National Guidance for post-COVID syndrome assessment clinics

This document will be revised further to the release of NICE/SIGN/RCGP guidance for post-COVID syndrome (also known as 'Long COVID') in December 2020. Local clinics, referral pathways and protocols will need to be reviewed and potentially updated to reflect the guidance published.

Equality and Health Inequalities Statement

Promoting equality and addressing health inequalities are at the heart of NHS England and NHS Improvement's values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and

- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities

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1. Purpose

The purpose of this document is to provide commissioning guidance on the development of a specification to assist local healthcare systems to establish post-COVID assessment clinics for patients experiencing long-term health effects following COVID-19 infection. Clinics will offer physical, cognitive and psychological assessments with the aim of providing consistent post-COVID syndrome services for all who need them, whether they were hospitalised or not and regardless of whether clinically diagnosed or by a SARS-CoV-2 test.

2. Background

- NHS England and NHS Improvement launched its five-point plan to support people with post-COVID syndrome (also known as 'Long COVID') in October 2020. One of the commitments was to establish post-COVID assessment clinics across England, which give patients access to multi-professional advice, so that they are put onto the right clinical pathway to treat their symptoms.

- It is recognised that many people experiencing ongoing health effects following COVID-19 infection managed their condition independently at home while acutely infected. It is also recognised that not all patients seriously impacted in the longer term were hospitalised or had a positive SARS-CoV-2 test.

- The number of patients who need post-COVID syndrome management focusing on recovery and rehabilitation is likely to grow as COVID-19 infection rates continue to rise.

- People with post-COVID syndrome have reported that whilst some GPs have been sympathetic, some have been unsure how to refer into treatment services.

- 67% of GPs surveyed reported that they are looking after patients with COVID-19 symptoms lasting longer than 12 weeks[1].

- There is increasing evidence that COVID-19 has a disproportionate impact on those in deprived populations and people in black and ethnic minority groups and exacerbates existing health inequalities.

- NHS England and NHS Improvement acknowledges the contribution of patient groups in developing this guidance and other post-COVID syndrome support plans.

[1] Royal College of General Practitioners. (2020) *Ongoing or persistent symptoms of Covid-19.* Parliamentary Inquiry. Available at: *https://committees.parliament.uk/writtenevidence/12976/html/*

3.   Clinical case definition of post-COVID syndrome

This guidance refers to patients who meet the clinical case definition of post-COVID syndrome.

The National Institute for Health and Care Excellence (NICE), the Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of General Practitioners (RCGP) have defined post-COVID syndrome as:

Signs and symptoms that develop during or following an infection consistent with COVID-19 which continue for more than 12 weeks and are not explained by an alternative diagnosis. The condition usually presents with clusters of symptoms, often overlapping, which may change over time and can affect any system within the body. Many people with post-COVID syndrome can also experience generalised pain, fatigue, persisting high temperature and psychiatric problems.

Post-COVID-19 syndrome may be considered before 12 weeks while the possibility of an alternative underlying disease is also being assessed.

4.   Evidence base

Headlines from the NICE/SIGN/RCGP evidence review here when available.

5.   Why is this guidance being issued?

In October 2020 NHS England and NHS Improvement announced a £10 million investment to help local services in every part of the country bring together the right professionals. These professionals will provide physical, cognitive and psychological assessments of those experiencing suspected post-COVID syndrome, so that they can be referred to the right specialist help.

The funding will be allocated to NHS England and NHS Improvement regional teams to allow the development of post-COVID assessment clinic(s) to serve local populations.

Funding will be allocated to NHS England and NHS Improvement's regional teams to work with healthcare systems to agree the best arrangement for delivery of these clinics, including how children and young people will be assessed. This will allow for pooling of the funding where joint clinics across healthcare systems would be deemed appropriate. Regional funding will be based on unweighted September 2020 GP registered populations.

Clinics should be nominated by 6 November 2020 and accepting patients by the end of November 2020.

6.   Scope

This guidance sets out the considerations for the establishment of post-COVID assessment clinics so that they meet the varied needs of this patient population. This includes patients who:

- remained at home or in a care setting during their acute COVID-19 illness and who had positive SARS-Cov-2 serology or clinically diagnosed in the absence of a positive test or were not tested at all
- were hospitalised during their COVID-19 infection and have been discharged

Some patients will need therapeutic input, rehabilitation, psychological support, specialist investigation or treatment once they have been assessed at the clinic, and it is the responsibility of the clinic to refer patients on to existing services as needed.

Clinic setting is for local determination and may be based in primary, secondary or community services, if there is prompt access to the appropriate diagnostics. A virtual element to the clinics can be considered.

As a minimum the post-COVID assessment clinics should:

- Be available, following clinician referral, to all affected patients, whether hospitalised or not
- Have access to a multidisciplinary team of professionals to account for the multi-system nature of post-COVID syndrome
- Support collaboration across localities where patients needs require this
- Have age appropriate arrangements in place for managing children and young people with post-COVID syndrome including support for psychological needs
- Have access to diagnostic tests
- Ensure coverage of the population in that geography
- Have a plan for ensuring equity of access (bearing in mind many population groups have been disproportionately affected by COVID-19)
- Have a local communications plan for raising awareness within the clinical community
- Have an external communication plan for informing and raising awareness with patients

Clinic accessibility and inclusion

All healthcare systems should consider health inequalities in the planning and delivery of post-COVID assessment clinics. This includes, but is not limited to:

- Being supportive to those with learning disability and/or autism or pre-existing mental health problems and being aware of diagnostic overshadowing (see here for further resources)
- Socio-economic inequalities
- Black, Asian and minority ethnic (BAME) group inequalities
- Lesbian, gay, bisexual and transgender plus (LGBT+) people

- Sex and gender
- Language and cultural barriers
- People with and existing disability such as visual or hearing impairment
- People in secure units
- Marriage and civil partnership
- Pregnancy and maternity
- Religion and belief

Healthcare systems should monitor the demographic data of those who have been referred and consider adapting referral pathways if needed.

Equity of access must be a key objective of the clinic. Consideration should be given to disadvantaged groups with regards to how they access and utilise healthcare services and to ensure that no one is discouraged or unable to benefit. This may require a proactive, potentially case finding approach in some populations to identifying those who may typically be less likely to access healthcare. Virtual or out-of-hospital clinics should be considered. Patients should not be disadvantaged from accessing services due to financial costs or language barriers and cultural beliefs. Consideration should also be paid to access for children and young people; clinics should have safeguarding policies in place and work closely with local authorities if social care needs are to be considered.

An Equalities and Health Inequalities Impact Assessment has been completed for this post COVID assessment clinic guidance.

7.   Referral routes into the patient pathway

There are three main referral routes:

1. People never admitted to hospital with their acute illness but managed independently or in the community.

Many people reporting post-COVID syndrome symptoms were not admitted to hospital during the acute phase of their infection.
- If new symptoms develop 6-12 weeks after the COVID-19 infection, an assessment should be carried out by the GP and their symptoms appropriately investigated for an alternative diagnosis. Post-COVID syndrome may involve symptoms changing and new symptoms developing over time and this should be considered.
- If no alternative diagnosis is made the patient should be screened using an appropriate tool (see appendix B) prior to referral to the post-COVID assessment clinic.
- Screening may be carried out by the GP or if the local system has one, by a COVID-19 single point of access, which assesses and triages people with post-COVID syndrome to the most appropriate service.
- Distinction between existing long-term conditions (LTCs) and COVID-19 related complications should be made. Clinicians in conjunction with their patients may decide it is more appropriate for patients with exacerbations of existing LTCs following a COVID-19 infection to be managed by usual services.

2. People hospitalised with COVID-19.

- A detailed discharge summary of the admission and ongoing related conditions should be provided to primary care, and social needs should include caring responsibilities the affected person had prior to hospitalisation that they may return to. Arrangements to assess any respiratory complications should be made according to British Thoracic Society guidance.
- Those with persisting symptoms or signs at discharge will benefit from a telephone or video assessment at 6 weeks post discharge, and where appropriate a subsequent face to face follow up or specialist referral.
- People who develop new symptoms after the 6-week follow up should be reviewed by their GP.
- An assessment and investigation of new symptoms after 6 weeks, in secondary care outpatient clinics or in primary care, should rule out alternative diagnosis, and if no alternative diagnosis is made, the patient should be screened using an appropriate tool (see appendix B) prior to referral to the post-COVID syndrome clinic.

3. People cared for in an Intensive Care Unit (ICU) or High Dependency Unit (HDU) with COVID-19.

- People with COVID-19 cared for in an ICU/HDU setting should undergo a multi-disciplinary team (MDT) assessment of rehabilitation needs at the point of step down to other inpatient facilities. Inpatient rehabilitation with defined goals should begin immediately.
- Further assessment of ongoing needs should be made at discharge from hospital with appropriate community service referral if needed, and an ICU clinic re-assessment made at 4-6 weeks post discharge.
- People who develop new symptoms after the 6-week follow up should be reviewed by their GP.
- An assessment and investigation of new symptoms after 6 weeks, in ICU outpatient should rule out alternative diagnosis, and if no alternative diagnosis is made, the patient should be screened using an appropriate tool (see appendix B) prior to referral to the post-COVID assessment clinic.
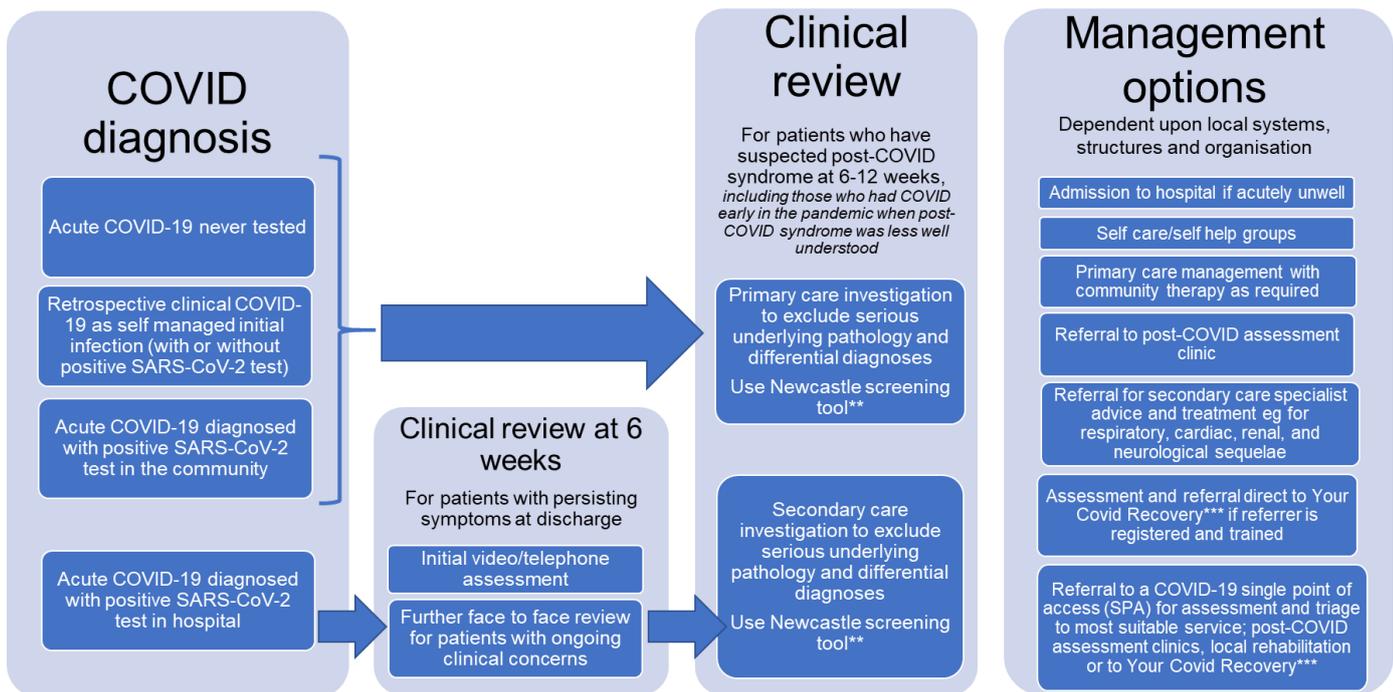
8.   The patient pathway

Some systems have designed their own models and illustrated patient pathways for managing people with post-COVID syndrome and these existing models may form the basis for the development of post-COVID assessment clinics.

The following is a proposed referral pathway adapted from one developed in the Royal College of General Practitioners House of Lords report (2020). This pathway is likely to be amended further to NICE/SIGN/RCGP post-COVID syndrome clinical case definition and guideline publication:

Post Covid syndrome referral routes*
(subject to amendment further to NICE/SIGN/RCGP guidance publication)

COVID diagnosis

Acute COVID-19 never tested

Retrospective clinical COVID-19 as self managed initial infection (with or without positive SARS-CoV-2 test)

Acute COVID-19 diagnosed with positive SARS-CoV-2 test in the community

Acute COVID-19 diagnosed with positive SARS-CoV-2 test in hospital

Clinical review at 6 weeks
For patients with persisting symptoms at discharge

Initial video/telephone assessment

Further face to face review for patients with ongoing clinical concerns

Clinical review
For patients who have suspected post-COVID syndrome at 6-12 weeks, *including those who had COVID early in the pandemic when post-COVID syndrome was less well understood*

Primary care investigation to exclude serious underlying pathology and differential diagnoses
Use Newcastle screening tool**

Secondary care investigation to exclude serious underlying pathology and differential diagnoses
Use Newcastle screening tool**

Management options
Dependent upon local systems, structures and organisation

Admission to hospital if acutely unwell

Self care/self help groups

Primary care management with community therapy as required

Referral to post-COVID assessment clinic

Referral for secondary care specialist advice and treatment eg for respiratory, cardiac, renal, and neurological sequelae

Assessment and referral direct to Your Covid Recovery*** if referrer is registered and trained

Referral to a COVID-19 single point of access (SPA) for assessment and triage to most suitable service; post-COVID assessment clinics, local rehabilitation or to Your Covid Recovery***

- * Based on a pathway in the Royal College of General Practitioners House of Lords report (2020). Pathway is likely to be amended further to NICE/SIGN/RCGP post-COVID syndrome guideline publication
- ** Newcastle post-COVID screening tool can be found in NHS England and NHS Improvement post-COVID assessment clinic commissioning guidance
- ***Your Covid Recovery is an online interactive platform for patients with post-COVID syndrome. Patient referral requires registration with yourcovidrecovery@uhl-tr.nhs.uk and a patient assessment that includes a 1 minute sit to stand test.

Referral to the clinic:

- Referral may be from multiple routes; primary care, secondary care and potentially community services, depending on local approach to referral pathways.
- Patients who were not admitted to hospital should be offered referral if they have been experiencing post-COVID syndrome symptoms for 12 weeks or longer. This may particularly apply to patients who had their acute COVID illness early in the pandemic when the potential for ongoing post-COVID syndrome symptoms was less well recognised.
- The NICE case definition should inform which patients are referred and at what stage of the illness. This case definition is expected in December 2020 and referral processes must be updated once this guidance is released.
- Patients experiencing significant distress or disability should be prioritised. Functional assessment tools and screening questionnaires have been developed by existing clinics and healthcare systems, such as in Yorkshire, Oxford, and Newcastle. Healthcare systems may wish to utilise these or develop them further. Please see appendix B for an example.

Referral on to other services:

Whilst some issues can be addressed immediately in the post-Covid assessment clinic if the right specialist is present, many patients will need further therapeutic input. Clinics should have clear pathways to ensure referral into appropriate services which may include rehabilitation, psychological support, specialist investigation or treatment, or to social care support services or the voluntary, community and social enterprise sector. The GP should receive communication from the clinic on the patients care, and consideration should be given to the provision of Med3/ fitness for work to avoid further appointments, unless the patient is discharged back to the care of primary care for ongoing management.

Clinicians should work together to ensure that physical and mental healthcare are integrated as closely as possible. Where available, patients with mental health and psychological issues with persisting physical problems may benefit from referral to integrated IAPT-LTC (Improving Access to Psychological Therapies) services or in the case of an under 18 year old, the relevant children and young people's mental health service. Transition between children's and adult services should be supported and services should work flexibility to provide support based on the needs of the young person. Where possible an episode of treatment should be completed before consideration of transition to ensure continuity of care.

For patients able to self-manage and access digital services Your COVID Recovery is an online tailored interactive self-management programme developed by NHS England and NHS Improvement with the University Hospitals Leicester NHS Trust. Paper manuals will soon be available for those without IT access and for those with disabilities precluding the use of digital media.

Services that might of particular benefit include:
- Specialist lung disease services, sleep clinics, and pulmonary rehabilitation
- Cardiac services
- Pain management
- Gastroenterology
- Rehabilitation services
- Dietetics and nutrition services
- Primary care led care including care coordinators and social prescribers
- Improving Access to Psychological therapies (IAPT) and other mental health services
- Co-morbidity management e.g. for diabetes or obesity
- Neurology
- Rheumatology
- Dermatology
- ENT
- Infectious disease services
- Occupational health

9. Post-COVID assessment clinic design

- A full history and appropriate examination should be undertaken with investigations performed if not already carried out to assess severity of symptoms burden and exclude underlying pathology that requires onward referral to another service. British Thoracic Society guidance has further information.

- The multi-system nature of post-COVID syndrome means that holistic assessment and treatment are likely to be needed, so clinics should be able to draw on multi-professional expertise and have access to a range of assessment and diagnostic tests.

- The clinics may be located on a single site, delivered across multiple sites or where appropriate, virtually. Accessibility should be a priority both in terms of geographical location and service delivery models. There will need to be the opportunity for patients to have a multidisciplinary assessment plus diagnostics, at least for the initial physical assessment. Addressing psychosocial and cognition may be done at the same time or subsequently, and potentially remotely using digital platforms or telephone. This should be determined by clinical need and especially considered if a full assessment is too onerous for the patient.

- The multi-system nature of COVID-19 and its psychological impact mean that a broad holistic assessment is most beneficial. Until the NICE/SIGN/RCGP guidance is issued this guidance has referred to the British Thoracic Society guidance identified that the post-COVID syndrome holistic assessment should at least include:

  - Assessment and management of breathlessness
  - Symptom or palliative care management where required
  - Assessment and management of oxygen requirements
  - Consideration of rehabilitation needs and onward referral where required
  - Psychosocial assessment (depression, anxiety disorders, PTSD, traumatic bereavement, psychosis screen, risk to self and/or others, COVID related life stresses such as debt, unemployment, relationship issues) and onward referral where required
  - Assessment and management of dysfunctional breathing
  - Cognitive function
  - Consideration of a new diagnosis of venous thromboembolic disease (VTE)
  - post-exertion malaise, fatigue and neurological symptoms.

- It is anticipated that the assessment may need to change as the NICE/SIGN/RCGP guidance is issued

- Diagnostics and testing should include all tests deemed appropriate for the presentation of the patient, but as a minimum imaging, cardiac investigation, physiological measurement and phlebotomy.

- Discharge to primary care for ongoing support, including social prescribing and care coordination where appropriate.

- Clinics treating children and young people should address safeguarding.

- Clinics should follow the Accessible Information Standard and have access to interpreters, including British Sign Language interpreters.

10.   Workforce

There is the opportunity for local systems to consider innovative and locally appropriate approaches to clinic leadership and skill-mix.

- Clinics may be led by secondary, primary of community care clinicians, including integrated care or advanced clinical practitioners, and from a range of specialties, with referral to other specialist teams as needed.

- Other members of the MDT including physiotherapists can provide strong support for assessment of respiratory function, strength and exercise tolerance.

- Specialist nursing functions and roles such as district nursing, community nursing, psychiatric nursing, clinical nurse specialists and general practice nurses for example can support holistic assessment and treatment of both the patient and wider family needs whilst also supporting the coordination of services more widely where appropriate.

- Occupational therapists can provide a personalised and occupation-focused approach to assessment such as cognition, delirium, mental health and functional outcome, independence and activity measures, including support for self-management and social prescribing.

- Psychologists can provide assessment of cognition, mental health, provide support for patients managing persistent symptoms and can also provide access into services such as IAPT, wider health, social care and third sector provision and pain, fatigue and neuro-rehab services.

- Dieticians can advise on the impact of COVID-19 on nutritional status, which may take the form of malnutrition or overweight and obesity. Clinics could include nutrition as part of both physical and psychological assessments.

- As part of their workforce planning, all healthcare systems should consider professional responsibility and accountability when regulation exists.

11.   Data and management information

NHS England and NHS Improvement are working with NHSX, NHS Digital, and the Professional Records Standards Body (PRSB) to develop clinical coding to record post-COVID syndrome in clinical information systems. Local commissioners should put in place a system of capturing data which enables monitoring of patient volumes, follow up and outcomes and service evaluation. Key metrics for routine collection will include:

- Number of referrals to service

- Time taken from referral to first contact

- Number of face-to-face (virtual) first contacts, and number of subsequent face-to-face (virtual) contacts by:

  o Age

  o Socio-economic group

  o Gender/ transgender

- o Sexual orientation

- o Ethnicity

And includes numbers of referrals of people:

- o With a learning disability/autism/hearing loss/visual impairment/prior diagnosis of dementia

- o From the criminal justice system

- o Who are homelessness or rough sleeping

- o Who are refugees and asylum seekers

- o Who are from Gypsy, Traveller, and Roma communities

- o In full time education

- Number of patients attending the clinic that were able to return to work.

12.   Key service outcomes

It will be critical to gather and analyse data, participate in shared learning and use this information to inform future practice and reduce unwarranted variation in the management and subsequent outcomes of patients with post-COVID syndrome symptoms. The data will be used to inform the management of patients, as well as informing service providers and commissioners in resource planning to maximise resource and service resilience.

NHS England and NHS Improvement London has reviewed the instruments available to monitor patient recovery trajectories and the impact of symptoms on an individual's functional status. Based on this review the use of two validated tools for routine collection are recommended:

1. **The COVID-19 Yorkshire Rehab Screening Tool** is a comprehensive multi-system telephone tool which has been developed by multi-disciplinary rehabilitation teams from Leeds, Airedale and Hull NHS Trusts to assess and capture symptoms and guide rehabilitation interventions. The tool can be found in appendix C.

2. **The post COVID-19 Functional Status Tool** is an ordinal, 6-point tool used to measure a variety of functional outcomes during recovery from COVID-19. The scale which has steps ranging from no symptoms to death can be used to measure the impact of symptoms on functional performance and the effect of interventions on the recovery trajectory. The post COVID-19 Functional Status Tool is intended to be used at a number of different time points during a patient's recovery in order to measure change in status and support an understanding of the patient's recovery trajectory. It may be completed either by clinical professionals or by the patient themselves with the use of the flowchart. If the patient has cognitive or other limitations which prevents them from providing responses, the tool is suitable for a family member or carer to respond on their behalf. The tool can be found in appendix D.

Recommended collection timepoints for both tools are:

- At the first post-COVID assessment clinic appointment

- 4-8 weeks after the first clinic appointment
- 6 months after the first clinic appointment

13.   NHS Standard Contract

CCGs may use the NHS Standard Contract to commission post-COVID syndrome assessment and management clinics. The service specification should be recorded in Schedule 2A of the Particulars of the Contract, where a non-mandatory model template for local determination and population is provided.

Guidance on developing the specification and populating the contract template is provided in the Contract Technical Guidance. Queries in using the contract can be sent to *nhscb.contractshelp@nhs.net.*

14.   Communications

Each commissioner should develop and implement plans to raise awareness of post-COVID assessment clinics in their clinical communities. These plans should cover communications to general practitioners, hospital doctors, registered nurses, pharmacists, clinical and health psychologists, psychological therapists (especially in IAPT services) and other allied health professionals and clinicians in primary, secondary, community, and tertiary care. Other public bodies, including secure unit services such as prisons, local councils, and education, should also be included in these plans, to ensure equitable access. Healthcare systems can utilise existing communications platforms, including formal NHS platforms, membership bodies, and voluntary organisations. Commissioners should also develop culturally relevant communications plans to raise awareness amongst patients and the public.

NHS England and NHS Improvement will support communications to patients and healthcare systems in parallel.

15.   Clinic resourcing

£10 million has been allocated for the establishment of post-COVID syndrome assessment clinics. It is proposed each healthcare system has access to a post-COVID syndrome clinic to serve their population. The exact geographic configuration of clinics will be agreed with NHS England and NHS Improvement regional leads supported by the newly established respiratory clinical networks, which are funded through the CVD-Respiratory System Development Funding, to assist with the coordination of the clinics in the context of a pathway of care for these patients.

Funding will be allocated based on unweighted September 2020 GP registered populations by region.

Key considerations in the allocation have included:

Inequalities and need: using unweighted GP allocation makes no adjustment for health inequalities or need. As the demographic of post-COVID syndrome patients is

not well understood, it is difficult to make needs-based adjustment. Consideration of the general CCG allocation formula was made as this includes an adjustment to reflect need for health inequalities, but this also weights for other factors, including age, which is not known to be a factor here. There is no precedent for isolated adjustments for health inequalities, and whilst this is possible it may be less transparent than unweighted population on basis of an unknown population. However, a health equality plan to address equity of access is one of the requirements of set up. An Equalities and Health Inequalities Impact Assessment has been completed for this guidance.

COVID-19 populations: funding has not been weighted according highest number of COVID-19 cases as infection rates are not static. Whilst the North of England is currently worst hit, the infection rate could rise in other parts of the country over the next 6 months, and the first wave also covered differing populations.

What population to use: the CCG weighted populations from the allocations model focuses resources on areas with older populations due to their higher needs for health care. This is not the primary population of interest as post-COVID syndrome-19 is reported to affect people of all ages. Unweighted populations are more appropriate.

What period to use for the populations: GP registered populations have been changing in recent months due to emigration and excess deaths. Allocations have previously used a 12 month average registered population in the formula, but this is not appropriate currently due to the changes observed in populations.

What month to use for populations: September 2020 registrations will not reflect the distribution of students at their term time address and if this age group is included in the distribution this will impact on how resources are distributed.

What age distribution to use: not enough is known about which populations are more likely to experience ongoing symptoms of COVID-19. Therefore, total population (all ages) have been used.

16. Governance and assurance

NHS England and NHS Improvement regional teams will work with healthcare systems and commissioners to systems to agree the best arrangement for delivery of these clinics, to determine geographic footprint and identify a provider(s) in order to ensure universal geographic coverage, support communications with patients and stakeholders and inform future delivery of service.

To access the funding for the establishment of the clinic the nominated regional lead will be required to provide assurance on the following:

- The named providers of the clinics

- Geographical coverage of the entire regional population by the clinics, including a plan for ensuring equity of access, and delivery of care (bearing in mind many population groups have been disproportionately affected by COVID-19.)

- Clinics have a nominated clinic lead, and appropriate MDT to account for the multi-system nature of post-COVID syndrome. As a minimum this should include specialist mental health input and ability to refer to IAPT, physiotherapy, occupational therapy, and dietetics. Patients with complex needs requiring coordinated input should have an individual rehabilitation prescription and access to specialist rehabilitation with a single point of access.

- Referral routes should include all affected patients whether hospitalised or not, and based on clinical diagnosis in the absence of a positive SARS-CoV-2 serology

- Evidence of internal and external communications plan for local clinical and patient community

- Post-COVID assessment clinics should

    - Be able to perform a physical assessment, that includes diagnostic testing, as a minimum imaging, physiological measurement and phlebotomy

    - Carry out a cognitive assessment, to assess any potential memory, attention, and concentration problems

    - Carry out a psychological assessment, to assess any depression, anxiety, PTSD, or another mental health condition

    - Commit to track and report on activity and service outcomes outlined in sections 11 and 12 above.

17.   The role of respiratory clinical networks

Respiratory networks are already involved in the planning for, and response to, the increase in admissions from COVID-19, and will soon also have a remit for children and young people with asthma, led by clinicians with paediatric expertise that can support the inclusion of planning of access to services for children.

Respiratory clinical networks may assist with the rapid establishment of these new assessment clinics for people with post-COVID syndrome, working in partnership with clinicians across primary, community or secondary care. Networks will identify a lead in the network to support the planning and implementation of the post-COVID assessment clinics for children and young people.

In particular, the networks should:

- Establish which lead commissioners in their local systems are coordinating the post-COVID assessment clinics; and

- Provide guidance and support for the establishment of the clinics within a coherent local pathway for post-COVID syndrome.

- Work in partnership with clinical leaders from other specialties to support implementation, recognising the multi-system nature of the condition

Appendices

Appendix A: Supporting resources

Please note these resources, or their online location, may be updated. Please contact england.clinicalpolicy@nhs.net if you require further information on accessing them.

- Your COVID Recovery: NHS online interactive platform for patients with post-COVID syndrome to self-manage their rehabilitation

- British Thoracic Society guidance

- e-Learning for Healthcare: *four CPD accredited 20-minute e-Learning modules*

- Royal College of General Practitioners House of Lords written evidence

- Clinical guide for front line staff to support the management of patients with a learning disability, autism or both during the coronavirus pandemic – relevant to all clinical specialties.

- After-care needs of inpatients recovering from COVID-19

- Allied health professionals' role in rehabilitation during and after COVID-19

- NICE/SIGN/RCGP Guideline Scope: management of the long-term effects of COVID-19

Appendix B: Newcastle post-COVID syndrome Follow-Up Screening Questionnaire

With thanks to Dr Graham Burns Consultant Physician in Respiratory and General Medicine, Newcastle upon Tyne Hospitals NHS Foundation Trust

(To be carried out 10-12 weeks after the acute illness)

The purpose of the questionnaire is to identify patients who may benefit from a comprehensive face to face multi-disciplinary assessment. It is designed to be used remotely and is equally applicable for patients who were either hospital inpatients or managed in the community during the acute phase of their illness.

Most patients who experienced severe symptoms during the acute phase will have residual problems such as fatigue, breathlessness, and poor sleep quality for several weeks. For the majority, these symptoms will resolve, albeit slowly. Unless there are very unusual features, the most appropriate course of action early in the post-acute phase may be advice on graduated physical rehabilitation and the passage of time.
A small proportion of patients however will go on to have symptoms that persist beyond 12 weeks, a condition commonly known as 'Long COVID'. Such individuals require more detailed investigation and are likely to need more intensive and specialist support.

This questionnaire is designed to screen for the issues that might prompt concern if still present 10-12 weeks after the acute illness. To facilitate application to a potentially large cohort the questions are limited and therefore may not necessarily comprehensive. If other issues are identified (that are not obviously related to a pre-exiting condition which may prompt an alternative route of referral) with a plausible and temporal relationship to the COVID illness, referral may still be considered. The full complexity of the post-COVID state and post-COVID syndrome is yet to be fully understood.

Section 1 (to be completed pre call)

Name………………………………………….

NHS number …………………………………………..

Date of Positive Swab…………………….
Date of Onset of symptoms………………………
Date of Discharge (for hospital admissions) …………………………..

Date of call _____
Person phoning _____ Role _____

Level of respiratory support during acute Illness:

ITU, Intubated ☐   ITU, not intubated ☐   Enhanced Respiratory support (e.g. CPAP) ☐

Supplemental oxygen ☐   Managed in the community ☐

Section 2

1. Have you made a full recovery or are you still troubled by symptoms?

   Symptoms ☐   Full Recovery ☐

2. Are you more breathless now than you were before your COVID illness?

   a. Is this more than you would have expected by now? ☐
      or
   b. Do you think you are on your way back to full fitness? ☐

3. Do you feel fatigued (worn out/lacking energy or zest) compared with how you were before your COVID illness?

   a. Is this more than you would have expected by now? ☐
      Or
   b. Do you think you are well on your way back to full fitness? ☐

4. Do you have a cough (different from any cough you may have had before COVID-19)?

        Yes ☐   No ☐

5. Do you get any palpitations? (sense that you can feel your heart pounding or racing)

        Yes ☐   No ☐

6. How is your physical strength? Do you feel so weak that it still limiting what you can do (more than you were pre your COVID illness)?

        Yes ☐   No ☐

7. Do you have any myalgia ('aching in your muscles')?

        Yes ☐   No ☐

8. Do you have anosmia ('no sense of smell')?

        Yes ☐   No ☐

9. Have you lost your sense of taste?

        Yes ☐   No ☐

10. Is your sleep disturbed (more than it was pre-COVID)?

        Yes ☐   No ☐

11. Have you had any nightmares or flashbacks?

        Yes ☐   No ☐

12. On your mood

c. Is your mood low/do you feel down in the dumps/lacking in motivation/no pleasure in anything?

Yes ☐   No ☐

d. Do you find yourself feeling anxious/worrying more than you used to?

Yes ☐   No ☐

13. Have you lost weight (> ½ stone, 3 Kg) since your COVID illness?

Yes ☐   No ☐

14. Any other symptoms (list)

Decision guide:
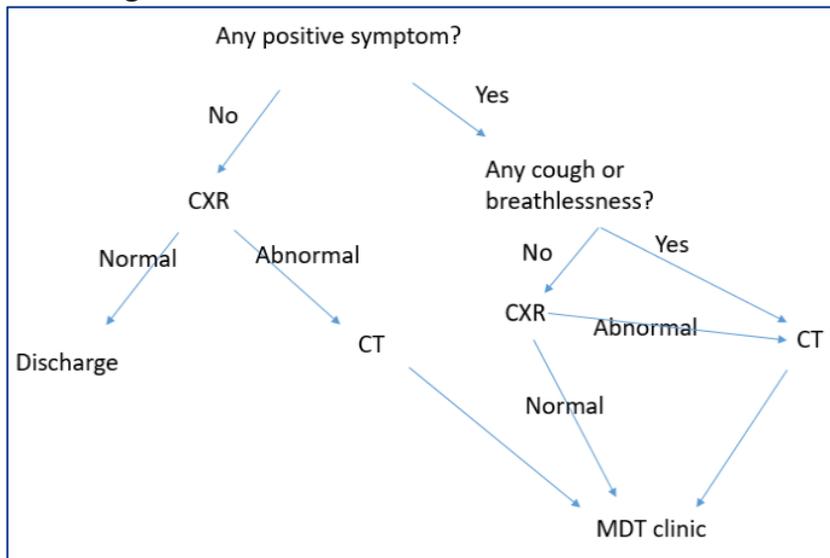
Appendix C: COVID-19 Yorkshire Rehabilitation Screening Tool

COVID-19 Yorkshire Rehab Screen
With thanks to

Dr Manoj Sivan Associate Professor and Consultant in Rehabilitation Medicine, University of Leeds, Leeds Teaching Hospitals NHS Trust and Leeds Community Healthcare Trust.

Dr Stephen Halpin Senior Research Fellow and Consultant in Rehabilitation Medicine, University of Leeds, Leeds Teaching Hospitals NHS Trust and Leeds Community Healthcare Trust.

Mr Jeremy Gee Community Advanced Clinical Practitioner and Physiotherapist, Airedale NHS Foundation Trust

Patient name and NHS number:

Time and date of call:

Staff member making call:

We are getting in touch with people who have been discharged after having had a diagnosis of coronavirus disease (COVID-19). The purpose of this call is to find out if you are experiencing problems related to your recent illness with coronavirus. We will document this in your clinical notes. We will use this information to direct you to services you may need and inform the development of these services in the future.
This call will take around 15 minutes. If there's any topics you don't want to talk about you can stop the conversation at any point.

Do you agree to talk to me about this today? Yes ☐ No ☐

Opening questions:

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

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

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

	• short term memory? Yes ☐ No ☐
13. Cognitive-Communication	*Have you or your family noticed any change in the way you communicate with people, such as making sense of things people say to you, putting thoughts into words, difficulty reading or having a conversation?* Yes ☐ No ☐ If Yes: rate the significance of impact on a scale of 0-10 (0 being no impact, 10 being significant impact) 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐
14. Anxiety	On a 0-10 scale, how severe is the anxiety you are experiencing? 0 means I am not anxious, 10 means I have extreme anxious. Now: 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐ Pre-COVID: 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐
15. Depression	On a 0-10 scale, how severe is the depression you are experiencing? 0 means I am not depressed, 10 means I have extreme depression. Now: 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐ Pre-COVID: 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐
16. PTSD screen	a) Have you had any unwanted memories of your illness or hospital admission whilst you were awake, so not counting dreams? Yes ☐ No ☐ If yes, how much do these memories bother you? (is the distress: mild ☐ / moderate ☐ / severe ☐ / extreme ☐) b) Have you had any unpleasant dreams about your illness or hospital admission? Yes☐ No☐ If yes, how much do these dreams bother you? (is the distress: mild ☐ / moderate ☐ / severe ☐ / extreme ☐) c) Have you tried to avoid thoughts or feelings about your illness or hospital admission? Yes ☐ No ☐ If yes, how much effort do you make to avoid these thoughts or feelings? (mild ☐ / moderate ☐ / severe ☐ / extreme ☐) d) Are you currently having thoughts about harming yourself in any way? Yes ☐ No ☐
17. Global Perceived Health	How good or bad is your health overall? 10 means the best health you can imagine. 0 means the worst health you can imagine. Now: 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐ Pre-COVID: 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐
18. Vocation	What is your employment situation and has your illness affected your ability to do your usual work? Occupation: _____ Employment status before COVID-19 Lockdown: _____ Employment status before you became ill: _____ Employment status now: _____
19. Family/carers views	Do you think your family or carer would have anything to add from their perspective?

Closing questions:

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

Appendix D: Post-COVID syndrome functional assessment scale

Post-COVID syndrome Functional Status Scale
With thanks to Dr Frederikus A. Klok, MD, FESC; Department of Thrombosis and Haemostasis, Leiden University Medical Center, Leiden, the Netherlands; Albinusdreef 2, 2300RC, Leiden, the Netherlands.
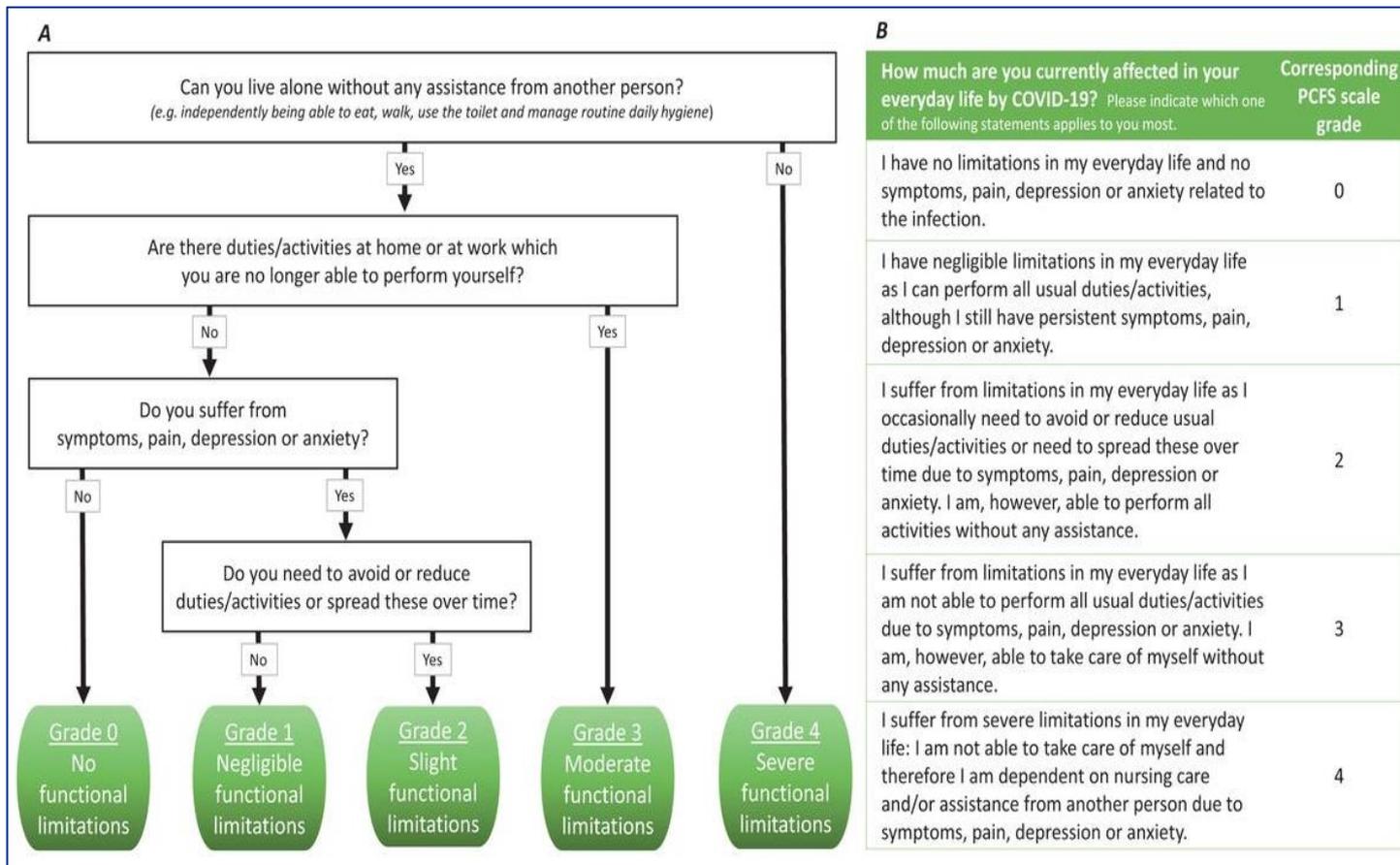

Table 1 Patient self-report methods for the Post-COVID-19 Functional Status (PCFS) Scale (Klok et al., 2020)

Post-COVID syndrome-19 functional Status Scale Structured Interview

STRUCTURED INTERVIEW

1. SURVIVAL	Corresponding PCFS scale grade if the answer is 'YES'
1.1 Has the patient died after the COVID-19 diagnosis?	D

2. CONSTANT CARE Explanation: meaning someone else needs to be available at all times. Care may be provided by either trained or an untrained caregiver. The patient will usually be bedridden and may be incontinent.	Corresponding PCFS scale grade if the answer is 'YES'
2.1 Do you require constant care?	4

3. BASIC ACTIVITIES OF DAILY LIVING (ADL) Explanation: assistance includes physical assistance, verbal instruction, or supervision by another person. It may be considered *essential* when there is a need for physical help (by another person) with an activity or for supervision, or the patient needs prompting or reminding to do a task. The need for supervision for safety reasons should be due to *objective danger* that is posed, rather than 'just in case'.	Corresponding PCFS scale grade if the answer is 'YES'
3.1 Is assistance essential for eating? (Eating without assistance: food and implements may be provided by others)	4
3.2 Is assistance essential for using the toilet? (Using toilet without assistance: reach toilet/commode; undress sufficiently; clean self; dress and leave)	4
3.3 Is assistance essential for routine daily hygiene? (Routine hygiene includes only washing face, doing hair, cleaning teeth/fitting false teeth. Implements may be provided by others without considering this as assistance)	4
3.4 Is assistance essential for walking? (Walking without assistance: if absolutely necessary, able to walk indoors or around house or ward, may use any aid, however not requiring physical help or verbal instruction or supervision from another person)	4

4. INSTRUMENTAL ACTIVITIES OF DAILY LIVING (iADL) Explanation: assistance includes physical assistance, verbal instruction, or supervision by another person. It may be considered *essential* when there is a need for physical help (by another person) with an activity or for supervision, or the patient needs prompting or reminding to do a task. The need for supervision for safety reasons should be due to *objective danger* that is posed, rather than 'just in case'.	Corresponding PCFS scale grade if the answer is 'YES'
4.1 Is assistance essential for basic household chores which are important for daily life? (E.g. preparing a simple meal, doing the dishes, take out the garbage; exclude chores that do not need to be done every day)	4
4.2 Is assistance essential for local travel? (Local travel without assistance: the patient may drive or use public transport to get around. Ability to use a taxi is sufficient, provided the patient can manage to call and instruct the driver)	4
4.3 Is assistance essential for local shopping? (The patient is not able to buy groceries or necessities by him or herself)	3

5. PARTICIPATION IN USUAL SOCIAL ROLES	Corresponding PCFS scale grade if the answer is 'YES'
Explanation: this section concerns impairment in fulfilment of major social roles (not social or financial circumstances).	
5.1 Is adjustment essential for duties/activities at home or at work/study because you are unable to perform these yourself (e.g. resulting in a change in the level of responsibility, a change from full-time to part-time work or a change in education)? (Work refers to both paid employment and voluntary work. Special arrangements which allow someone to return to work, even though normally he/she wouldn't be able to work, should be considered as adjustment of work.)	3
5.2 Do you occasionally need to avoid or reduce duties/activities at home or at work/study or do you need to spread these over time (while you are basically able to perform all those activities)?	2
5.3 Can you no longer take good care of loved ones as before? (Taking good care includes babysitting, looking after your partner, parents, grandchildren or dependent others.)	3
5.4 Since the COVID-19 diagnosis, have there been problems with relationships or have you become isolated? (These problems include communication problems, difficulties in relationships with people at home or at work/study, loss of friendships (increase in) isolation, etc.)	3
5.5 Are you restricted in participating in social and leisure activities? (Comprising hobbies and interests, including going to a restaurant, bar, cinema, going for walks, playing games, reading books, etc.)	2

6. SYMPTOM CHECKLIST	Corresponding PCFS scale grade if the answer is 'YES'
Explanation: these can be any symptoms or problems reported by the patients or found on physical examination. Symptoms include but are not limited to: dyspnoea, pain, fatigue, muscle weakness, memory loss, depression and anxiety.	
6.1 Do you report symptoms through which usual duties/activities need to be avoided, reduced or spread over time?	2
6.2 Do you report any symptoms, resulting from COVID-19, without experiencing functional limitations?	1
6.3 Do you have problems with relaxing or do you experience COVID-19 as a trauma? ('Trauma' is defined as: suffering from intrusive memories, flashbacks or avoidance responses, associated with having experienced COVID-19.)	1

Assigning a grade on the post-COVID-19 functional status scale

The overall rating is simply the poorest functional status indicated by the patient's answers (the highest grade corresponds with the most limitations). If a respondent has no limitations or symptoms, then the appropriate scale grade is 0.

Final PCFS scale grade: _____

What was your PCFS scale grade *before* COVID-19? _____

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