history is guided by the results of the preassessment questionnaire. It allows for screening of health conditions which are not suitable for the rehab programme, e.g., myocarditis or VTE that are not treated yet. Risk of cardiovascular, respiratory and fatigue symptoms is assessed to check whether further medical assessment is required (people are free to return after discussion on these symptoms with a medical professional). Clinical reasoning is used to determine if Dysautonomia is too severe to participate in some upright exercise.

If appropriate and safe a 30 sec sit/stand test is used to assess what level of activity should be recommended.

4. Programme: Weeks 1–6 are fully remote and consist of weekly one-to-one calls, build your own activity, online group exercise and access to online resources, including advice as well as being sent a COVID-rehab handbook that contains further advice and log/diary for participants to track progress.

Weeks 7–12 mirrors week 1-6, with the exception of group exercise which is in person (gym-based). Patients are also encouraged to complete 'build your own' activity in the gym setting also. At week 12 participants are discharged but can continue to access the online resources and the gym for a further 3 months.

Should a patient request or require a more gradual progression through the programme they have an option to remain on a digital only pathway until they are sufficiently prepared to advance into a gym setting.

The one-to-one weekly calls are with upskilled personal trainers who have undertaken CIMSPA accredited CPD. If needed, a patient's situation can be escalated to discussion at a fortnightly multidisciplinary team (MDT) meeting. Participants can have their activity levels adjusted to accommodate fluctuating symptoms, or even drop out and re-refer later. The MDT consists of cardio-pulmonary specialist, physician, mental and physical health practitioners.

Outcomes

To date there have been 1700 referrals over 41 sites. 78% female and 84% Caucasian. Average age: 45

Based on 150 people who have completed the programme, after 12 weeks patient-reported outcomes showed the following improvements:

- 39% improvement in breathlessness, 70% improvement in emotional wellbeing, 45% improvement in functional capacity, 41% improvement in fitness. 3% reported no improvement in any clinical outcome.
- Dropout rate was 27% primarily due to work commitments preventing attendance of gym sessions in weeks 7-12. There were no serious adverse events.
- Participant feedback was that they valued the comprehensive, individualised programme, which was easy to understand, and they could build a relationship with their rehabilitation specialist.

Questions from panel

Q. As it is technology-based, is the population representative of our sociodemographic?

What is the economic impact for corporate colleagues in terms of return to work?

A. Only have postcode data, but the sociodemographic is broadly in line with national data. Being technology based hasn't been flagged as a barrier.

There is a huge demand from corporate clients. Use of Nuffield services has risen.

Q. Do you have confidence intervals, measures of precision for the data? This is a before and after study with no controls.

A. Confidence intervals can be provided. Difficult to find control data, so planning to use a waiting list control in future analyses. Happy to re-analyse if NHS control data can be provided.

Q. Who pays for the therapy, particularly the gym membership? Is cost a factor for the high level of dropout?

A. It is fully funded by Nuffield Health and therefore free for participants. The main reason for the high dropout rate is that by weeks 7–12 participants are returning to work and other commitments prevent them from attending classes.

Q. What is a rehabilitation specialist in this context?

A. Exercise professionals who have been upskilled/trained to deliver rehabilitation by completing CIMSPA accredited CPD developed by Nuffield Health.

Q. Part of the programme is run as a group (group exercise classes). What have been the benefits of group work, and has that been fully realised?

A. Participants have formed informal groups within the programme, but this has not been formalised or evaluated.

Q. What is the cost per participant for rolling out?

A. £200-300 per capita for the 12 weeks based on initial cost-benefit-analysis of pilot cohort but will be re-evaluated against larger data set in September 2021.

References to other work or publications to support your testimony' (if applicable):

<https://www.frontiersin.org/articles/10.3389/fpubh.2021.628333/full> protocol paper

<https://www.isrctn.com/ISRCTN14707226?q=14707226&filters=&sort=&offset=1&totalResults=1&page=1&pageSize=10&searchType=basic-search>

Disclosure:

Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.

None

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Locke 2021

Section A: Developer to complete	
Name:	Bette Locke
Role:	Expert Witness – Practitioner
Institution/Organisation (where applicable):	AHP Professional Advisor (Rehabilitation) Chief Nursing Officer's Directorate Scottish Government
Guideline title:	Managing the long-term effects of COVID-19: update
Guideline Committee:	Expert Advisory Panel for the update of NG188
Subject of expert testimony:	Rehabilitation
Evidence gaps or uncertainties:	<p>What monitoring is helpful to assess deterioration or recovery in people with ongoing physical and mental health symptoms and problems of functioning and disability following acute COVID-19?</p> <p>What symptoms or signs indicate that referral to specialist care is needed for assessment or management of post-COVID-19 syndrome?</p> <p>What components should be included in a service model for the delivery of services to adults, children and young people with post-COVID-19 syndrome?</p>
<p>The following questions were agreed by the expert advisory panel as being most important for the expert testimony to address:</p> <ul style="list-style-type: none"> • What <u>assessments</u> (in primary care) and information on the referral form do you need to have before a person starts their rehabilitation? • Who do you <u>accept referrals</u> from? • What are the <u>barriers</u> to starting rehabilitation (e.g. blood tests not completed in primary care)? • Do you <u>provide any advice</u> for management of people in primary care (for example, where waiting lists are long and there is a delay in accessing specialist management and rehabilitation?) • How do you <u>identify people</u> who are appropriate for your rehab programme and how do you identify those who need to be referred to other care pathways for management of their symptoms? • What <u>assessment</u> do you undertake prior to starting a rehabilitation programme (face to face or virtual)? • What are the <u>components</u> of the rehab programme you offer (length of time, virtual or face to face, how many sessions), is it multimodality and what healthcare professionals are involved? • What ranges of symptoms do you see, have you seen '<u>clusters</u>' of symptoms (phenotypes) and what approaches have you used/ have worked well/ what were the outcomes with different symptom clusters? • How do you take account of <u>fluctuating symptoms</u> within the rehab programme (e.g. can the person re-access if they relapse, or does it require a new referral)? 	

- What are the criteria for discharge from your programme and subsequent follow-up?
- Are there any data about outcomes from your programme (number entered, completed, withdrawn [why?]) any improvement on QoL seen? Which outcome tools are you using (clinical tools and patient reported outcomes)?

Section B: Expert to complete

Summary testimony:

Results of a scoping survey of existing services for people with long COVID were presented. The survey showed that support is incorporated into existing services, but not all people with long COVID have access to a multidisciplinary assessment for rehabilitation needs. Psychology and vocational rehab services are not always available. There are very few, if any long COVID clinics in Scotland. Feedback is that they are not appropriate due to:

- Geography (rurality etc)
- Low demand
- Workforce availability
- Concern re historical lack of services for other conditions CFS/ME, chronic pain, fibromyalgia, LTC management
- Concern re short term funding, what happens when funding ends?
- Future trajectory of long COVID – will they still be needed in a few years' time?

Rehabilitation services have had a 30% increase in demand, but few referrals are for long COVID. Generally, patients are seen within community rehabilitation services and in primary care.

General points on Long COVID Rehabilitation services:

- Challenges of access and coordination of care for people with long COVID
- Desire to not over-medicalise long COVID but there is a lack of AHPs to deliver non-medical support
- Some areas have developed, or want to develop, separate pathways so that existing service provision is not affected
- Separate pathways require additional funding
- Different demographics to those who usually access rehabilitation services so needs not necessarily met. E.g., younger working age. If they are keen to return to work a 4-month waiting list for rehab isn't helpful.
- Physical and mental health issues – need for integrated approach, not always available within existing rehab services
- Long COVID services should be based within primary care
- Staff shortages due to long COVID. In some health boards 25% of sickness absence has been reported as being due to long COVID. This puts a strain on existing services without development of additional pathways.

Screening for rehabilitation is moving away from tests to a 'good conversation' model where discussion is held with the patient to determine what matters to them and what their goals are. This can determine what investigations are needed. At this point the patient should also be directed to self-help resources as appropriate. Assessment is multidisciplinary and can face-to-face or via telephone or video consultation. Increasingly there are requests to use MS Teams as the meeting can be recorded.

All rehabilitation services are time limited and have a defined number of sessions or weeks. Most are moving to a more goal orientated approach where discharge is based on meeting

goals. With the fluctuating nature of long COVID, goals need to be redefined and people need to know how to get back into the service if needed after they have been discharged.

Examples of good practice in rehab services include InS:PIRE (Intensive Care Syndrome: Promoting Independence and Return to Employment) and HARP – healthy active rehab programme – which is not condition specific.

Questions from panel

Q. Can you expand on the impact on current provision. It is a complex problem and a ‘rob Peter to pay Paul’ scenario.

A. Yes, there is a tension. Long COVID services divert resource from rehab services to the detriment of patients with other conditions. Therefore, some boards would like extra funding for a separate pathway for long COVID patients. However, the question is for how long would this be funded? The number of long COVID patients being referred into services is low. We are also trying to increase and establish occupational therapy services in primary care to get people back into employment.

Q. How do we support people to ‘get ready for rehab’?

A. Primary care provide management, support and advice.

Q. What training is required for HCPs to conduct a ‘good conversation’?

A. There is significant training for a ‘good conversation’ as part of the ‘What Matters to You?’ programme, in line with Realistic Medicine. This is being rolled out across health boards and health and social care partnerships. The conversation is held with the patient then they are signposted to appropriate services and facilities (healthcare, third sector, etc)

Q. There is desperation amongst patients about how to get help. There is not low demand, people just don’t know how to access help and GPs don’t know what support is available to refer onto. Some places are working effectively for long COVID patients, and their models could be used elsewhere.

A. The information in this testimony is what has been reported as part of this investigation. It is a question about ability to access. If referral pathways for long-COVID are embedded into existing pathways then hopefully GPs are able to refer using those.

Q. Are there plans to include patient representatives in the planned structure for COVID patients in Scotland?

In England it was a huge relief to GPs to be able to refer to a long COVID clinic.

GPs in Scotland are not aware of pathways for long COVID. It has not been advertised that rehab services is the route, so GPs aren’t aware of this.

A. Care co-ordination still needs to be addressed.

The demand from patients with long COVID is unknown. We need to supplement community rehab teams to support people with long COVID. Waiting lists for community rehab teams are 4–6 months.

References to other work or publications to support your testimony’ (if applicable):

South Ayrshire Health and Social Care Partnership available at:
south-ayrshire.gov.uk

BACPR: The Future available at:
[www.bacpr.com/Resources/Dr Janet McKay.pdf](http://www.bacpr.com/Resources/Dr%20Janet%20McKay.pdf)

Disclosure:

Please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry.

None

Declaration of interests: Please complete NICE's [declaration of interests \(DOI\) form](#) and return it with this form.

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