

**National Institute for Health and
Care Excellence**

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

**[F] Evidence reviews for service
organisation**

NICE guideline NG188

December 2020

Guideline version (Final)



Disclaimer

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Literature search	4
Review question 8	4
Included studies	5
Key components	10
Disease severity	10
Follow up and monitoring	10
Multidisciplinary teams	10
Individualised interventions	10
Mode of delivery	11
Subgroups	11
Strengths and limitations	12
Expert panel discussion	12
Relative value of different outcomes	12
Quality of the evidence	13
Trade-off between benefits and harms	13
Implementation and resource considerations	14
Other considerations	15
Appendix 1 Methods used to develop the guidance	16
Appendix 2 Review protocol	17
Appendix 3 Literature search strategy	18
Appendix 4 Study flow diagram	19
Appendix 5 Included studies	20
Appendix 6 Evidence tables	21
Greenhalgh 2020b	22
Kopp 2020	24
O'Brien 2020	26
Rovere-Querini 2020	29
Salawu 2020	30
Sivan 2020	32
Appendix 7 Excluded studies	34
Appendix 8 Expert testimony	35

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

COVID-19 rapid evidence review: managing the long-term effects of COVID-19 (NG188)

Review question 8: service organisation

December 2020

Literature search

NICE's information services team identified relevant evidence through focused evidence searches between 22 and 28 October 2020 (see [appendix 3](#)). Additional studies were also considered from NICE surveillance up to 28 October 2020. Results from the literature searches and surveillance were screened using their titles and abstracts for relevance against the criteria from the protocol (see [appendix 2](#)). Four reviewers screened titles and abstracts. Having identified the evidence, four reviewers assessed the full text references of potentially relevant evidence to determine whether they met the inclusion criteria for this evidence review. All uncertainties were discussed and referred to an adviser if needed. See [appendix 4](#) for the study flow chart of included studies.

To complement this search, the Healthcare Improvement Scotland knowledge management team conducted a search to identify qualitative evidence to support the questions in this review. See [Managing the long-term effects of COVID-19: the views and experiences of patients, their families and carers](#) for more information. The search for patient experience evidence identified five qualitative studies relevant to the overall review. The themes emerging from these studies were considered alongside the quantitative evidence and included where appropriate. This review will be referred to in this document as 'patient lived experience'.

Review question 8

What components should be included in a service model for the delivery of services to people with post-COVID-19 syndrome?

Although the review question 8 focused on post-COVID-19 syndrome, the panel concluded that service delivery should not be confined to people who experience symptoms beyond 12 weeks. The evidence, patient experience and the panel's experience pointed to the need for support for those experiencing ongoing symptoms beyond 4 weeks, to help avoid deterioration in people's conditions and enable people to receive early preventative support.

The review protocol is shown in [appendix 2](#).

Included studies

In total 4104 references were identified through the searches. Of these 505 were included and ordered for full text assessment. A total of 58 references were included for the whole guideline, 7 of which were included for this review. These included studies from published and grey literature sources. Due to the paucity of evidence, searches were extended to all study designs and included service models based on case series, narrative reviews and expert consensus. Of the 7 service models, 3 were derived from institutional case studies, 2 from narrative reviews, 1 from a case series and 1 from a parliamentary report. Three of the models were developed in the UK, 2 in Italy and 1 study in Austria and 1 in Ireland. None of the service models reported patient or outcome data. See [table 1](#) for a brief overview of the included studies.

The panel noted the lack of evidence on service models and agreed that expert testimony would be of value to this question to capture evidence outside the published literature. Expert testimony was provided from a service that specialised in post COVID-19 complications, The Royal College of Psychiatrists and from the online support service [YourCOVIDRecovery](#). See [appendix 8](#) for each expert testimony.

Table 1: Overview of Included studies for review question 8: hospitalised patients

Study	Country, study design, dates	Population	COVID-19 disease severity	Time of follow-up	Main service model components
Gemelli 2020	Italy, Case study and narrative review, 2020	Post-acute COVID-19 older patients (age not defined)	Not reported	Infection monitoring proposed as 1 month after the onset of symptoms and at 3, 6, and 12 months but no follow up described for other areas	<p>Integrated multidisciplinary day care hospital</p> <ul style="list-style-type: none"> Comprehensive multisystem examination involving multiple healthcare visits to capture symptoms and carry out relevant investigations. Detailed model for the first assessment to gather minimum data set, subsequent stages customised based on findings. Specific exercise protocol based on the SPRINTT project.
Greenhalgh 2020b	UK, Parliamentary report, September 2020	<p>A. People who were very ill with acute COVID-19 with long-term organ damage along with weakness and debility;</p> <p>B. People with mild illness in the acute stage but with some evidence of long-term organ damage;</p> <p>C. People who have persistent symptoms after COVID-19 but without organ damage.</p>	Mild, severe and critical	Not reported	<p>4-tier clinical service approach</p> <ul style="list-style-type: none"> Tier 1 self management Tier 2 Generalist assessment, support, and rehabilitation Tier 3 Specialist assessment, support, and rehabilitation Tier 4 Specialist management of specific complications
Kopp 2020	Austria, Narrative review	Patients who experienced severe or critical COVID-19	Moderate, severe or critical	1-2 months post discharge	<p>Interdisciplinary model for scheduling post-discharge cardiopulmonary care</p> <p>Diagnostic testing and follow up care coordination by GP</p>

Study	Country, study design, dates	Population	COVID-19 disease severity	Time of follow-up	Main service model components
		illness or patients with chronic conditions experienced moderate, severe or critical COVID-19 illness.			<ul style="list-style-type: none"> • Referral and continued follow-up when indicated. • Hospital discharge personnel coordinate follow-up laboratory and radiological examinations, schedule a subsequent appointment with the patient's general practitioner or internist, and provide patient with written instructions. • The interdisciplinary model provides guidance for specialist referral and testing • After 2 months: Follow up as needed and at the discretion of managing specialists
O'Brien 2020	Ireland, Case study, 2020	Patients with a hospital diagnosis of COVID-19 pneumonia (ICU and non-ICU)	Moderate, severe and critical	8-12 weeks and 12 weeks post discharge	<p>Integrated multidisciplinary model of COVID-19 recovery care</p> <ul style="list-style-type: none"> • Hybrid model of virtual and in-person clinics • Supported by a weekly multidisciplinary meeting involving all supporting specialties • Multidisciplinary approach encourages appropriate discharge to integrated community care with referral to relevant community services • 8 to 12 weeks post-discharge virtual clinic – follow up chest X-ray and blood testing with MDT assessment to triage to in person or virtual follow up and also if mental health follow-up is required • 12-week post-discharge in person clinic – enhanced follow up for all ICU patients and non-ICU with clinical concerns • Enhanced schedule of investigations including pulmonary function testing and 6-min walk testing, CT thorax or an echocardiogram depending on clinical indications • Post COVID Mental health service includes initial screening, follow up screening including telephone and postal questionnaire, full clinical assessment and case-by-case intervention.

Study	Country, study design, dates	Population	COVID-19 disease severity	Time of follow-up	Main service model components
Rovere-Querini 2020	Case series and service model	COVID-19 survivors discharged from hospital (n=453) A&E (n=90) Hospital ward/ICU (n=363)	Moderate, severe, critical	4 weeks, 12 weeks and 6 months post discharge	<p>Post-COVID-19 follow-up clinic</p> <ul style="list-style-type: none"> Physical examination Respiratory evaluation (peripheral oxygen saturation, respiratory rate, dyspnoea assessment, lung ultrasound and pulmonary function) Cardiovascular assessment (electrocardiography, echocardiography) Nutritional assessment (anthropometrics, mini Nutritional Assessment screening tool) Neurological examination including cognitive tests Mental health assessment Quality of life assessment through the WHO Quality of Life (WHOQOL)-BREF questionnaire and screening of insomnia, anxiety, and post-traumatic stress disorder (PTSD) through validated indicators are performed in all patients Severe COVID-19 patients undergo a specific pulmonary follow-up through pulmonary function tests (PFT), impulse oscillometry and lung CT scan
Salawu 2020	UK, narrative review, 2020	Discharged COVID-19 patients (ICU and non-ICU)	Moderate, severe, critical	4 to 6 weeks and 12 weeks post discharge	<p>Multidisciplinary tele-rehabilitation model</p> <ul style="list-style-type: none"> Remote monitoring at 4 to 6 weeks and 12 weeks post discharge for rehabilitation needs. 4 to 6-week assessment used to identify suitable patients who may benefit from a tele-rehabilitation programme and opportunity to enrol 12-week nurse-led assessment: repeat CXR reviewed, refer to MDT rehabilitation if a need for specialist rehabilitation is identified Discharged COVID-19 patients managed along two streams based on ICU/non-ICU status identified by coding system

Study	Country, study design, dates	Population	COVID-19 disease severity	Time of follow-up	Main service model components
					<ul style="list-style-type: none"> • Bespoke interventions tailored to individual circumstances based on the assessment • Adaptable design of pathway to allow addition of interventions, as further evidence emerges • Supervised twice weekly exercise sessions with pacing
Sivan 2020	UK, case study, 2020	Discharged and non-hospitalised survivors of COVID-19	Not reported	6 weeks and 12 weeks post discharge	<p>Assessment and rehabilitation pathway:</p> <ul style="list-style-type: none"> • Telephone screening (C-19 YRS) at 6- and 12-weeks post-discharge for hospitalised individuals and ad hoc in primary care whenever patient presents. • If individuals are improving at 6 weeks and prefer to continue with self-management measures, they will continue to be monitored at 12 week follow up • The screening tool enables prompt detection of post-discharge symptoms and referral to specialist services/professionals based on needs. • The services in the pathway are either existing rehabilitation services or new services identified to manage complex post-COVID cases which could not be managed by existing services. • MDT must have specialist expertise to perform a detailed work-up of the individual and provide targeted interventions either face to face or using remote tele-consultation methods, or a combination.

Key components

Very low-quality evidence from narrative descriptions of service models indicated the following emergent themes for model components:

Disease severity

Most models were focused on people discharged from hospital following more severe illness, including those needing intensive care. Only 2 models also covered non-hospitalised patients.

Follow up and monitoring

Most models included an initial follow up monitoring component between 4 and 8 weeks since hospital discharge, or at the point of presentation in general practice for non-hospitalised patients, and a further follow up at 12 weeks. Some models also included longer term follow up components at 6 and 12 months, particularly for serious functional impairment. The patient lived experience evidence indicated that patient experience of follow-up in primary care, even with a telephone call, had a positive effect on their views of healthcare services.

Multidisciplinary teams

All of the service models included multidisciplinary components, highlighting the need to integrate specialist expertise to allow comprehensive investigation and individualised management strategies, including rehabilitation. The composition of the multidisciplinary teams (MDTs) varied, but the most common disciplines represented were respiratory medicine, rehabilitation, neurology, psychology, physiotherapy, occupational therapy. One model (O'Brien 2020) also included a separate post COVID-19 mental health MDT comprising psychology, psychiatry and liaison and community services. Some models stipulated the need for clearly defined roles, including pathway co-ordinators and a clinician contact responsible for overall care and navigating the system.

Individualised interventions

Most models stressed the importance of individualised management strategies, beginning with self-management interventions. These include attention to general health, rest and relaxation, careful self-pacing of tolerable exercise and setting

COVID-19 rapid evidence review: managing the long-term effects of COVID-19 (December 2020) 10 of 42

achievable goals. This was supported by the patient lived experience evidence, which indicated that patients attempted various forms of self-care, such as taking supplements, and made adjustments to their lifestyle, for example by reducing physical activity, to accommodate long-term symptoms of COVID-19. The patient lived experience data further indicated that providing knowledge and understanding of their condition helped people manage their anxiety.

Mode of delivery

The service models demonstrated differing approaches to the use of remote and face to face components in clinical practice. Some models focused on virtual assessment and rehabilitation, some primarily involved face-to-face components and others were hybrid approaches combining both modes of delivery. The models were based on indirect evidence from previous coronaviruses or on expert opinion. Two of the models used the same telephone screening tool (C19-YRS) developed specifically for screening people who are recovering from COVID-19 in the community for new or ongoing symptoms. No validation data was reported for the screening tool.

Subgroups

All the service models included components for people who had been discharged from hospital. Two models included components for people who had not been admitted to hospital. The only component specific to people in primary care was to conduct follow up assessment on presentation and not at a prescribed timepoint.

One model (Gemelli 2020) was configured specifically for older people without defining the age group. The model included an in-person clinic component with multiple healthcare visits to carry out investigations and individualise management strategies. An exercise component was included in this model for physical rehabilitation.

One model (Kopp 2020) was specific to cardiopulmonary follow-up of people discharged from hospital following severe or critical COVID-19 illness and people with chronic conditions discharged from hospital following moderate, severe or critical COVID-19 illness. This model provided guidance for specialist referral and

testing dependent upon the patient's signs and symptoms, as well as radiological and laboratory findings.

Strengths and limitations

Please note that GRADE is not used for NICE rapid COVID-19 guidelines. Risk of bias assessment is conducted.

This review sought to identify components of service models for the delivery of services to people with post-COVID-19 syndrome. Due to the novelty of the topic and the sparseness of the evidence base, the search was extended to include descriptive and analytic study designs. All of the included studies were limited by their descriptive design without any direct evidence to support the proposed service models. The models were either proposed or in the early stages of implementation without any reported validation or outcome data. Some of the models were reported to be in the early stages of implementation with further validation research needed.

A further limitation of the studies is that they may have been developed in the early stages of the pandemic and therefore may not reflect the current health service context. Only 1 of the models (Rovere Querini 2020) reported the date of development, with the model developed using a case series of patients between April and June 2020. The other models were also submitted for publication within the first 6 months of the pandemic. A further consequence of the short timeframe for evidence to emerge is the focus on people admitted to hospital and very limited evidence on those not admitted.

Expert panel discussion

This section describes how the expert panel considered the evidence in relation to the recommendations within the guidance.

Relative value of different outcomes

The quantitative outcomes the expert panel expected to see in the evidence were the proportion of post-COVID-19 patients being correctly identified; assessed and referred; and effectively managed and supported thereafter, using a particular service model. Further outcomes of interest were accessibility and timely referral, and individual components of service models. However, in the absence of any COVID-19 rapid evidence review: managing the long-term effects of COVID-19 (December 2020) 12 of 42

patient data, only components of proposed service models were reported in the studies. These components informed the panel discussions and reinforced some recommendations in the guideline sections on investigation and assessment, and management and rehabilitation.

Quality of the evidence

The panel noted the very low quality of evidence, the lack of data on patient outcomes and the possibility that the proposed service models may reflect the early part of the pandemic and not current practice. Whilst some preliminary data was provided via [expert testimony](#), the proposed models had not been validated. Therefore, whilst the expert testimony informed the panel's discussion of the components of a service model, the panel used their own expertise to discuss the components of service models that would be of value, based on their experiences, the limited evidence in the review and the patient lived experience data.

Trade-off between benefits and harms

The main components of a service model advocated by the panel were the use of MDTs with specialist expertise, individualised interventions beginning with self-management, and the use of both remote and in-person modes of delivery. However, differing patient views and experiences of face-to-face and remote assessment emerged from the patient lived experience evidence, which further underlines the need to allow for patient preferences in the mode of service delivery. Some patients reported a desire for face-to-face consultations to support the holistic assessment and care they thought they needed, whilst a positive view expressed about telemedicine was that it did increase accessibility of primary care during periods of societal restrictions aimed at controlling the spread of COVID-19.

The panel agreed that as well as ensuring the right breadth of expertise, having an MDT with input from other services and clear referral pathways can help to prevent people receiving disjointed care from multiple specialists and delayed appointments. This was supported by the patient lived experience evidence, which described both the difficulty in accessing the GP service and variability in GP's knowledge and understanding of the wide range of symptoms covered by the condition. Some patients favoured a 'one-stop' clinic with multidisciplinary teams there to assess

symptoms affecting a wide range of body systems. In addition to the core composition of the MDT, the panel stressed that expertise from other disciplines should be added depending on the person's age and symptoms. For example, this might include rheumatology, neurology rehabilitation, cardiology, paediatrics, dietetics, speech and language therapy, nursing and pharmacy.

The patient lived experience evidence supported other components proposed by the published service models, in particular the need for personalised care and a case manager or single point of contact to overcome barriers to accessing services, and the need for meaningful referral pathways.

The panel noted the importance of including components in service delivery that were not covered in the published models, including return to work and social prescribing interventions, and that sources of support should be provided for these where possible. The panel emphasised the value of digital self-management resources, but also noted the accessibility and digital literacy issues. The panel agreed that individualised care is vital and that shared decision making should be an integral part of the service delivery model.

The panel recognised that different areas of the UK have different service needs and resources, and therefore agreed that no single model would apply to all areas. For example, highly populated urban areas may need a different service configuration from rural areas. However, the panel agreed a multidisciplinary clinic for assessment was one option that could avoid multiple referrals and provide a single point for care. This could be 'one-stop' services to help keep appointments to a minimum, although the panel acknowledged that this might not be feasible for all services or desirable for all patients.

Implementation and resource considerations

In the absence of conclusive evidence on specific service delivery components, the panel considered that recommendations should take the form of general principles. This would allow for variations in service delivery across the devolved nations and enable local and regional adaptation of the guideline. The panel also expressed concern over the impact on existing services for other conditions and agreed that

resources should not be diverted from these services to new COVID-19 rehabilitation services.

Other considerations

A research priority emerged from the evidence review, for studies to optimise and evaluate the service model, including virtual and remote modes of delivery. This was considered by the panel and incorporated as a research recommendation, as detailed in the guideline.

Appendix 1 Methods used to develop the guidance

Please refer to [methods document](#) for details of the methods used to develop the guidance.

Appendix 2 Review protocol

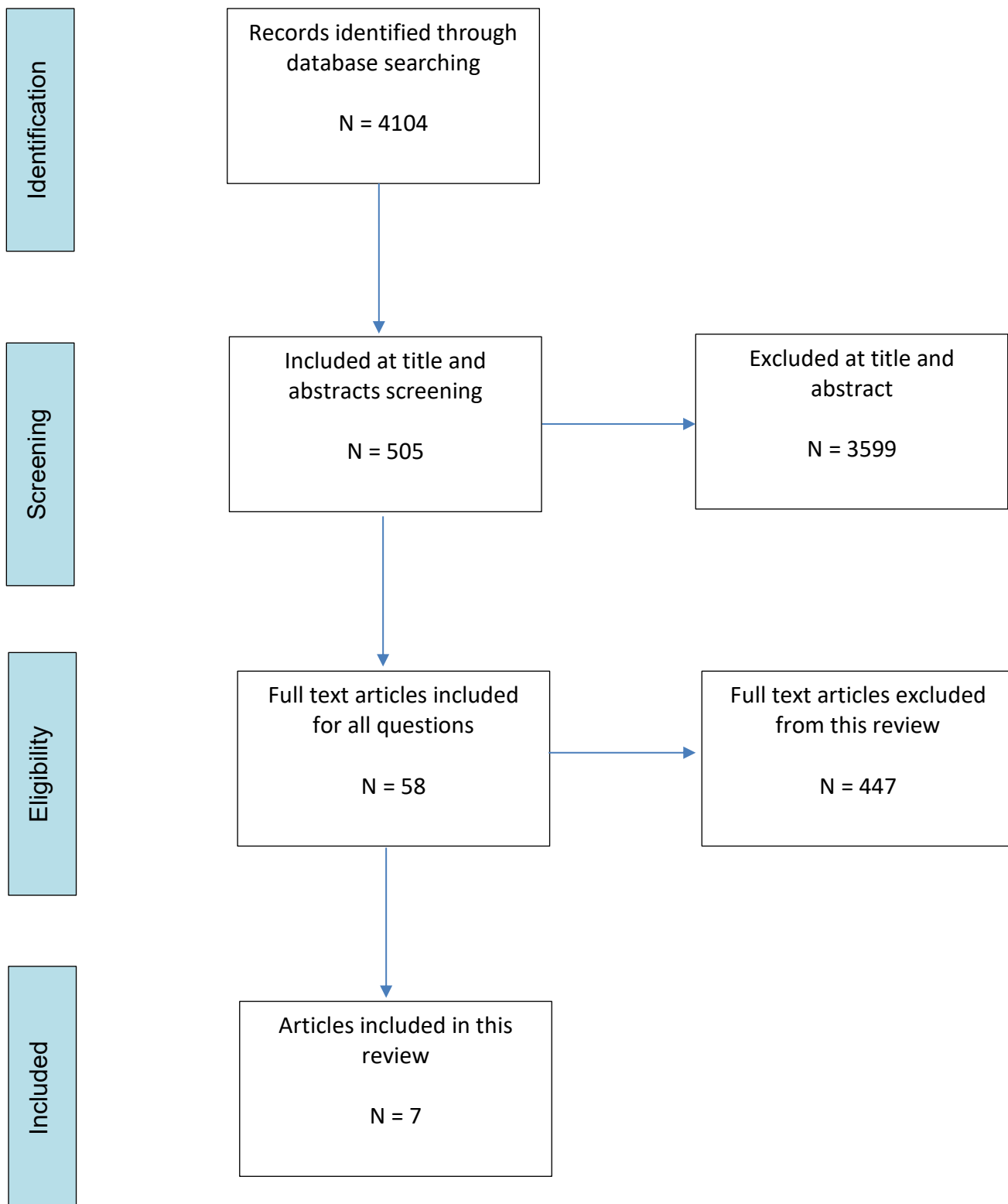
Review question 8: What components should be included in a service model for the delivery of services to people with post-COVID-19 syndrome (PCS)?

Criteria	Notes
Population	Adults and children who are experiencing new or ongoing symptoms: <ul style="list-style-type: none"> • 4 to 12 weeks from onset of acute COVID-19 illness • 12 weeks from onset of acute COVID-19 illness
Service configuration	<ul style="list-style-type: none"> • Service models and configuration
Comparators	Any or no comparator
Outcomes/evaluation/approach	<ul style="list-style-type: none"> • Proportion of PCS patients being correctly identified; assessed and referred; and effectively managed/ treated/ supported thereafter, using a particular service model • Accessibility and timely referral • Individual components identified including but not limited to: <ul style="list-style-type: none"> ○ Interventions (including specialist and multidisciplinary teams) ○ Self-referral routes ○ Employment support/information/links with benefits agencies/ employment housing
Settings	Any
Subgroups	<ul style="list-style-type: none"> • Groups as defined in the EIA for example, age, sex, ethnicity • Diagnosis of COVID-19 (e.g. confirmed or high clinical suspicion) • Duration of symptoms • Combinations of components
Study types	Any The following study design types for this question are preferred. Where these studies are not identified, other study designs will be considered. <ul style="list-style-type: none"> • RCTs • Systematic reviews of RCTs and observational studies • Prospective and retrospective observational studies
Countries	Any
Timepoints	Follow-up
Other exclusions	None

Appendix 3 Literature search strategy

Please refer to the [search history record](#) for full details of the search.

Appendix 4 Study flow diagram



Appendix 5 Included studies

Gemelli Against COVID-19 Post-Acute Care Study, Group (2020) Post-COVID-19 global health strategies: the need for an interdisciplinary approach. *Aging clinical and experimental research* 32(8): 1613 to 1620

Greenhalgh, T; Ladds, E; Knight, M 'Long Covid': evidence, recommendations and priority research questions. (2020) *Written evidence (COV0050)*

Kopp, Kristen, Lichtenauer, Michael, Motloch, Lukas Jaroslaw et al. (2020) Interdisciplinary Model for Scheduling Post-discharge Cardiopulmonary Care of Patients Following Severe and Critical SARS-CoV-2 (Coronavirus) Infection. *Frontiers in cardiovascular medicine* 7: 157

O'Brien H, Tracey MJ, Ottewill C, O'Brien ME, Morgan RK, Costello RW, Gunaratnam C, Ryan D, McElvaney NG, McConkey SJ, McNally C, Curley GF, MacHale S, Gillan D, Pender N, Barry H, de Barra E, Kiernan FM, Sulaiman I, Hurley K (2020) An integrated multidisciplinary model of COVID-19 recovery care. *Irish journal of medical science*

Rovere Querini, Patrizia, De Lorenzo, Rebecca, Conte, Caterina et al. (2020) Post-COVID-19 follow-up clinic: depicting chronicity of a new disease. *Acta bio-medica: Atenei Parmensis* 91(9s): 22 to 28

Salawu, Abayomi, Green, Angela, Crooks, Michael G et al. (2020) A Proposal for Multidisciplinary Tele-Rehabilitation in the Assessment and Rehabilitation of COVID-19 Survivors. *International journal of environmental research and public health* 17(13)

Sivan, Manoj, Halpin, Stephen, Hollingworth, Lisa et al. (2020) Development of an integrated rehabilitation pathway for individuals recovering from COVID-19 in the community. *Journal of rehabilitation medicine* 52(8): jrm00089

Appendix 6 Evidence tables

Gemelli 2020

Bibliographic reference/s	Gemelli Against COVID-19 Post-Acute Care Study Group., Landi, F., Gremese, E. et al. Post-COVID-19 global health strategies: the need for an interdisciplinary approach. Aging Clin Exp Res 32, 1613 to 1620 (2020)
Questions relevant to?	Service models
Publication status	Published
Study type	Narrative review and Case study
Quality	Very low quality
Objective	To describe the importance of the interdisciplinary approach – coordinated by geriatrician – to cope with the potential post-acute care needs of recovered COVID-19 patients.
Study date	Not reported
COVID-19 prevalence (high/low) if reported	Not reported
Country/ Setting	Italy
Population (including n)	Post-acute COVID-19 older patients (age not defined, but risk highlighted in >70 years)
Time since acute COVID-19 illness	Not reported
Interventions/ Prognostic factors	See proposed model
Baseline characteristics	Not reported
Inclusion and exclusion criteria	Not reported
Follow up	Not reported (Infection monitoring proposed as 1 month after the onset of symptoms and at 3, 6, and 12 months but no follow up described for other areas)
Proposed model	<p>The authors propose a comprehensive multisystem examination involving a number of healthcare visits to capture symptoms and carry out relevant investigations.</p> <p>In the described Post-COVID-19 Day Hospital, internal medicine and geriatric specialists are integrated with infectious disease physicians, pneumologists, immuno-rheumatologists, and other specialists into the management of the SARS-CoV-2 infection. This organisation allows developing tailored management strategies and the thorough investigation and description of the peculiar clinical consequence of COVID-19.</p> <p>Propose a detailed model for the first assessment (minimum data set for the assessment of COVID-19 patients), providing that subsequent stages can be customised based on the initial findings.</p> <p>Most patients do not need a specific rehabilitation programme but a physical activity program; for this reason, a specific exercise protocol based on the SPRINTT project has been implemented.</p>

Comments (e.g. source of funding, statistical analysis, any major limitations or issues with studies)	<p>Limitations</p> <p>No patient data reported or testing/validation of the proposed service model.</p> <p>Patient transfer between hospital departments may lead to infection control and logistical problems, including difficulties for patients navigating the hospital and attending on multiple visits.</p>
Additional references	N/A

Greenhalgh 2020b

Bibliographic reference/s	Greenhalgh, T; Ladds, E; Knight, M ‘Long Covid’: evidence, recommendations and priority research. Written evidence (COV0050)
Questions relevant to?	Risk factors, signs and symptoms, investigations, interventions, referral, service models.
Publication status	Published
Study type	Report
Quality	Very low quality
Objective	Not stated
Study date	23/9/20
COVID-19 prevalence (high/low) if reported	Not reported
Country/ Setting	UK
Population (including n)	<p>Patients with long Covid falling into three groups:</p> <p>A. People who were very ill (perhaps on ITU) with acute Covid-19 and now have significant long-term organ damage (e.g. lungs, heart, brain, kidneys) along with weakness and debility;</p> <p>B. People who were not so ill in the acute stage but who also now have some evidence of long-term organ damage; and</p> <p>C. People who have persistent symptoms after Covid-19 but who do not have persisting organ damage.</p>
Time since acute COVID-19 illness	3 weeks or more
Interventions/ Prognostic factors	See main recommendations
Baseline characteristics	Not applicable
Inclusion and exclusion criteria	Not applicable
Follow up	3 weeks or more
Main recommendations and research priorities	<p>A 4-tier clinical service should be developed:</p> <p>a) Tier 1: resources and support for self-care.</p> <ul style="list-style-type: none"> • Accurate information about the disease and its likely course • Resources to support self-care (including online programmes) • Careful pacing and self-monitoring towards recovery

	<p>b) Tier 2: generalist care including a therapeutic relationship in general practice and a community-based interdisciplinary rehabilitation service led by allied health professionals.</p> <ul style="list-style-type: none"> • Therapeutic relationship with a generalist clinician. Full history, clinical examination and functional assessment • Confirm that long Covid is the likely or possible diagnosis (even in the absence of a positive test), and document on medical record • Basic tests (e.g. bloods, ECG, X-rays, pulse oximetry) if appropriate to exclude alternative diagnoses (e.g. sepsis) and rule out serious complications. Note: not all patients will need such tests • Generalist rehabilitation support (remote or face to face) • Ongoing monitoring and support (e.g. by telephone, video, or in-person check-ups) as needed • Management of other long-term conditions <p>c) Tier 3: specialist care including system-based investigation, management and rehabilitation.</p> <ul style="list-style-type: none"> • Dedicated Covid-19 rehabilitation clinic (usually respiratory but sometimes neuro- or cardiac) • Personalised rehabilitation plan with (e.g.) breathing exercises, supervised pacing and psychological support • Referral to other specialties as appropriate e.g. cardiology, neurology, haematology, psychiatry • Testing according to specialist guidelines (e.g. CT, MRI) • Dialogue and agreed division of responsibility between secondary (and tertiary care) <p>d) Tier 4: specialist management of specific complications.</p> <ul style="list-style-type: none"> • Inpatient admission <p>Priority areas for research:</p> <p>a) Basic science studies on upstream causes, including genetics and metabolomics.</p> <p>b) Observational studies of long-term outcome, especially in non-hospitalised patients.</p> <p>c) Trials of interventions, including different rehabilitation protocols.</p> <p>d) Studies to optimise and evaluate the service model, including virtual wards and remote care.</p> <p>e) Interdisciplinary studies of how socio-economic and racial disadvantage affects the development, course and outcome of long COVID.</p>
<p>Comments (e.g. source of funding, statistical analysis, any major limitations or issues with studies)</p>	<p>This report was submitted as written evidence to the parliamentary select committee.</p>
<p>Additional references</p>	<p>N/A</p>

Kopp 2020

Bibliographic reference/s	Kopp, Kristen, Lichtenauer, Michael, Motloch, Lukas Jaroslaw et al. (2020) Interdisciplinary Model for Scheduling Post-discharge Cardiopulmonary Care of Patients Following Severe and Critical SARS-CoV-2 (Coronavirus) Infection. Frontiers in cardiovascular medicine 7: 157
Questions relevant to?	Service models
Publication status	Published
Study type	Narrative review
Quality	Very low quality
Objective	To propose an Interdisciplinary model for scheduling post-discharge cardiopulmonary care following severe and critical SARS-CoV-2 infection
Study date	Not reported
COVID-19 prevalence (high/low) if reported	Not reported
Country/ Setting	International studies reviewed
Population (including n)	<ul style="list-style-type: none"> • Patients who experienced severe* illness defined as individuals who had respiratory frequency >30 breaths per minute, SpO₂ < 94% on room air at sea level, a ratio of arterial partial pressure of oxygen to fraction of inspired oxygen (PaO₂/FiO₂) <300 mmHg, or lung infiltrates 50% (e.g., patients treated at an ICU requiring invasive ventilation or CPAP during SARS-CoV-2 infection) • Patients who experienced critical* illness, defined as individuals who had respiratory failure, septic shock, and/or multiple organ dysfunction (e.g., patients treated at an ICU requiring ECMO during SARS-CoV-2 infection) • Patients with chronic conditions (e.g., COPD, cardiomyopathy, coronary artery disease, cancer, chronic kidney disease, hepatic disease, and uncontrolled diabetes) in the presence of disease exacerbation or progression during/following moderate*, severe and critical SARS-CoV-2 infection, where moderate infection is defined as individuals with evidence of lower respiratory disease by clinical assessment, imaging and a saturation of oxygen (SpO₂) > 94% on room air at sea level. <p>*NIH definitions of moderate, severe and critical illness</p>
Time since acute COVID-19 illness	Not reported
Interventions/ Prognostic factors	See proposed model
Baseline characteristics	Not reported
Study type	Narrative review
Quality	Very low quality
Inclusion and exclusion criteria	Not reported
Follow up	1 to 2 months post-discharge

Bibliographic reference/s	Kopp, Kristen, Lichtenauer, Michael, Motloch, Lukas Jaroslaw et al. (2020) Interdisciplinary Model for Scheduling Post-discharge Cardiopulmonary Care of Patients Following Severe and Critical SARS-CoV-2 (Coronavirus) Infection. Frontiers in cardiovascular medicine 7: 157
Questions relevant to?	Service models
Publication status	Published
Proposed model	<p>Care pathway presented for:</p> <ul style="list-style-type: none"> • Diagnostic Testing, Care Coordination by GP/Internist • Referral and continued follow-up when indicated. <p>GP/internist:</p> <ul style="list-style-type: none"> • Clinical evaluation of symptoms (dyspnoea, fatigue, psychological disorders) • Auscultation (determine signs of pulmonary fibrosis), • Oxygen saturation • ECG • Evaluation of laboratory, radiology and clinical findings, discussion with patient • Referral for further specialist examinations (e.g., pulmonologist, cardiologist) if indicated • Referral to neurologist, nephrologist, endocrinologist by suspicion of sequelae • Evaluate, prescribe, discuss discharge medications, any O2 use, and care plan with patient, provide written instructions • Involve social worker/psychologist if further support needed <p>Pulmonologist (if indicated):</p> <ul style="list-style-type: none"> • CT evaluation and discussion with patient • Physical exam: signs and symptoms • Lung function test • 6-min walk test • Blood-gas test • Re-evaluation of medications, O2 use • Determine need for rehabilitation or intermediate/long-term care • Address primary/secondary prevention measures where applicable • Plan 6- and 12-month follow-up by any evidence of reduced functional capacity • Communicate findings and treatment plan to patient and general practitioner <p>Cardiologist Physical exam: signs and symptoms ECG Transthoracic echocardiography Re-evaluation/adjustments of medications</p>

Bibliographic reference/s	Kopp, Kristen, Lichtenauer, Michael, Motloch, Lukas Jaroslaw et al. (2020) Interdisciplinary Model for Scheduling Post-discharge Cardiopulmonary Care of Patients Following Severe and Critical SARS-CoV-2 (Coronavirus) Infection. Frontiers in cardiovascular medicine 7: 157
Questions relevant to?	Service models
Publication status	Published
	<p>For patients with signs of heart failure: enrollment in heart failure program; for all HF patients: evaluate need for visiting heart failure nurse/rehabilitation program</p> <ul style="list-style-type: none"> • For patients with arrhythmias, plan further evaluation (i.e., Holter monitoring, event recorder) • Address primary/secondary prevention measures where applicable • Schedule follow-up if appropriate • Communicate findings and treatment plan to patient and general practitioner <p>Hospital discharge personnel coordinate follow-up laboratory and radiological examinations, schedule a subsequent appointment with the patient's general practitioner or internist, and provide patient with written instructions. The patient's primary care physician or internist will serve as follow-up care coordinator. The interdisciplinary model provides guidance for specialist referral and testing dependent upon the patient's signs and symptoms, as well as radiological and laboratory findings.</p> <p>After 2 months: Follow up as needed and at the discretion of managing specialists</p>
Comments (e.g. source of funding, statistical analysis, any major limitations, or issues with studies)	Limitations: Model proposed based on indirect data from SARS/MERS
Additional references	N/A

O'Brien 2020

Bibliographic reference/s	O'Brien H, Tracey MJ, Ottewill C, O'Brien ME, Morgan RK, Costello RW, Gunaratnam C, Ryan D, McElvaney NG, McConkey SJ, McNally C, Curley GF, MacHale S, Gillan D, Pender N, Barry H, de Barra E, Kiernan FM, Sulaiman I, Hurley K (2020) An integrated multidisciplinary model of COVID-19 recovery care. Irish journal of medical science
Questions relevant to?	Service models
Publication status	Published

COVID-19 rapid evidence review: managing the long-term effects of COVID-19 (December 2020) 26 of 42

Study type	Case study
Quality	Very low quality
Objective	To describe the establishment of a COVID Recovery Service, a multidisciplinary service for comprehensive follow-up of patients with a hospital diagnosis of COVID-19 pneumonia.
Study date	Not reported (Patients were discharged March 15 to June 30, 2020)
COVID-19 prevalence (high/low) if reported	Not reported
Country/ Setting	Republic of Ireland
Population (including n)	Patients with a hospital diagnosis of COVID-19 pneumonia (n=174) (22% ICU and 78% non-ICU)
Time since acute COVID-19 illness	Not reported
Interventions/ Prognostic factors	See proposed model
Baseline characteristics	Not applicable
Inclusion and exclusion criteria	Enrolment into the pathway is based on a diagnosis of pneumonia on the admission chest X-ray, with a positive PCR test or a clinical diagnosis of COVID-19
Follow up	8 to 12 weeks post discharge, 12 weeks post discharge, 6- and 12-months post discharge
Proposed model	<p>Proposed pathway:</p> <p>The COVID recovery outpatient service consists of an enhanced and virtual pathway, supported by a weekly multidisciplinary meeting involving all supporting specialties. This multidisciplinary approach encourages appropriate discharge to integrated community care with referral to relevant community services.</p> <p>8 to 12 weeks post-discharge virtual clinic:</p> <ul style="list-style-type: none"> • All patients have a follow-up chest X-ray, blood testing (full blood count, renal, liver and bone biochemistry, BNP, D-dimer, and serum sample for SARS-CoV-2 antibody), and complete a standardised phone-based assessment of symptoms, mental health status, and quality of life. Subsequently, their cases are discussed at the COVID recovery multidisciplinary meeting (MDM). • A consensus is reached by the MDM to triage the patient to in-person or virtual follow-up and also if mental health follow-up is required. • Patients who were admitted to the ward, but did not require ICU admission or non-invasive ventilation, have a virtual follow-up and are discharged to community services unless a significant residual impairment is identified. • This virtual follow-up will ascertain their level of residual symptoms after COVID-19, functional capacity, quality of life scores, and the presence of mental health difficulties using a standardized questionnaire (SF-36). • Virtual clinic is run by a physician associate (PA) with oversight and governance from respiratory and infectious diseases, psychiatry, and ICU consultants.

	<p>12 weeks post-discharge in-person clinic:</p> <ul style="list-style-type: none"> • All patients who were admitted to the ICU, or who required noninvasive ventilation at ward level, have enhanced follow-up at an in-person clinic. • Patients admitted to the ward, but who did not require ICU admission or non-invasive ventilation but present clinical concerns from virtual clinical, also receive enhanced follow up at in-person clinic. • This cohort of patients then receives an enhanced schedule of investigations including pulmonary function testing and 6-min walk testing, and some may require a CT thorax or an echocardiogram depending on clinical indications. • Patients with greater medical, rehabilitation, and psychiatric and psychological needs will have an in-person assessment and may need a follow-up in a specialised survivorship clinic for 6 to 12 months. <p>Multidisciplinary Post COVID mental health service:</p> <ul style="list-style-type: none"> • The COVID recovery service implements a brief telephone screening including both mental health and cognitive symptoms. • Following the initial screening, those deemed in need of further mental health assessment and intervention are followed-up with stage 2 screening, comprising telephone call and postal questionnaires from the COVID mental health service (COVPSYCH) team. • The telephone call will include a brief objective and subjective screen of cognition. • If the stage 2 screen is positive, a clinic or virtual appointment will be arranged with the COVPSYCH team within 4 weeks, whereby a full clinical assessment will be carried out, including cognitive testing where appropriate. • If required, pharmacological and therapeutic intervention is delivered on a case-by-case basis. <p>Patient data:</p> <p>50 patients have been reviewed at the MDM, 26/50 have been discharged to their GP, while 24/50 will require follow-up in the in-person COVID recovery clinic and with other specialty clinics.</p>
<p>Comments (e.g. source of funding, statistical analysis, any major limitations or issues with studies)</p>	<p>Limitations:</p> <p>Limitations exist in assessing patients over the phone, particularly in regard to language barriers with patients who do not speak English as their first language.</p> <p>While the SF-36 is an excellent tool to assess functional and cognitive limitations following an acute illness, patients may be reluctant to discuss sensitive mental health questions over the phone. This may result in underestimation of the burden of health issues.</p> <p>Challenges:</p> <p>The practicalities of organising an in-person clinic for any patient group during the rapidly evolving phases of a pandemic are challenging. Social distancing has reduced the volume of patients assessed in one sitting and creates difficulties for patients navigating the hospital for their various investigations.</p> <p>Outsourcing of some initial investigations to satellite sites has helped to ensure that all relevant investigations are completed in accordance with our scheduling guidelines. However, there have already been some non-attendances in the critical patient group as a result of mental and physical barriers post COVID-19.</p>
<p>Additional references</p>	<p>N/A</p>

Rovere-Querini 2020

Bibliographic reference/s	Rovere Querini, Patrizia, De Lorenzo, Rebecca, Conte, Caterina et al. (2020) Post-COVID-19 follow-up clinic: depicting chronicity of a new disease. Acta bio-medica: Atenei Parmensis 91(9s): 22 to 28
Questions relevant to?	Service models
Publication status	Published
Study type	Case series
Quality	Very low quality
Objective	To describe a multidisciplinary COVID-19 follow-up outpatient clinic to identify and address the clinical needs of COVID-19 survivors
Study date	7 April to 5 June, 2020
COVID-19 prevalence (high/low) if reported	Not reported
Country/ Setting	Italy
Population (including n)	COVID-19 survivors discharged from hospital (n=453) Subgroups discharged from emergency dept (n=90) Discharged from hospital ward/ICU (n=363)
Time since acute COVID-19 illness	Not reported
Investigations	See main results
Baseline characteristics	Most patients were males (68%). Median (interquartile range, IQR) age in the follow-up cohort was 59 (49 to 68) years. The characteristics of the follow-up cohort are similar to those of the whole hospitalised cohort of COVID-19 in terms of demographics, comorbidities, and COVID-19 severity upon ED presentation.
Inclusion and exclusion criteria	Inclusion: Post-discharge hospitalised patients surviving COVID-19
Follow up	Outpatient visits are scheduled at 4 weeks, 3 months and 6 months after hospital discharge.
Main results	453 patients were followed up out of a total of 860 hospitalised. The follow up model includes physical examination, respiratory evaluation (peripheral oxygen saturation, respiratory rate, dyspnoea assessment, lung ultrasound and pulmonary function), cardiovascular assessment (electrocardiography, echocardiography), nutritional assessment (anthropometrics, mini Nutritional Assessment screening tool), neurological examination including cognitive tests, and mental health assessment. Quality of life assessment through the World Health Organization Quality of Life (WHOQOL)–BREF questionnaire and screening of insomnia, anxiety, and post-traumatic stress disorder (PTSD) through validated indicators are performed in all patients.
Comments (e.g. source of funding, statistical analysis, any major limitations,	Limitations: <ul style="list-style-type: none"> • No service components were described beyond investigations. • Details of components at different follow up time points were not described.

or issues with studies)	<ul style="list-style-type: none"> • Potential interventions were only discussed from a narrative review of the literature • No analysis of patient data was reported. <p>Challenges: Reasons for patients' failure to follow up included: i) missed phone calls (40%), ii) refusal to follow-up due to subjective recovery or work commitments (20%), iii) long distance of the hospital from home (15%), iv) stay in rehabilitation institutes (15%), and v) impossibility to physically reach the hospital due to transportation difficulties (10%).</p>
Additional references	N/A

Salawu 2020

Bibliographic reference/s	Salawu, Abayomi, Green, Angela, Crooks, Michael G et al. (2020) A Proposal for Multidisciplinary Tele-Rehabilitation in the Assessment and Rehabilitation of COVID-19 Survivors. International journal of environmental research and public health 17(13)
Questions relevant to?	Monitoring, Service models
Publication status	Published
Study type	Narrative review and pathway model description
Quality	Very low quality
Objective	To propose a model of a care pathway to mitigate against the impact on the rehabilitation services due to the response of the UK National Health Service in managing the COVID-19 crisis. The care pathway aims to evaluate the post recovery rehabilitation and the clinical needs of patients following infection with the SARS-Cov-2 virus.
Study date/	Not reported (published 7/7/20)
COVID-19 prevalence (high/low) if reported	Not reported
Country/ Setting	UK
Population (including n)	COVID-19 patients requiring critical care/non-invasive respiratory support COVID-19 patients not requiring critical care/non-invasive respiratory support
Time since acute COVID-19 illness	4 to 6 weeks and 12 weeks post discharge
Interventions/ Prognostic factors	Multi-disciplinary tele-rehabilitation
Baseline characteristics	Not reported
Inclusion and exclusion criteria	Not reported
Follow up	4 to 6 weeks and 12 weeks post discharge

Proposed model	<p>Recommended pathway:</p> <ul style="list-style-type: none"> • The care pathway aims to evaluate the post recovery rehabilitation and the clinical needs of patients following infection with the SARS-Cov-2 virus. • The pathway has an embedded multidisciplinary tele-rehabilitation component to assess and deliver therapy to patients based on the identified needs. • Discharged COVID-19 patients will be managed along two streams based on whether they had intensive care input with respiratory support: mechanical ventilation, CPAP (continuous positive airway pressure) or high flow nasal oxygen (Stream 1), or not (Stream 2). • Electronic coding will enable patients who had a hospital admission where they tested positive for COVID-19 to be identified to a pathway administrator. • The codes also identify which patients require intensive respiratory support (i.e., stream 1) from those who are able to remain on a ward (stream 2). • The pathway administrator will receive weekly updates and then book patients into the appropriate assessment clinics. • The pathway will incorporate two assessment points at four-to-six weeks and 12 weeks where clinicians make contact remotely with the patients. • The four to six-week assessment will be used to identify suitable patients who may benefit from a tele-rehabilitation program and providing them with the opportunity to enrol. A multidisciplinary rehabilitation telephone screening tool will be used for the rehabilitation assessment at the four-to-six weeks post discharge. The telephone screening tool is based on the domains of the ICF. • The screening tool was further modified to explore key medical and functional sequelae of COVID-19, as identified in the various guidelines issued by the UK professional bodies for rehabilitation medicine, respiratory medicine, intensive care medicine, and allied healthcare professionals. • Bespoke interventions tailored to individual circumstances will be provided based on the assessment. • The tele-rehabilitation therapy programme suite will incorporate the core principles of PR of reducing anxiety relating to breathlessness and additionally optimise the aerobic capacity, strength, endurance, and functional ability of the patients. There will also be an early focus on managing fatigue and pacing since profound fatigue appears to be a distinct limiting factor in the recovery of these patients. • The pathway was designed to be adaptable, and, as further evidence of clinically effective therapy and treatment of COVID-19 emerges, these programs and apps could be added to the pathway The program will use attend anywhere® an NHS digital-approved secure video conferencing platform to deliver structured exercises • Supervised exercise sessions will be provided two times each week. Activities will be commenced at mild intensity with progression over subsequent weeks to moderate intensity as tolerated by trained therapists to patients identified as requiring such intervention. • The rehabilitation process is a continuous interactive process that requires the frequent monitoring of the patient's functional ability, which is used to guide and adjust therapy delivery based on the patient's progress.
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	<ul style="list-style-type: none"> The screening assessment tool was piloted in 2 UK regions as part of a quality improvement program to allow for feasibility and a comparison of data trends.
Comments (e.g. source of funding, statistical analysis, any major limitations or issues with studies)	<p>Other relevant information is presented relevant to service models.</p> <p>Limitations:</p> <p>The proposal was based on the clinical experience of the authors and the local/regional service circumstances.</p> <p>No validation data was presented. Further research is needed to validate the model.</p>
Additional references	N/A

Sivan 2020

Bibliographic reference/s	Sivan, Manoj, Halpin, Stephen, Hollingworth, Lisa et al. (2020) Development of an integrated rehabilitation pathway for individuals recovering from COVID-19 in the community. Journal of rehabilitation medicine 52(8): jrm00089
Questions relevant to?	Service models
Publication status	Published
Study type	Case study
Quality	Very low quality
Objective	To describe the development of an integrated rehabilitation pathway using telemedicine approach to manage these sequelae in a systematic and efficient way.
Study date	Not reported
COVID-19 prevalence (high/low) if reported	Not reported
Country/ Setting	UK
Population (including n)	Not reported
Time since acute COVID-19 illness	Not reported
Investigations	Telephone screening tool
Baseline characteristics	Not reported
Inclusion and exclusion criteria	Not reported
Follow up	6- and 12-weeks post-discharge for hospitalised individuals or administered in primary care at unspecified timepoints for individuals who did not need hospitalisation whenever they present to the GP.
Main components	Clinicians caring for individuals at various points in the COVID rehabilitation pathway can use the C-19 YRS screening tool to capture ongoing symptoms. In secondary care this screening is performed by the multidisciplinary team following up discharged patients at 6 and 12 weeks.

	<p>In primary care the primary care clinician or GP administers the tool whenever they present.</p> <p>If individuals are improving and prefer to continue with self-management measures, they will continue to be monitored and will be contacted again for a subsequent screening consultation after approximately 6 weeks.</p> <p>The symptoms covered by the tool are breathlessness, voice, swallowing, nutrition, mobility, fatigue, personal care, usual activities, pain/discomfort, anxiety, depression, post-traumatic.</p> <p>The tool enables prompt detection of post-discharge symptoms referral to specialist services/professionals based on needs.</p> <p>The multidisciplinary team used a consensus method to develop referral criteria that can be applied to the C19-YRS screening tool to determine management of individuals in appropriate rehabilitation services.</p> <p>The services described in the pathway were either existing rehabilitation services or new services identified to manage complex post-COVID cases which the team felt could not be managed by existing services.</p> <p>The MDT must have the expertise to perform a detailed work-up of the individual and provide targeted interventions either via a face-to-face appointment with appropriate personal protective equipment (PPE) or using remote tele-consultation methods, or a combination.</p>
<p>Comments (e.g. source of funding, statistical analysis, any major limitations or issues with studies)</p>	<p>Limitations:</p> <ul style="list-style-type: none"> • No validation reported. Future research is needed for validation of the pathway.
<p>Additional references</p>	<p>Related publications:</p> <p>Sivan, M. (2020) Remote assessment for identifying COVID-19 post-acute care needs. <i>Aging Clinical and Experimental Research</i> 32(10): 2167 to 2168</p> <p>Sivan, M.; Halpin, S.; Gee, J. (2020) Assessing long-term rehabilitation needs in COVID-19 survivors using a telephone screening tool (C19-YRS tool). <i>Advances in Clinical Neurosciences and Rehabilitation</i> 19(4): 14 to 17</p> <p>Both publications describe the development of the C19-YRS telephone screening tool</p>

Appendix 7 Excluded studies

Please refer to the full list of [excluded studies](#) for this guideline.

Appendix 8 Expert testimony

Expert testimony to inform NICE guideline development: Royal College of Psychiatrists

Section A: Developer to complete	
Name:	George Roycroft
Role:	Head of Policy and Campaigns
Institution/Organisation (where applicable):	Royal College of Psychiatrists
Guideline title:	Management of the long-term effects of COVID-19
Guideline Committee:	Expert panel convened for development of this guideline. Meeting 4: 19-11-20.
Subject of expert testimony:	Service models (mental health focus)
Evidence gaps or uncertainties:	Very limited evidence in the literature about the components required for a service for management of the long-term effects of COVID-19
Section B: Expert to complete	
Summary testimony:	
<p>Suggested model</p> <p>People with post-COVID-19 syndrome experience a range of symptoms which are highly variable and multisystemic, including physical, psychiatric, and neuropsychological problems. This means that an integrated care pathway for patients with post COVID-19 syndrome should meet the needs of mental health problems which have a range of severity, complexity, and risk.</p> <p>Patients with increasingly complex mental and physical comorbidity require different expertise and services to meet their mental health needs. This would be applicable to post COVID-19 syndrome, with the most complex and high-risk patients requiring psychiatric expertise, predominantly from Liaison Psychiatry and Neuropsychiatry</p> <p>A stepped care approach is a way that allows different services with different expertise to focus on patients with problems of different degrees of severity and complexity.</p> <p>This includes the following steps:</p> <ul style="list-style-type: none"> • Supported self-care (primary and secondary care staff) • Comorbid anxiety and depression with a low level of complexity (psychological therapy services [IAPT], primary and secondary care staff with appropriate expertise) • Comorbid mental health problems requiring more complex psychological interventions (psychological therapists with additional expertise clinical and health psychology, medical psychotherapy) • High level of complexity and risk (liaison psychiatry services) 	

In addition to the assessment and management of complex cases, psychiatrists can also participate in the multidisciplinary discussion of cases, facilitating the movement of patients up and down the different levels as their needs change.

Developing an integrated care pathway based on this framework requires a single commissioning process, agreed funding for each part of the service and common referral protocols. As well as integrated management of post COVID-19 syndrome, the pathway should link with services managing acute COVID-19 infection to help prevent the development of longer-term symptoms.

Examples of COVID-19 services being set up

The following are examples of new service models being developed across the country that we are including for information rather than endorsing the different approaches being taken.

Southern Health NHS Foundation Trust

A hub and spoke model, setting up a service for ICS. It will be a community-based MDT with strong psychiatric presence with initial referral by primary care, then rapid assessment and signposting to most appropriate intervention. There is menu of interventions which will include MyCoVIDRecovery website. If more severe needs, then care coordination of specialist services, referral to community therapy, pulmonary team, cardiac team, IAPT (combinations of these as required).

The idea is both to signpost people early to services to stop them suffering in silence, but also to reduce over-investigation of weird and wonderful symptoms which clinician may not connect to CoVID.

Early stages but plan has been agreed by local ICS, primary care, acute care and MH services all engaged, and clinical and commissioning input (as well as expert by experience input).

ELFT/ Bedfordshire hospitals NHS trust

Set up an integrated psychological/psychiatric/IAPT offer for post ITU/Critical Care Pathway patients. This aims to pick up COVID patients coming out of ITU on the critical care pathway specifically and also people coming out of hospital generally if the resource is available.

They are working on the IAPT integration and have used liaison psychiatry within current resource to start this off. It is a remote offer but the clinicians are integrated into the acute trust set up. People coming through this Pathway would ideally transfer into the long covid community health service. They would aim to have the same approach with integrated psychology/psychiatry and hopefully IAPT. For now post covid resp goes to resp psychology, and cognitive problems would go into secondary care memory assessment services if needed.

North Wales

In North Wales, they are creating a clearer pathway for patients with persistent physical symptoms (not just post – Covid) which will cover all age groups. They are in talks with GP, liaison psychiatry, also involving chronic pain teams, liaison teams, GPwSI, Physiotherapy, occupational therapy, psychologists working with children.

Northern Clinical Network

In the process of setting up a long covid clinic with partners from primary care and the acute trust and are developing it at the moment with an initial cohort of NHS staff.

Patients get online screening tools in advance and sends them back. Then has an initial screening appointment with GP and mental health, MDT discussion and if appropriate, this then goes to a hospital appointment - 30 minutes with medics (resp/ cardiology) and 30 minutes with AHP's looking at rehab. Then MDT to discuss final plan going forward.

'Not sure if psych is going in with the GP's or the medics at the moment - think it is more likely GP's given possible high prevalence of mental health.'

'The psych bit is to look at initial assessment and triage into appropriate level of service - self help, support worker services (wellbeing for life), IAPT or the specialist persistent physical symptom service that I work in for the most complex'

Colchester, Essex

There is a planned Post COVID Clinic that will be Consultant Clinic delivered. It will consider: anxiety, depression, OCD, Post Covid Stress Disorder, Post Covid Fatigue Disorder, psychosis and substance misuse. Assessment will be using clinical interviews and scales, and treatment including the best available choice of medications, therapy etc.

Guy's and St Thomas Hospital

Has Critical Care Recovery Clinic where the neuropsychiatry team reviews the covid-19 patients who have required ICU admission

Expert testimony to inform NICE guideline development: UCLH Post-COVID Service

Section A: Developer to complete	
Name:	Michael Marks
Role:	Honorary Consultant Physician in Infectious Disease
Institution/Organisation (where applicable):	UCLH Post-COVID Service
Guideline title:	Management of the long-term effects of COVID-19
Guideline Committee:	Expert panel convened for development of this guideline. Meeting 4: 19-11-20.
Subject of expert testimony:	Service delivery for post- COVID-19 syndrome (PCS) clinics.
Evidence gaps or uncertainties:	There is a lack of evidence on the set up and organisation of PCS clinics, therefore expert testimony invited.

Section B: Expert to complete

Summary testimony:

Service started May 2020. Initial patient consult in TB truck with physio, OT radiographer. A gap was identified in healthcare provision and post COVID-19 complications.

As many visits face to face as possible.

Made recommendation for integrated implementation: Physiotherapists leading on rehabilitation, clinicians leading on medical. Referral as necessary to IAPT. Established a MDT bringing together services as needed to discuss patients.

A lot of effort was put into seeing community patients first; referrals were received from 290 different GP practices – this is high. Now restricting down to local (North Central) London commissioning and strengthening interface with community.

Cohorts: offer an appointment to every admission to UCLH with COVID-19 (if laboratory or clinical diagnosis). This includes patients seen in Emergency Department, that went home and were still symptomatic at 4–6 weeks. Safety netting serviced by Infectious Diseases (ID) team, they would call and people with persistent symptoms were booked into PCS clinic.

Patients referred from primary care from 6 weeks after symptom onset. If they were less than 6 weeks after symptom onset then they were seen by ID service.

NHS staff could self refer or were referred by colleagues.

1000 appts so far, ¾ of these were 'in person'.

455 of these 1000 appointments were from 12 week time point in 1st wave.

Median age of community patients- for women was 48, 52 for men – lower than hospitalised population. Bias survival towards lower age. More females attended the PCS clinic, compared to national picture of increased hospital admissions for men for acute COVID-19.

Nationally, individuals of black, Asian and minority ethnic groups are overrepresented as inpatients for COVID-19. See here (referring to slide set) blue is GP referral, red is hospital recall, green is borough average. Referrals to PCS clinic from hospital inpatients reflects national picture that BAME overrepresented. For GP referrals in blue (on slide set), there is a far lower overrepresentation of white Caucasian ethnicity. Whether this represents biological features or access to care is unclear.

How was the service set up?

The service evolved over time. We try and see all 1st appointments face to face (it is hard to assess fatigue remotely). Current appointment structure is 30 minutes with a doctor, 30 minutes with a physiotherapist.

People are referred onwards for rehabilitation on the basis of diagnosis, clinical course and struct assessment of symptoms (including use of PHQ2 and GAD2, PTSD screen, assessment of breathing pattern, fatigue SOB, all patients have a chest X ray done).

Increasingly we are asking GPs to organise CXR before referral as a triage test, based on residual CXR change. Patients do a 1 minute Sit to Stand test with physiotherapist, and a standard set of blood tests are taken, to look for evidence of ongoing inflammation, ongoing VTE, myocardial inflammation. Other tests depend on symptoms that the person has.

Data from 455 patients after 12 weeks of symptoms:

From real clinical appointments

Majority are community managed, this reflects that we have put a lot of effort into community managed patients. We don't take hospitalised patient from other sites other than transfer or 2nd opinion. Relatively few hospitals have well established primary care pathways.

For community patients – 66% female. Significantly younger.

Hospitalised patients – reflective of national – 2/3 male and older.

For those who were admitted for acute COVID-19 management, 2/3 were at ward level, remaining 1/3 required significant ventilation support (CPAP or intubation).

Many patients lack laboratory confirmation of diagnosis, especially from outside of hospital. Majority of hospitalised did have PCR diagnosis.

Did do serology for some time, but only 36% positive, so we stopped as it did not change clinical management. The test is about 85% sensitive, which means that some people in primary care may not have had COVID-19, but it hasn't changed clinical pathways.

Most patients report severe ongoing impact on health, when they rank health now compared to pre-COVID (100 normal best health) it is striking that everyone reports deficits, average about 80% of best health at 12 weeks. The primary care group report the largest decrease relative to baseline.

Large portion of those from primary care report that they are too unwell to return to work. (figures on slide), hospitalised patients are similar.

Frequency of symptoms as proportion of symptom burden (those seen in >2% people)

Breathlessness and fatigue overwhelmingly the most common symptoms in all groups. Some palpitations. Range odd symptoms. Community patients much higher prevalence of multiple distinct symptoms, particularly chest pain. Hard to collect structured data on brain fog because it is a commonly used phrase, along with fatigue. Post exertional malaise also commonly reported.

Do use structured questionnaires about breathlessness in the service- MRC breathlessness scale 1 -5 (extremely bad on minimal or no exertion). 30% of community patients score 3 or above; the threshold for pulmonary rehabilitation in individuals with respiratory disease. Breathless scores lower in community patients, but significant burden.

In terms of impact on mental health and interplay of symptomatology, community referred patients have higher anxiety and depression scores on PHQ and GAD – v frequently higher scores than hospitalised patients. Anecdotally this may be because community patients have been managing alone without access to care for a long time.

In terms of what happens next in our service one the person has been assessed;

-if they desaturate on exercise tolerance test or CXR abnormal or clin susp – do CTPA to see if due to fibrosis or VTE

-6MWT and capillary blood gas if severe fatigue or abnormal STS. Occasionally Cardiopulmonary exercise test if troponins up, then echo 1st then CMR for Myocarditis.

-Palpitations and autonomic – holter monitors with autonomic MDT for referring. Reasonable number seem to develop very high RHR and HR increase on minimal exertion – HR 15 on walking on flat – RHR 90-100.

Monthly combined clinic for shared clinics – neuro post COVID clinic with national hospital. All feeds into rehab plan including weekly MDT.

Multiple distinct groups but there is overlap. Outcomes might predict ILD, VTE. Symptoms are complex – cognition, fatigue post exertion malaise – breathing pattern disorder, autonomic dysfunction and anxiety, depression. Use a structured approach to unpick – may present with fatigue and breathless but driven by different things.

Are seeing people with ongoing inflammatory changes in lungs – more common in hospitalised people – trialling on steroids.

5% incidence of persist pulmonary fibrosis at 6 months. Lower in community patients.

Follow up results of 80 patients at 6-12 week visit. 25% resolved, 26% little fibrosis, little severe and then a mix. An issue in small proportion of people but significant issue.

Big emphasis on physio and exercise phys. 1 in 10 desaturate on STS at 14 weeks post illness. Image people as ?VTE or fibrosis. Nearly all have normal imaging. Mixed results on validating with walk test and gases.

Individuals maintain oxygen, but profound lactic acidosis in fairly mild 6MWT. More work needed to understand what is driving this.

In terms of implications for fatigue and rehab planning – greatest requirement is for fatigue management – in house and community. Capacity problem. May often be told that referral for fatigue management has no capacity. Small number of specialist units.

Breathing retraining very necessary in some patients and see marked improvements in these people.

Implementing UCL developed COVID recovery app and building a business case for in house psychiatry – GAD and PHQ through to IAPT but capacity issues in IAPT generally and more so at the moment.

Proactive management model so patients can flag areas of concern. After initial visit try to move to remote but significant number stay face to face.

Community and post hospital have different phenotypes. Comprehensive assessment for end organ damage which influences the rehab pathway. Tension between investment and rehabilitation. Yield quite low on many tests. Many patients want to know if heart and lungs normal and reassurance from normal tests seems to have significant psychological value. Maximise learning to share with integrated care – can't be kept in secondary care. Issues in terms of representation of populations currently accessing care and whether true differences in symptomatology or inverse care law – certain people more able to access services. Need all combined service – not just physiotherapist or doctor. Majority of patients are improving over time with right input.

Questions:

(chair directs specific and service delivery)

Q- interested in prop of patients not able to work and support able to offer them?

Within clinic offer appropriate rehab goals – for NHS staff liaison with Occupational health, support for patient to advocate phased return to work.

Q- Have you looked at rationalising investigations? Have you looked at BNP as screening blood? BNP normal no significant heart issue?

Looked at a number of screening tools – unlikely to have severe ventricular dysfunction but RHR 110, so people still need cardiac investigation and cardiologist in MDT. Recent data from cover scan group – cardiac MRI changes in absence of biomarkers. Agree need screening and can't do CMR on everyone. Find a balance.

Q- what was significant difference in the needs of older people as opposed to the cohort you are mainly dealing with?

In community patients don't see a significant proportion of elderly patients. In hospitalised, patients have more with increased care needs following discharge – complications for stroke and also in hospital for other things and acquired COVID-19 in hospital. No obvious clinical difference but likely care needs increased.

Q- guidance on setting up PCS clinics recommends a screening tool – do you do this? If you do does it add anything?

A - Not used a screening tool to date as none validated. Initially take any community referral where clinician referring felt there were ongoing symptoms. Introduced 2 steps – GP to organise CXR and STS in primary care – triage urgency of primary care referral rather than not seeing individuals. Different to triage on screening test when we don't understand the symptom complex. Presented things have been done on no money – commissioning may be different. This is probably 3 times a week – whole day clinic. That alone is pretty close to 60% of consultant time on top of which have their own clinics and admin support.

Expert testimony to inform NICE guideline development: Your COVID Recovery

Section A: Developer to complete	
Name:	Sally Singh
Role:	Professor of Pulmonary & Cardiac Rehabilitation / Head of Pulmonary and Cardiac Rehabilitation
Institution/Organisation (where applicable):	University of Leicester / University Hospitals of Leicester NHS Trust
Guideline title:	Management of the long-term effects of COVID-19
Guideline Committee:	Expert Advisory Panel on Management of the long-term effects of COVID-19 (guideline developed jointly by NICE, SIGN, RCGP)
Subject of expert testimony:	Pulmonary and cardiac rehabilitation. Testimony provides example of a nationally recognised online COVID-19 rehabilitation portal, offering both public access, and access to a more specialist online rehabilitation programme through professional referral.
Evidence gaps or uncertainties:	Very limited evidence in the literature about the components required for a service for management of the long-term effects of COVID-19
Section B: Expert to complete	
Summary testimony:	
<p>“Your Covid Recovery” features an online (web-based) portal to help people who are recovering from COVID-19; this includes two stages:</p> <p>Publicly accessible information to help people recovering from COVID-19: An open, publicly available web site containing general information on all aspects of recovering from COVID-19 including physical, emotional and psychological wellbeing. The site offers general advice on recovery, returning to work and information for families and carers of patients with post-COVID syndrome (also known as Long COVID). It also signposts to other agencies such as the British Lung Foundation and the Samaritans.</p> <p>Access to a more specialist online, interactive rehabilitation platform specifically for patients with post-COVID syndrome; and tailored to individuals. This is available through a professional referral and face-to-face assessment from a healthcare professional – people/patients may ask their health care provider to be referred. Patients can set their own goals, and access interactive rehabilitation components specific to being able to achieve their goals. The components address many of the major symptoms so far reported to be associated with COVID-19 (e.g. breathlessness, fatigue, fear and sleep disturbance) A symptom tracker is included.</p> <p>Rehabilitation post COVID-19</p>	

Pulmonary and cardiac rehabilitation services provide a comprehensive platform to deliver a recovery programme to the post COVID-19 population. However, there is likely to be a need to adapt and enhance the service with further integration of the wider multi-disciplinary team.

Conventionally cardiac and pulmonary rehabilitation is delivered face to face. There is the potential to deliver alternative formats of rehabilitation to meet the demand such as YourCovidRecovery.

Early data from a face to face rehabilitation programme delivered by experienced staff (n=14; mean age 58 years, 50% female) for patients discharged from hospital at least 12 weeks previously showed significant improvements in exercise tolerance and a significant reduction in fatigue. There are no significant differences reported for anxiety and depression (measure by HADS) or cognition (measured by MoCA).

YourCOVIDRecovery interactive digital rehabilitation platform (stage 2)

YourCOVIDRecovery is an online recovery programme for those who are affected by and are experiencing ongoing symptoms following their COVID-19 illness. It was developed by a core multi-professional team representing many professional societies and is supported by patients post COVID-19 (particularly on content/navigation review) who have been in hospital or community managed for COVID-19.

It is an interactive and tailored package supported by health care professionals with resources to cover all the main symptoms reported post COVID-19.

It has been based upon previously deployed interactive rehabilitation programmes such as Activate Your Heart and SPACE for COPD.

Prior to being considered for YourCOVIDRecovery, screening in either primary or secondary care is required to rule out significant complications of COVID-19 or any other underlying disease that require further investigations or treatment.

Training has been put in place for systems to deliver YourCOVIDRecovery locally – comprising training manuals, a training video and a virtual training session. Over 150 teams are currently registered across England for training to deliver the intervention.

There are plans to develop a manual for people/patients with no digital access, including exploration of potential 'EasyRead' options.

Expert testimony papers are posted on the NICE website with other sources of evidence when the draft guideline is published. Any content that is academic in confidence should be highlighted and will be removed before publication if the status remains at this point in time.

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