NHS England and NHS Improvement London

COVID-19: Guidance for the commissioning of clinics for recovery and rehabilitation

Version: 1.0 For Release

Circulated date: 31st July 2020

Review date: 31st October 2020

This document will continue to be reviewed and re-released to reflect new and emerging evidence. Please email england.londoncagsupport@nhs.net to request the most recent version.

Disclaimer: The evidence regarding the impact of COVID-19 on patients is rapidly emerging and the extent of rehabilitation needs of people who are recovering from COVID-19 are not yet fully known. This document is based on the available evidence at the time and will be continuously reviewed to ensure alignment with the evolving data.

Acknowledgments

The project team would like to acknowledge the substantial support of UCLPartners under its Managing Director, Professor Mike Roberts, in the coordination and preparation of this guidance. The team would also like to acknowledge the contributions of the following individuals who have supported the delivery of this document in a short timeframe.

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Version Control

Version	Date Agreed	Date Circulated	Amendments agreed
1	31/07/2020	03/08/2020	N/A

Upcoming release schedule and expected content

Version	Expected circulated date	Expected updates
2	30/10/2020	Reflection of new and emerging evidence, amendments as a result of feedback from the system and additional areas identified through implementation

1 Executive summary

Rehabilitation is a core component of recovery from a major injury, illness or disease, acknowledged as effective in improving independence, restoring function and managing the impacts of long-term disabilities. Rehabilitation should be patient-centred and tailored to meet the needs of the patient (and their family/carers), supporting individuals to achieve their maximum potential for physical, cognitive, psychosocial functions and quality of life.

The evidence regarding the impact of COVID-19 on patients is rapidly emerging and the extent of rehabilitation needs of people who are recovering from COVID-19 are not yet fully known. This document is based on the available evidence at the time and will be continuously reviewed to ensure alignment with the evolving data.

The design and delivery of rehabilitation services for COVID-19 survivors is the responsibility of each Integrated Care Systems (ICS). The services should aim to provide a multi-disciplinary, whole system approach to the planning and commissioning of post-COVID-19 and post-ICU rehabilitation services

It is intended that this framework reflects the evidence and requirements of multidisciplinary rehabilitation for the population and will support local service decision making. Based on the current evidence, the frameworks aim to provide guidance provision of a post COVID-19 rehabilitation service. It is designed to meet the varied needs of the patient population who require rehabilitation support as part of their COVID-19 recovery. This includes provision for patients:

- discharged from ICU to hospital wards
- discharged from hospital wards to the community
- who have been managed within the community setting but still have rehabilitation needs

The framework aims to:

- Provide pan-London principles that guide the standards for the minimum provision of COVID-19 recovery and rehabilitation provision across the London STP/ICSs.
- Provide ICS/STP commissioners with consistent guidance from which to ensure alignment and meet the demand for services/needs of the population
- Support clinicians across London to conduct patient assessments and provide subsequent care including appropriate referrals
- Recognise the gaps in service provision which need addressing otherwise there is a risk to perpetuate existing health inequalities

2 Key recommendations

It is recognized that there are patients across London with existing rehabilitation needs resulting from other conditions such as those with stroke. The development and configuration of services for post COVID-19 rehabilitation should not inadvertently worsen access for this cohort and this opportunity should be used to improve the provision of rehabilitation services at population level across London. Pan London

work has commenced to explore collaborative working across different condition specific rehabilitation services.

Post-COVID-19 care for patients requires coordination and collaboration across primary care as well as specialist services. The intensity of support from specialist services will be dependent on holistic assessment of individual patient need. The key principles to delivering post COVID-19 services are:

1. There should be a single co-ordinator of care so that at an ICS level, equity of access for all and a holistic approach can be maintained for post COVID evaluation of needs. This should include a systematic assessment of physical, cognitive and psychosocial impairments.
2. Rehabilitation assessment and support should be holistic and encompass both physical and non-physical considerations in order to truly reflect a biopsychosocial approach.
3. The use of existing services across primary, secondary, community and voluntary sectors is encouraged. This requires strong collaboration and active signposting to available services in order to support the spectrum of patient needs.
4. Post ICU clinics should be provided within acute trusts under the lead of a consultant intensivist. A wide range of multi-disciplinary professionals including representation from a number of different specialties should be involved in order to conduct a comprehensive assessment of needs and subsequent provision of support required.
5. Patients and their families/carers should be involved in discussions and decisions regarding the care as well as repeated goal setting, with effective communication between them and their clinical team at every point of transfer along their pathway

3 Why are we issuing this guidance?

3.1 Background and context

The COVID-19 pandemic has had a significant impact on the population with patients often requiring ongoing care and support beyond their initial recovery. This places enormous pressure on existing recovery and rehabilitation services across all levels (Figure 1 and Appendix 1 - Categories of rehabilitation need) that have had to rapidly reconfigure and develop innovative approaches in order to maintain a level of provision.

Consistent with the persistent issues seen in other Coronaviruses (CoV) and life-threatening illnesses, there is emergent evidence of long-term complications across cognitive, psychological, and physical spheres. Whilst it is recognised that the permanence of these changes is not yet known, it offers an opportunity to improve patient care pathways and subsequent quality of life, ensuring that services are coordinated and meet the needs of the population.

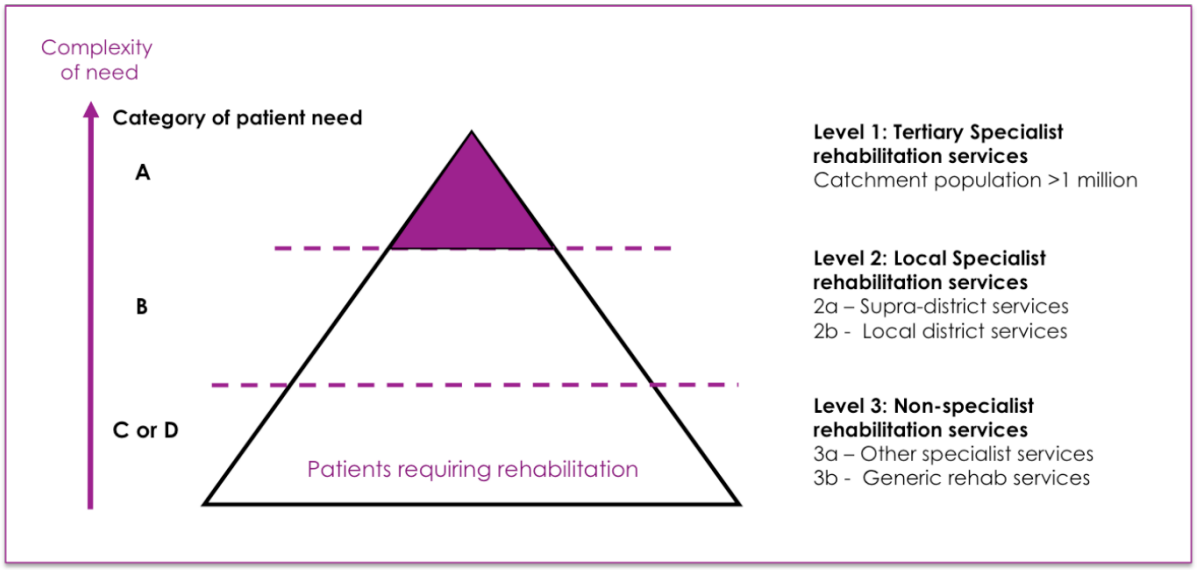


Figure 1 :Levels of specialisation in rehabilitation service provision in England

Rehabilitation is a core element of the care pathway demonstrated to be effective in improving independence, restoring function and managing the impacts of long-term disabilities. Rehabilitation should be patient-centred and tailored to meet the needs of the patient (and their family/carers) supporting individuals to achieve their maximum potential for physical, cognitive, psychosocial functions and quality of life. Patient goals for rehabilitation vary according to the recovery trajectory and stage of their condition though early rehabilitation is considered optimal best practice.

A significant number of patients requiring rehabilitation will have been admitted to hospital or an intensive care unit (ICU) and the impact of hospitalisation and/or critical illness on a patient's wellbeing, requires a holistic approach to consider the physical, psychological, cognitive and social impacts.

Of those patients admitted to an ICU, more than half will have features, across one domain of the now widely accepted syndrome, Post-Intensive Care Syndrome (PICS). PICS encompasses recognized clinical features affecting three domains; physical, cognitive and psychosocial wellbeing. Consequently, patients who presented with severe COVID-19 requiring ICU care are at high risk of PICS. The prevalence of PICS in people who have received ICU treatment for COVID-19 is not yet known, but an increase in rehabilitation demand to address the clinical manifestations of PICS is already being realised.

Importantly, a significant proportion of people who have had COVID-19, but not hospitalized and managed in the community will also require rehabilitation and support from community services. There is a need to identify and support patients across both acute and community settings, reflecting the unique challenges posed by COVID-19.

Additionally, it is vital to recognise that there are patients across London with existing rehabilitation needs resulting from other conditions such as stroke. The development and configuration of services for post COVID-19 rehabilitation should not inadvertently worsen access for this cohort and this opportunity should be used to improve the provision of rehabilitation services at population level across London.

Much remains unknown about the long-term consequences of COVID-19, but the early initiation of physical, psychological, cognitive and social rehabilitation in the recovery process, providing the appropriate support and follow-up across both acute and community settings is required. To achieve this a multidisciplinary approach to support these patients is required and this needs to be adaptive to the novel challenges presented by COVID-19. A regional framework and pan-London principles has subsequently been developed to support providers across primary, secondary and community care improve patient outcomes, reduce variation and maximise recovery.

3.2 Purpose

It is acknowledged that the design and delivery of rehabilitation services for COVID-19 survivors is the responsibility of each Integrated Care Systems (ICS). It is intended that this framework reflects the evidence and requirements of multidisciplinary rehabilitation for the population and will support local service decision making.

Specifications should seek to adhere to the consensus standards as a minimum. These provide a framework that reflects the evidence and requirements of multidisciplinary rehabilitation for the population.

3.3 Aims and Objectives

The overall aim is to provide all patients recovering from COVID-19 across London with coordinated access to services that meet their rehabilitation needs and supports them in their recovery to achieve their target outcomes.

The objectives of the post COVID-19 rehabilitation service are:

- To make rehabilitation provision accessible to all patients who are recovering from the impacts of COVID-19 ensuring that there is equity of access to consistent, holistic rehabilitative care across all care settings
- To support holistic personalised assessments that identify patients at risk and determining a treatment plan that ensures a consistent approach to ongoing care that incorporates, where necessary, any specialist assessments and support for family and carers. This will involve taking a personalised care approach and working in partnership with social care and the local voluntary and community sector, where appropriate.
- To support the integration of out-of-hospital care where possible and strengthen the collaboration between specialist rehabilitation pathways where available
- To facilitate the collection of data to develop an understanding of which interventions are effective and describe the range of outcomes for patients with COVID-19 requiring rehabilitation support. To enable monitoring and auditing of data to inform service provision and future development.
- The patient's assessment will be holistic and conducted in partnership across health and social care. It will seek to gain an accurate understanding of the patient's physical and mental health and wellbeing. This will involve undertaking a personalised care approach and working in partnership with social care, where appropriate.

3.4 Scope

A post COVID-19 rehabilitation service needs to be designed to meet the varied needs of the patient population who have been identified to require rehabilitation support as part of their COVID-19 recovery. This includes patients:

- discharged from ICU to hospital wards
- discharged from hospital wards to the community
- who have been managed within a community setting, but still have rehabilitation needs.

Whilst some cohorts may require a modified approach, exclusion criteria should be limited to:

- Those under a threshold age for adult services (<16 years)
- Category A patients with highly complex needs who require specialised rehabilitation services beyond the scope of local specialist services

3.5 Core Standards

Appendix 2 - Core standards for post-COVID-19 rehabilitation care describes evidence-based core standards for an ICS/STP with regards to a post COVID-19 rehabilitation service, across all sectors of care. Two tables describe a series of consensus statements to inform the service requirements, development and delivery of a rehabilitation service for COVID-19 survivors. These consensus statements have been tested with subject experts and a patient group.

4 The care pathways involved

- Figure 1 outlines the pathway for patients that were admitted to ICU until hospital discharge and subsequent referral to the post-ICU clinic.
- Figure 2 shows a care pathway for patients discharged from the ward (but who did not require ICU admission).
- Figure 4 shows a care pathway for patients who never require admission to acute settings but have persistent symptoms or develop ongoing, abnormal sequelae as a result of COVID-19 necessitating further investigation and care.
- Figure 4 shows the post-discharge pathway for patients who require admission to ICU.
- Figure 5 outlines the local post-COVID-19 clinic encompassing a holistic, multidisciplinary approach

4.1 Patient pathway post-ICU discharge

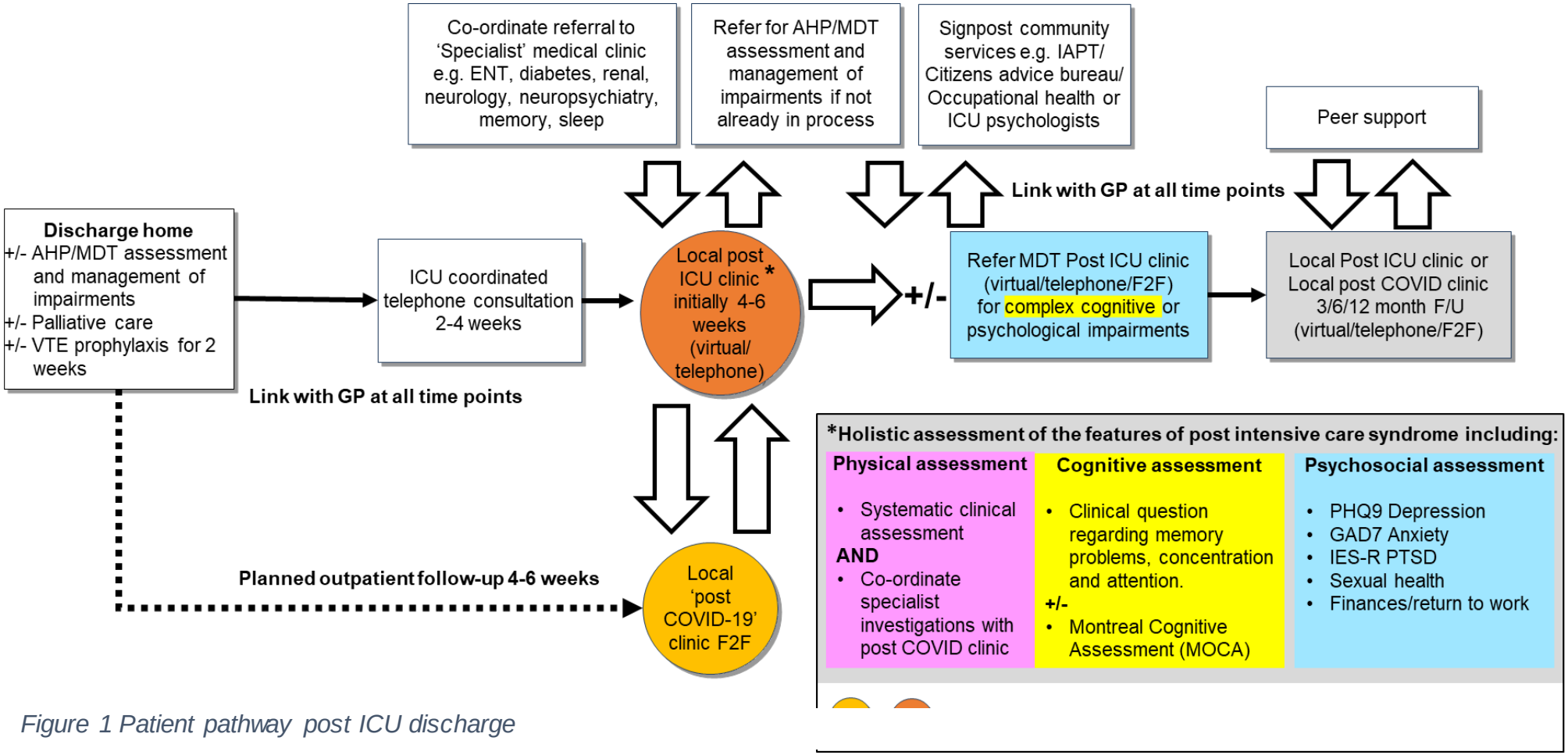
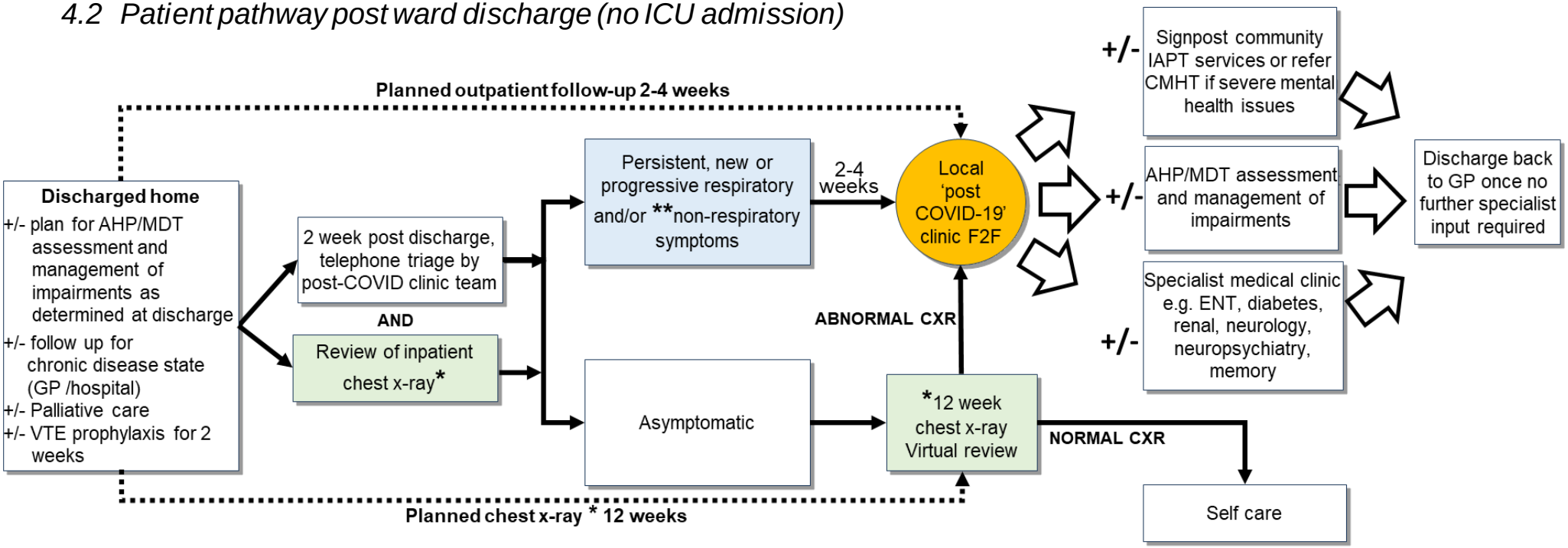


Figure 1 Patient pathway post ICU discharge

4.2 Patient pathway post ward discharge (no ICU admission)



* **Chest x-ray (CXR)** while an inpatient. If any concern re suspected malignancy then to order a 6 week CXR; otherwise 12 week CXR

Indicates a link to another process chart

** **Non-respiratory COVID symptoms:**

- Fatigue
- Chronic pain
- Mental health
- Insomnia
- Memory loss
- Headache
- Dizziness
- Dermatological
- Neurological / cognitive
- Cardiovascular

Figure 2 Patient pathway post ward discharge (no ICU admission)

4.3 Primary Care/Community referral pathway to the post-COVID-19 clinic

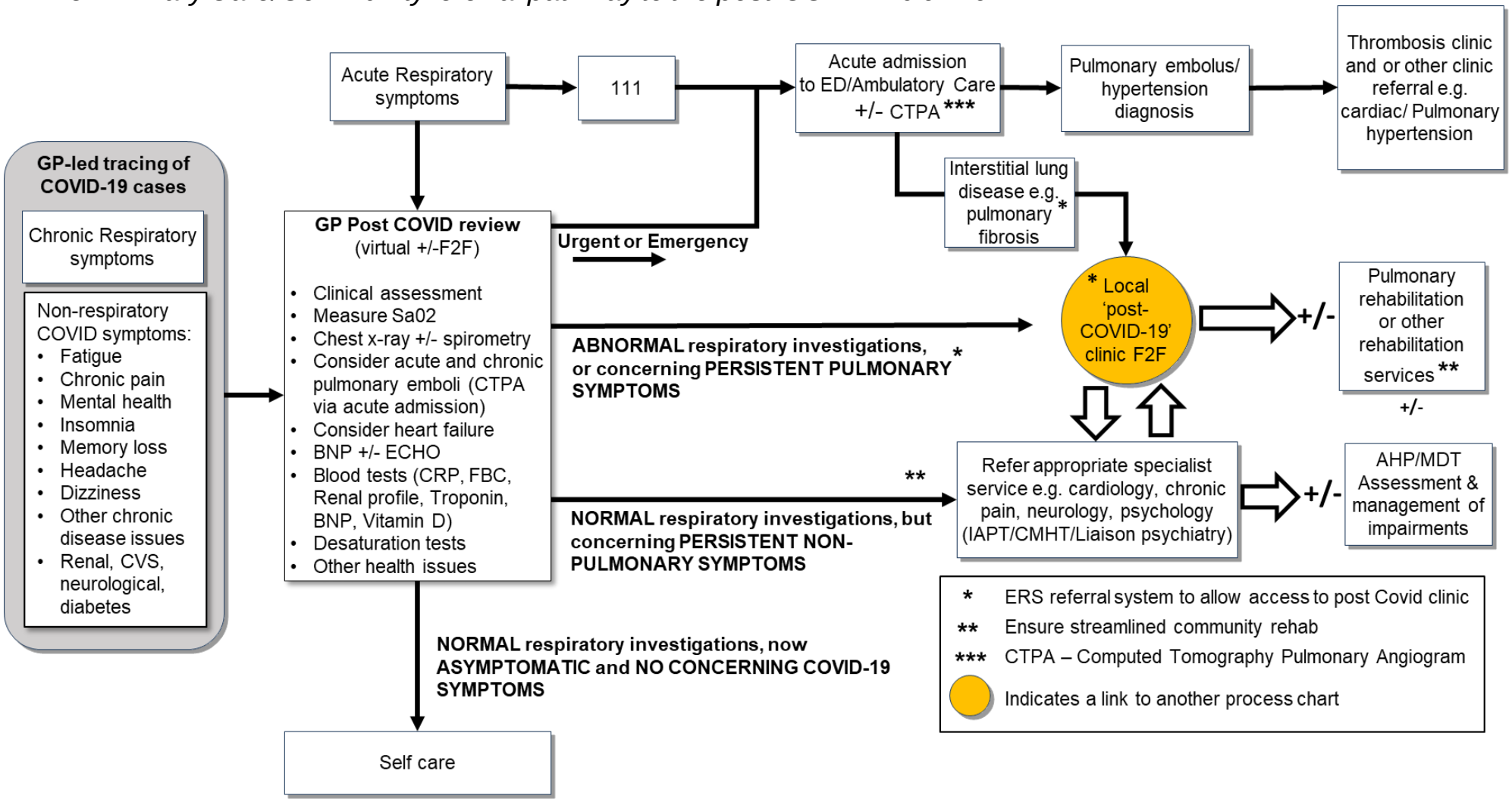


Figure 3 Primary Care/Community referral pathway to the post-COVID-19 clinic

4.4 Patient discharge from ICU

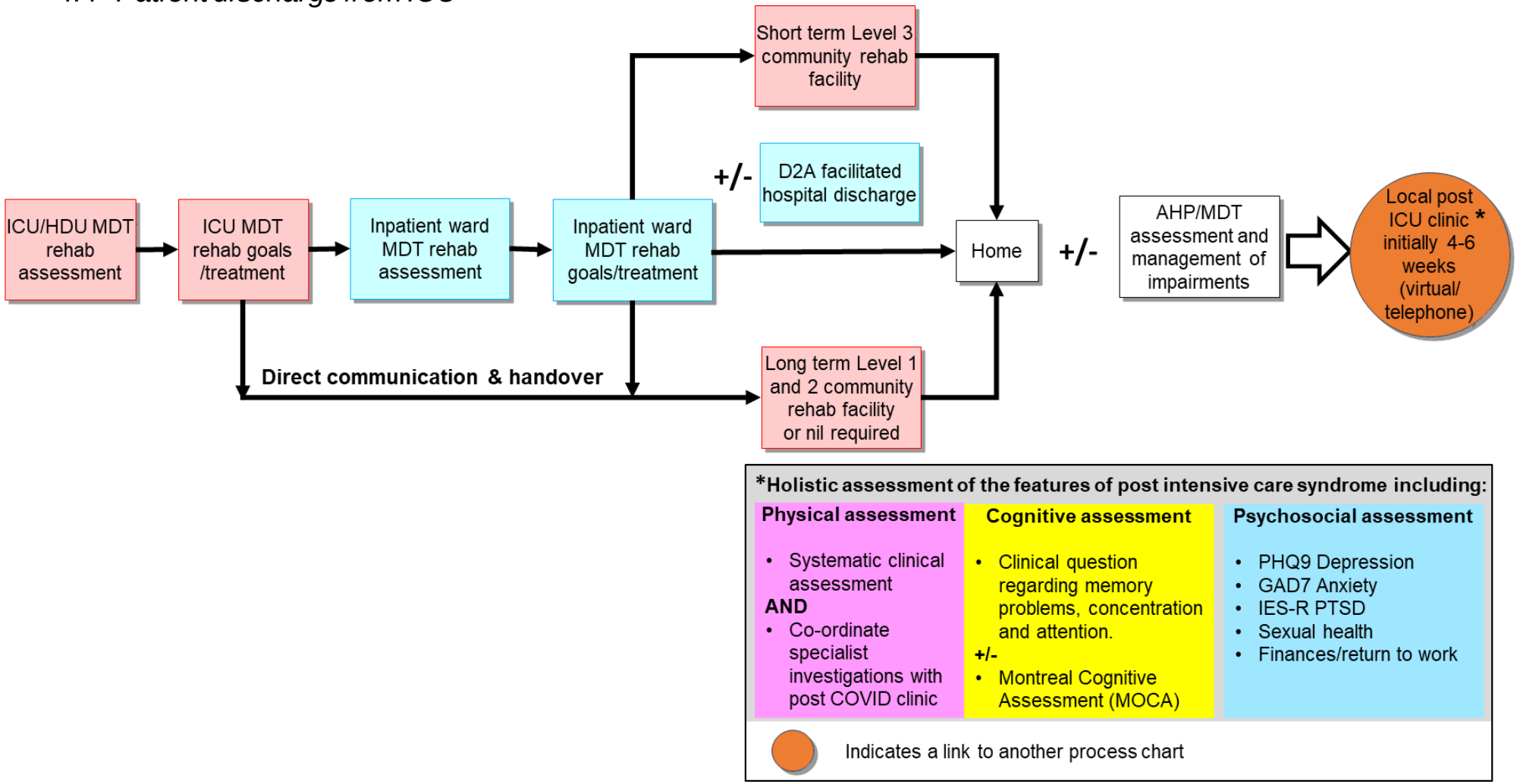
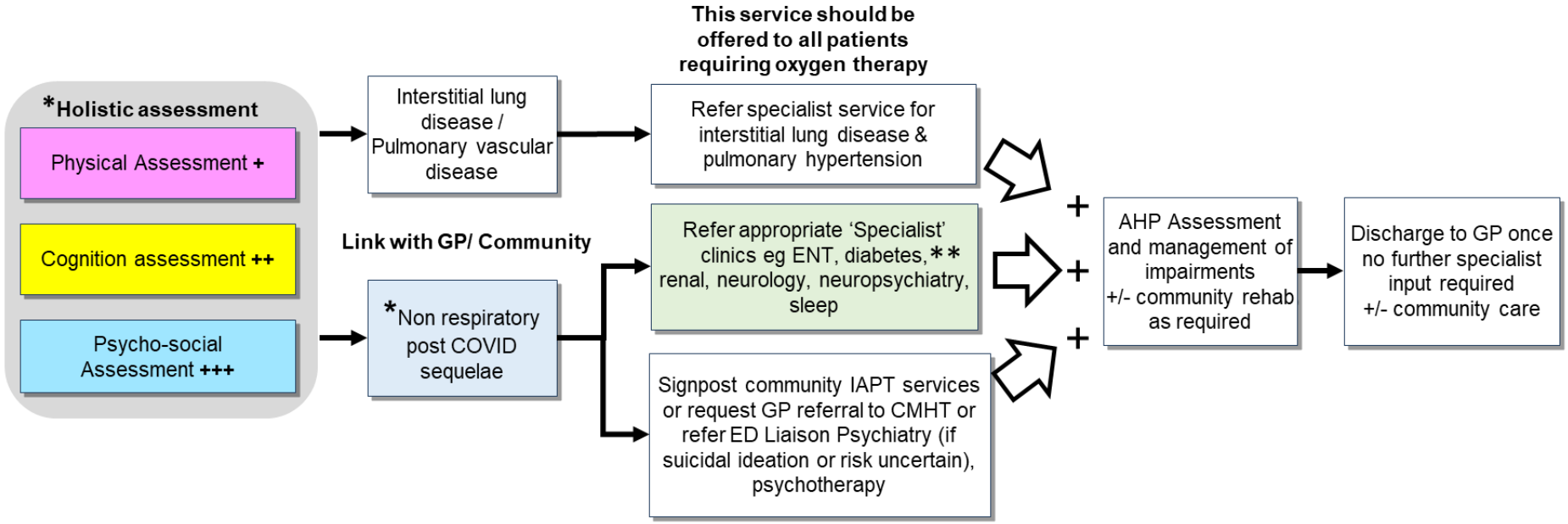


Figure 4 Patient discharge from ICU

4.5 Local post COVID-19 clinic



+ Physical assessment	++ Cognitive assessment	+++ Psychosocial assessment	* Non-respiratory COVID symptoms:
Clinical assessment with: • Chest x-ray +/- PFTs +/- CTPA +/- ECHO +/- 6MWT +/- assessment of any chronic health issues	• Clinical question regarding memory problems, concentration and attention. +/- Montreal Cognitive Assessment (MOCA)	• PHQ2 or 9 (Depression) • GAD2 or 7 (Anxiety) • IES-R or Trauma screening questionnaire (PTSD)	• Fatigue • Headache • Chronic pain • Dizziness • Mental health • Dermatological • Insomnia • Neurological • Memory loss • Cardiovascular ** Cardiology / renal/ diabetes colleagues should be involved as one stop availability

Figure 5 Local post COVID-19 clinic

5 The service pathways involved

Whilst much remains unknown about the lasting impacts of COVID-19 and the recovery trajectory for patients, rehabilitation services should be aligned with three main pillars:

- Physical health
- Cognitive health
- Psychosocial health

Services should focus on the restoration of function and return to normal levels of activity and independence, the management of any disabilities, compensation for lost function, and improving the quality of life for patients as they continue to recover from COVID-19.

Assessment and provision of services should also consider any pre-existing health care conditions which the patient may have and the continuation of appropriate and optimised management for these conditions.

It is critical that rehabilitation efforts are aligned and integrated with Infection Prevention and Control (IPC) measures with staff using PPE appropriate to their risk exposure.

The previous pages set out the service pathways for the COVID-19 patients who will attend 'local post-COVID-19' and/or 'post-ICU' clinic. It is to be noted that ICU psychologists also provide therapy to ICU survivors with psychological difficulties, as well as assessment, so should be included as one of the potential referral pathways (along with IAPT and liaison psychiatry). Examples of existing pathways are contained within

6 Appendix 3 – Respondents to survey on the Consensus Statement

The following lists shows the groups of respondents to the survey on the consensus statement, broken down by profession, clinical area and ICS/STP.

6.1 Professional group

Answer choices:	**Number of responses:**
Clinician	26
Commissioner	7
Operational Manager	6
Social Care	4
Other (CSU, Chair, COVID renewal programme manager)	3
Academics	2
Total respondents: 47 (1 with dual role)	

6.2 Clinical area.

Responses:	**Number of responses:**
Critical Care	5
Intensive Care / anaesthetics	2
GP	2
Physiotherapy	2
Critical Care Psychiatry	1
Acute speech and language therapy	1
Adult Social Care	1
Corporate nursing	1
Liaison Psychiatry	1
Neurological infection	1
Neuro rehabilitation	1
Occupational therapy	1
Reablement	1
Rehabilitation medicine	1
Respiratory medicine	1
Total respondents: 23	

6.3 London ICS

ICS /STP	**Number of responses:**
SWL	13
NEL	9
SEL	8
NCL	3
NWL	6
Other: (West Essex, Essex, Herts & West Essex, University of Liverpool, NHSE/I)	5
Total respondents: 44	

Appendix 4 - Case Studies.

6.4 Referral sources

Post-ICU clinics for Post-COVID-19 should be delivered in a 'hub and spoke' model (Figure 4) across ICSs. The 'hub' is a post-ICU multi-professional service with access to any of the following; an occupational therapy, clinical psychology or neuro/liaison psychiatry to evaluate complex psychological or cognitive deficits.

There is currently insufficient capacity to carry out those psychological and cognitive assessments with are only five London hospitals with critical care psychologists (not all full-time) embedded in the follow-up team. It is established GPICS policy for every ICU to have access to clinical psychology time, so this is an ideal opportunity for that policy to be implemented.

The 'spokes' are either 'local post-COVID-19' clinics delivered primarily by respiratory physicians or post-ICU services led by intensivist and/or ICU nurse specialists where there is limited access to specialist input to evaluate and manage the complex psychological and/or cognitive impairment.

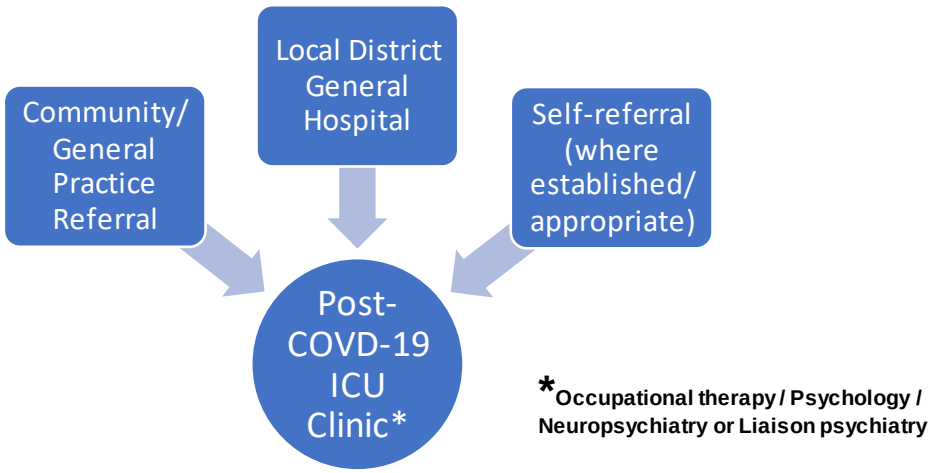


Figure 4 Hub and Spoke Model for Post-ICU clinics

The provider for 'post-COVID-19' clinics should be able to receive referrals from a wide range of services that have conducted an assessment and determined further assessment and referral is needed. Referrals can be received from, but are not limited to, the following settings:

- Primary Care
- Secondary Care
- Tertiary Care
- Community Services
- Self-referral where appropriate

Appropriate referral is typically made by a consultant, GP or community healthcare team.

Within primary and community care there are several ways that clinicians can identify patients who may require ongoing surveillance to identify persistent symptoms that warrant referral to the local 'post-COVID-19 clinic'. Primarily, this is through:

- Using READ/SNOMED codes that have been recorded during a consultation for suspected COVID-19 or influenza either at a GP clinic or Hot Hub site
- Routine follow-up for patients identified as COVID-19 within Primary and Community Care settings or Emergency Departments (zero length of stay) – 14-28 days post initial diagnosis.

Where a referral is not considered appropriate at that particular time, patients should be proactively reassessed.

6.5 Local Post-COVID-19 clinic

6.5.1 Initial Assessment

An assessment should be completed within 4-6 weeks of a patients discharge from hospital or follow-up with Primary Care/Community Services; and before this timeframe, if significant symptoms are evident. This should be conducted by a clinician involved in the delivery of the local 'post-COVID-19 clinic' who is able to ascertain the extent of rehabilitation needs and is aware of the service options available to the patient within the ICS/STP. It is imperative that assessment should include the patient's family/carers and adopt a personalised care approach that seeks to plan and provide care based on what matters to the individual.

The referrer should be informed of any outcomes from the assessment within 1 week. This should include:

- An MDT evaluation of physical, cognitive and psychosocial need and management of impairments, including a holistic assessment of the features of post intensive care syndrome where appropriate
- A recommendation of service(s) most likely to meet the assessed need including signposting to community mental health services
- An indication of the benefits and possible outcomes as a result of the use of the service
- An indication of the likely duration of rehabilitation needs (and further support needs on discharge from the service).

6.5.2 Outpatient Recovery Service

The Coronavirus-19 (COVID-19) pandemic has affected a large number of patients, many of whom were young and without co-morbidity and many who are older with pre-existing physical and mental health conditions. A full spectrum of post COVID, pulmonary and non-pulmonary sequelae are being increasingly identified and yet it is unclear which relate specifically to the virus and which relate to the management of the disease.

Local post-COVID-19 clinics for patients should be holistic and therefore encompass consideration of both pulmonary and non-pulmonary sequelae:

- Physical: Pulmonary versus Non-pulmonary
    - Cardiology
    - Urology

  - Neuromuscular
  - Neuropathy
  - Endocrine
  - General function: Dietary/nutrition, pressure ulcers, fatigue, oral health and hygiene, speech and language,

- Non-physical: Psychological and neuro-psychological (cognitive impairment):
  - Delirium
  - Cognitive impairment
  - Mental health
  - Sleep disturbance

- Social: Impaired activities of daily living

There are various models for the delivery of rehabilitation provision which will be dependent on the local resources available. Where possible, joint clinics should be considered to streamline the patient pathway. Good communication between services is vital to support patients achieve the best possible outcomes.

Signposting to rehabilitation services across community settings and the voluntary sector should be considered in addition to those within acute settings to ensure patients can access services that are convenient to them and promote independence (e.g. peer support groups).

The core standards (Appendix 2 - Core standards for post-COVID-19 rehabilitation care) further detail the level of service provision recommended to Trusts. See also Appendix 5 - Commitments for ICS/STP commissioners & providers.

6.6 Post-ICU Clinic

Patients who are admitted to ICU with more severe manifestation of COVID-19 are at greater risk of the recognised complications of an extended ICU stay as well as those linked to the virus itself.

There is an array of pulmonary complications most notably interstitial lung disease including organising pneumonia, pulmonary fibrosis and pulmonary vascular disease e.g. pulmonary emboli. Some specific non-pulmonary complications related to the ICU management of COVID-19 pneumonitis have been recognised e.g. the pressure injuries related to prone positioning leading to injury to skin, shoulders and the nerves supplying the feet and hands can lead to new impairments affecting the ability to complete activities of daily living independently e.g. walking, dressing, cooking or attending to personal care i.e. bathing or showering.

Psychologically, the COVID-19 pandemic and 'lockdown' presented the unique burden of being without the support of family, friend or relatives and several patients experienced bereavement of family and friends while on ICU. The environment within ICU was also unique during the pandemic with staff wearing full personal protective equipment (PPE) and patients cared for in environments not usually used for delivering ICU care. Many COVID-19 patients were transferred from the original admitting ICU to a neighbouring ICU due to capacity or issues with a lack of equipment.

The prevalence of ICU delirium due to these factors and high levels of sedation increases the risk of post-traumatic stress disorder. Additionally, for many they are challenges with learning to recover and rehabilitate from new impairments and this can lead to anxiety and other psychological challenges adjusting to their new health status. Guidance on post COVID-19 immunity and infectivity is lacking and has created a stigma for some patients who have survived COVID-19 and with it brought additional psychological burden (Appendix 6 - Psychological and Neuro- Psychological follow-up).

6.6.1 Post-ICU Clinic (COVID-19) Assessment

An assessment should be completed by the ward MDT planning hospital discharge, which will either be supported with or without discharge to assess or reablement services. The medical team responsible for ward-based medical care will co-ordinate hospital discharge and plan follow-up into a Local 'post-COVID-19' clinic and/or a 'post-ICU' clinic.

It should be noted that some local 'post-COVID-19' clinics were developed during the wake of the pandemic and were not fully operational when some patients had already been discharged home. Some existing Post-ICU clinics were faced with having to move away from face-to-face and embrace virtual or video consultations. This required an initial telephone or a video consultation by a member of the Local 'post-COVID-19' clinic to the ward-only patients and for the post ICU clinic team to contact patients managed in ICU to plan their clinic appointment or chest x-ray and virtual review. A close collaboration is therefore required between local 'post-COVID-19' and Post-ICU clinics to determine who takes responsibility for the rehabilitation of these post-COVID-19 ICU patients that are discharged from hospital.

There was limited ICU bed capacity because of the acute surge in patient numbers affected by COVID-19. Therefore, a significant number of patients had to be transferred between neighbouring ICUs within an ICS. There needs to be a discussion within each ICS regarding which ICU (either the admitting ICU or the ICU the patient was transferred to or in which they spent the majority of their ICU stay) takes on the responsibility for the Post-ICU clinic assessment. The suggestion is that the ICU where the majority of the ICU stay was conducted should take on the responsibility for the Post-ICU clinic assessment as that Unit would better understand the ICU journey.

The initial assessment in either the local 'post COVID' or 'Post-ICU' clinic is to ascertain the extent of the rehabilitation needs and enable an initial rehabilitation plan to be developed with awareness of the service options available to the patient within the ICS/STP. It is imperative that this assessment should include the patient's family/carers and adopt a personalised care approach that seeks to plan and provide care based on what matters to the individual. Where both a local 'post-COVID-19' and 'Post-ICU' clinic exist, good communication between the services must be established to prevent duplication and to identify which will take on the responsibility as the single care co-ordinator. The referrer should be informed of any outcomes from the assessment within one week of the clinic consultation. This may include:

- An MDT evaluation of physical, cognitive and psychosocial need and management of impairments, including a holistic assessment of the features of post intensive care syndrome

- A recommendation of service(s) most likely to meet the assessed need including signposting to community mental health services
- An indication of the benefits and possible outcomes as a result of the use of the service
- An indication of the likely duration of rehabilitation needs (and further support needs on discharge from the service)

6.6.2 Inpatient Recovery Services

ICU recovery and rehabilitation should be led by a multidisciplinary team comprising allied healthcare professionals (AHP) with input from the ICU consultant and nursing team. Post ICU services sometimes include ward-based follow-up with input from an ICU consultant or nurse in addition to the AHP led rehabilitation. Where no inpatient service exists an outpatient service may be established with clinic consultations delivered by either the ICU consultant or nurse with variable support from allied healthcare professionals.

6.6.3 Outpatient Recovery Services

There are a wide variety of post ICU recovery clinic services that exist, many are either uni-professional (led by ICU consultant and/or nurse) or multi-professional clinic (ICU consultant and/or nurse with any of the following AHPs; occupational therapist, psychologist, physiotherapist, pharmacist, dietician, speech and language therapist).

Historically, the clinic type is primarily determined by local resources within individual Trusts with very few commissioned. Consequently, there is a wide variability of the type and number of established post ICU recovery services within integrated care systems. The FICM survey: Life after Critical Illness will help inform about the gap in the provision of these services and the potential need to develop 'hub' and 'spoke' models between well-established multi-professional clinics supporting newer uni-professional clinics ensuring equity of access for all. Any clinic requires administration support to ensure clinic consultations are communicated to GPs.

NHS contracting rules need to be fully understood to ensure only clinical sequelae related to the ICU admission are addressed. Other non-ICU related conditions should be referred back to the GP. Close collaboration between secondary and primary care is required to improve the post-ICU care of these patients.

7 How to implement successfully

To implement a Local 'Post-COVID-19' and/or a 'Post-ICU' clinic several factors need consideration:

1) Number of ICU patients affected by COVID-19 linking in with informatics and audit teams
2) Frequency of clinics required to see ALL patients (link in with outpatient services to identify clinic space to deliver clinic)
3) Confirm whether or not patients transferred into the ICU will be offered post ICU clinic review or originating ICU will assume responsibility for follow-up (communicate this decision with neighbouring ICUs within the ICS)

4) Identify the workforce available to deliver the post ICU clinic inclusive of ICU consultant/nurse, administrators and AHPs. Ensuring liaison with therapies leads within the Trust.
5) Confirm the model to be used telephone versus virtual (video) versus face-to-face (dependant on point 6).
6) Co-ordination between the 'Post-ICU' clinic and Local 'Post-COVID-19' clinic, if available, delivered by respiratory physicians. (determine whether face-to-face or virtual model of clinic to be used –dependant on point 5)
7) Understand availability of community services particularly psychology i.e. talking therapies, community physiotherapy
8) Establish pathway for patients identified with significant psychiatric risk e.g. suicidal ideation. Link in with local liaison psychiatry leads.
9) Establish administration processes, booking appointments, IT infrastructures, and clinic letter creation using existing IT resources.

7.1 Discharge Planning

Discharge planning should commence in a timely manner, immediately after the holistic, multi-disciplinary assessment with the patient and their family/carers involved throughout.

Prior to discharge, a discharge planning meeting should be held involving the clinician responsible for the care of the patient, the care coordinator, the individual and their family/carers. If required to coordinate care following a patient's discharge from the service, a case manager should also be identified and participate within the meeting.

A discharge care plan should also be produced to facilitate a smooth transition following discharge and should cover:

- Further patient goals and target outcomes
- Assessed needs (including adaptions to the home or equipment)
    - Providers should inform CCGs of any ongoing equipment needs as soon as they are identified and should work closely with CCGs to ensure that any specialist equipment post-discharge is provided prior to discharge in order to prevent any delays.
- Provision of further support including a coordination approach with other relevant agencies including housing and social services including anticipated future needs and recommendations for ongoing care
- Role of the family and or carers
    - The patient, family and other carers should receive advice and/or training with regards to the management of on-going needs including physical management and cognitive problems
    - Information and advice on how to prevent or reduce future needs
    - Information about and signposting to peer support and voluntary organisations which the patient may benefit from

Upon discharge, the patients GP and other healthcare professionals involved in their care should be informed about the patients discharge and be sent a discharge report within 1 week. This should include a summary of care and progress made from each discipline involved, an evaluation of any continuing needs and arrangement of any follow-up required outside the service.

7.2 Workforce

Local post-COVID-19 clinics should be provided within acute trusts under the lead of a consultant trained and accredited in respiratory medicine. When required, they will need to liaise with some or all of the following:

- Allied health professional e.g. physiotherapy, occupational therapy and psychology
- Medical specialties e.g. post-ICU, cardiology, neurology, ENT, dermatology, memory clinics
- Mental health services e.g. liaison psychiatry, neuropsychiatry to conduct a comprehensive needs assessment and provide the support required.

Minimum staffing levels need to be set out at a service level. There should be a clearly defined mechanism for ensuring that the input from different specialties remains coordinated. Where possible, it is advocated that a care coordinator role is established to help manage the patients care, act as a single point of contact and bring together the different specialists the patient may need. This may be the respiratory physician, general practitioner or post-ICU team dependent on the extent of the patient's needs.

An ideal role to engage with patients and support Personalised Care approaches would be a Social Prescribing Link Worker, Health and Wellbeing Coach or Care Coordinator. These roles:

- have the skills and time available to build a good and continuous relationship with the person
- having direct relationships with local voluntary and community groups whose support may be crucial to that person's holistic recovery
- are based in Primary Care, so can follow the person on their rehabilitation pathway out into the community.

These roles can all potentially be supported by the Primary Care Network Directed Enhanced Service (PCN DES) contract Additional Roles Reimbursement Scheme (ARRS).

7.3 Active Rehabilitation

Patients and their family/carers should work together with members of the MDT to:

- Establish a set of goals, both short-term and long-term
- Review progress against goals at regular, frequent intervals with adjustments to the provision of services made accordingly

7.4 Personalised Care

To ensure that rehabilitation is tailored to individuals' needs requires taking a Personalised Care approach. Essentially this involves gaining a richer picture of the patient as a person, to know what their life was like pre-Covid, what skills and assets they possess that can help accelerate and maintain their recovery and understand how they ideally would like to live once the rehabilitation process is complete.

7.4.1 Support Planning and Supported Self-Management

This knowledge can be gained through a holistic conversation as part of Personalised Care and Support Planning, carried out by a trained professional, such as a Social

Prescribing Link Worker. Once a profile of the person has been completed, the person can be helped to plan what their recovery pathway may entail. This would include understanding what broader support needs they may have, how these could be addressed, and how these other interventions will need to coordinate with their rehabilitation. This could involve support from a range of statutory and voluntary sector partners, which ideally should be brought together as a virtual Multi-Disciplinary Team (MDT) around the person. Besides physical rehabilitation, other interventions may include among others:

- Psychological Therapies
- Social Welfare Legal Advice
- Housing Support
- Debt Relief
- Unemployment Support
- Peer Support
- Self-Management Education
- Health Coaching

7.4.2 Measuring Impact

To help the healthcare system understand whether that person's goals are being met, the Link Worker will stay in contact with the patient over a number of weeks or even months. They may use the ONS-4 Wellbeing Score, or the Patient Activation Measure (PAM) to help measure the progress being made. These questionnaires can be completed with the person in their first holistic conversation as a baseline measure, and again during subsequent conversations to see what changes have taken place.

Changes to the PAM score in particular are important to capture. 'Patient activation' refers to a person's knowledge, skills and confidence to manage their health. Depending on a patient's answers to the questions, they receive a score out of 100, and are placed into four broad levels of activation. The levels correlate to different health behaviours.

Those in levels 1 and 2 tend to be more easily overwhelmed by healthcare advice and/ or disengage from managing their conditions. Those in levels 3 and 4 are more engaged with managing their health and can still cope under stressful conditions. As a result, people with higher levels of activation tend to use healthcare services less frequently and have better outcomes than those with lower levels of activation.

The PAM can be used to tailor interventions to individual needs, significantly increasing the likelihood that people will adopt behaviours that contribute to better health. Since activation can be improved (with associated health benefits), it can also be used as an outcome measure.

It is recommended to require community services to submit data as part of the community rehab data set. This data will eventually be used for tracking COVID-19 rehabilitation once the dataset and its mode of collection are agreed by London CAG.

7.4.3 Recovery Pathways

Conceptually there is a clear fit with the ambitions of rehabilitation and Personalised Care, and given the multi-system impacts of severe Covid-19 infections there is

particular relevance to embedding this approach now. There are key opportunities for engaging with patients in this way in the care pathway. These include:

- When triaging for patient needs at the point of stepping down from ICU
- When entering the specialist acute or inpatient rehabilitation processes
- At the point of a supported discharge from hospital
- When the patient is seen in specialist community rehabilitation or in community rehabilitation and reintegration facilities
- When the patient is seen in Primary Care in subsequent visits

Ideally, capturing holistic information about patients (particularly those at risk of severe Covid-19 complications) would take place before infection, as part of a proactive, preventative approach.

7.5 Interdependencies with other pathways

The provision of a post-COVID-19 clinic will be part of a wider rehabilitation and/or specialty pathway. Integration and effective communication between primary, secondary, community providers, other relevant agencies as well as existing, established specialty rehabilitation provision will optimise the referral and attainment of positive outcomes for patients within the system.

Service providers should ensure that there are mechanisms in place to support effective communication and understanding of role between the specialties and agencies involved.

8 Service outcomes

8.1 NHS Outcomes Framework Domains & Indicators

	Domain	contribution to achieving
1	Preventing people from dying prematurely	
2	Enhancing quality of life for people with long-term conditions	**X**
3	Helping people to recover from episodes of ill-health or following injury	**X**
4	Ensuring people have a positive experience of care	**X**
5	Treating and caring for people in safe environment and protecting them from avoidable harm	**X**

8.2 Key Service Outcomes

Outcomes should be meaningful to those utilising rehabilitation services. Key Service Outcomes will be to:

- Identify physical, cognitive and psychological conditions impacting quality of life and the return to pre-COVID levels of function
- Identify psychological conditions affecting the wellbeing of the patient's family
- Implement a holistic rehabilitation plan involving available acute hospital and community services to aid recovery, reduce the risk of re-hospitalisation, re-infection and mortality.
- Ensure existing health problems are optimized and health prevention e.g. vaccination, social distancing, shielding advice, smoking cessation and alcohol intake advice is given or patients are signposted to services
- Provide advice on return to work and application of benefits with signposting to occupational health, human resources and Citizens advice bureau
- Provide advice regarding driving (DVLA notification of medical conditions is highlighted) and air travel or 'fitness to fly' should be included

9 Contingent factors affecting implementation

9.1 Engagement with patients and family/ carers

Rehabilitation should be a collaborative process and thus it is important that patients and family/carers are engaged in all aspects of the rehabilitation pathway to optimise effectiveness of the service and the outcomes for the patient.

It is crucial that patients and their families and/or carers are involved in the service design as well as have ample opportunity to provide feedback on the service in order to support the identification of gaps, improve services and evaluate change. A concerted effort should be made to engage those that may belong to groups typically considered hard to reach to ensure that feedback is received from a diverse group that reflects the local population.

9.2 Data

Providers of post-COVID-19 clinics should be involved in active reporting of process and outcomes to the relevant datasets. Providers must ensure that this is submitted in a timely manner.

Further work is being undertaken to identify the recommended data items that would comprise a key Covid-19 rehabilitation dataset needed to facilitate improvements in Covid-19 recovery. This process identifies where the data is currently collected and would propose recommendations for additional items to supplement current data sources.

9.3 Governance

Each service will be accountable to the Trust and the ICS/STP.

Robust monitoring and evaluation are critical in ensuring that services remain efficient and effective. The service should undertake regular reviews of its processes and

identify positive and negative lessons from patient care in order to continually seek to improve. As part of clinical governance, the service should also consider education and training for staff, patient safety reviews and involvement in clinical audits and research.

Providers are also required to work within the information governance framework as directed by NHS England and NHS Improvement. COVID-19 as created significant challenges to the way providers access and use data, particularly as methods for delivery of care have had to adapt. A new notice has been issued to support the use of confidential patient information for purposes relating to COVID-19.

9.4 Funding

At the time of writing, it is unclear if any additional funding will be made available for the provision of post-COVID-19 rehabilitation. However, work has commenced considering the delivery of rehabilitation provision within London beyond COVID-19 including work to enhance specialist pathways whilst maintaining individual identity, the workforce and improved education for the public and patients

9.5 Health Inequalities

Equity of access across each ICS/STP and reducing variation of outcomes is a key objective of the service. There is increasing evidence of COVID-19 having a disproportionate impact on particular patient cohorts and a recently published review conducted by Public Health England has demonstrated that COVID-19 mirrors and, within certain groups, exacerbates existing health inequalities. Subsequently, particular consideration should be given to these groups with regards to how they access and utilize healthcare services and to ensure that no one is discouraged or unable to benefit from the provision of post-COVID-19 clinics.

This may require a modified, proactive approach to identifying those who may typically be less likely to access healthcare. Patients should not be disadvantaged from accessing services due to financial costs (eg travel costs or lost wages) or language barriers and cultural beliefs. Resources should be distributed across regions according to population size and demand for service.

9.6 Impact of COVID-19 on service delivery

Local post-COVID-19 clinics are largely coordinated by respiratory teams and this requires close collaboration between the ICU and respiratory teams to ensure a single point of care co-ordination for patients who attend both clinics. The co-ordination and planning of hospital discharge and follow-up are always important, but during this pandemic there has been minimal operational outpatient services. This mandated telephone consultations to be conducted to assess patients and plan follow-up.

A small number of patients required had longer and more complex rehabilitation, sometimes involving transfer to level 3 short term local rehabilitation. The discharge from these facilitates is not always recognised, requiring telephone contact with patients.

Community services have been significantly reduced due to the redeployment of AHPs into secondary care resulting in a limited workforce to deliver community and

pulmonary rehabilitation. The 'lockdown' and the need to observe social distancing and AHPs requirement to wear PPE also limited the access to rehabilitation services. The mode of delivery of any clinic was affected during the COVID pandemic and saw a shift from 'face-to-face' to 'virtual' or 'telephone' clinics. The capacity to deliver face-to-face clinics was significantly reduced due to social distancing rules. The virtual platform allows 'shielding' workforce to be utilised which can be extremely helpful. However, the accessibility to virtual platforms is not universal in NHS Trusts. There remain significant issues with accessibility and the ability to connect via technology for many patients who do not have a smart phone or computer or IT knowledge. This issue leads to prolonged clinic appointments and the need to default often to connecting via telephone. Such phone conversations miss out on helpful aspects to understanding the patient's living environment or to permit a virtual examination.

10 Conclusion

This document provides a framework and minimum standards to which these clinics should align with to ensure the optimal management and recovery of patients across London. Upon approval from the London Clinical Advisory Group, this guidance will be communicated to acute and community trust providers and London LMCs to support the design and implementation of post-COVID-19 clinics within each ICS/STP.

APPENDIX 1: Categories of patient need and levels of service

11 Appendix 1 - Categories of rehabilitation need

The Specialised Services National Definition Set defines four categories of rehabilitation need (categories A-D) and three different levels of service provision (Levels 1-3).

These have been set out below:

Specialised rehabilitation services are delivered by:

- *Level 1 units - these provide specialised rehabilitation services to patients with Category A needs. Serves a* catchment population > 1 million and taking a selected population of patients with highly complex needs (>85% category A).

Non-specialised rehabilitation services are delivered by:

- *Level 2 units - these provide 'local specialist rehabilitation' service to patients with Category B needs (but which may also accept certain patients with Category A needs, where the unit has appropriate facilities, expertise and staffing ratios). Serves a catchment population of 500,000.*

- *Level 3 services - these provide rehabilitation in the context of acute or intermediate care services to Category C and D patients.*

(Adapted from Specialised Services National Definition Set No.7 Specialised Rehabilitation Services for Brain Injury and Complex Disability (all ages) (3rd Edition)

Under this specification, post-COVID-19 clinics encompass all activity in Level 3 and some Level 2 activity.

12 Appendix 2 - Core standards for post-COVID-19 rehabilitation care

12.1 Objective and principles

All London citizens should have the right to an equivalent standard of care regardless of which part they live in. The delivery of these rehabilitation service for COVID-19 survivors is the responsibility of each Sustainability and Transformation Partnership (STP)/Integrated Care System (ICS). The hub and spoke and the specifics of each service will be determined at the ICS level although all will adhere to consensus standards as a minimum.

NHS England and NHS Improvement London recognises that patients across London recovering from COVID-19 require equitable access to consistent holistic rehabilitative care across all settings.

This paper describes evidence-based core standards for an ICS with regard to a post COVID-19 rehabilitation service, across all sectors of care. Two tables describe a series of consensus statements to inform the service requirements, development and delivery of a rehabilitation service for COVID-19 survivors. These consensus statements were tested with subject experts including patients and health care professionals. The output of this process is a guidance document on the minimum standards for STPs/ICSs to implement services for COVID rehabilitation.

A. For non-critical care patients who were managed on a ward only or in the community.
B. For patients who required critical care input as part of their management

These statements are supported by a patient pathway flow chart (Figure) and a case study of an existing well-functioning rehabilitation service (

13 Appendix 3 – Respondents to survey on the Consensus Statement

The following lists shows the groups of respondents to the survey on the consensus statement, broken down by profession, clinical area and ICS/STP.

13.1 Professional group

Answer choices:	**Number of responses:**
Clinician	26
Commissioner	7
Operational Manager	6
Social Care	4
Other (CSU, Chair, COVID renewal programme manager)	3
Academics	2
Total respondents: 47 (1 with dual role)	

13.2 Clinical area.

Responses:	**Number of responses:**
Critical Care	5
Intensive Care / anaesthetics	2
GP	2
Physiotherapy	2
Critical Care Psychiatry	1
Acute speech and language therapy	1
Adult Social Care	1
Corporate nursing	1
Liaison Psychiatry	1
Neurological infection	1
Neuro rehabilitation	1
Occupational therapy	1
Reablement	1
Rehabilitation medicine	1
Respiratory medicine	1
Total respondents: 23	

13.3 London ICS

ICS /STP	**Number of responses:**
SWL	13
NEL	9
SEL	8
NCL	3
NWL	6
Other: (West Essex, Essex, Herts & West Essex, University of Liverpool, NHSE/I)	5
Total respondents: 44	

Appendix 4 - Case Studies). In addition, the following principles are advocated:

- Rehabilitation services should meet minimum standards set for the London region, along with the aim to standardise care and reduce variation
- The specific commissioning and organisation of services is the responsibility of each ICS
- Existing Critical Care and Community Rehabilitation Services for COVID-19 survivors should be reviewed and expanded in a collaborative and standardised manner across London. The service should address physical, cognitive and psychosocial domains of care.
- There should be integrated planning and close networking links between Level 1, 2 and 3 rehabilitation services, with adequate capacity at all levels (Figure 1). Providers need to review workforce capacity and make plans to ensure these services are effective and sustainable.
- Critical care, acute medical and specialist rehabilitation teams should work closely together to develop rehabilitation pathways for patients who are recovering following treatment in critical care (level 3) and/or high dependency care (level 2) (whether for COVID-related illness or other critical illnesses).
- The rehabilitation pathway for patients managed at home or discharged home should be integrated with joint health and social care planning and involve multi-agency care.
- The patient pathway should have a single point of contact (in-patient and out-patient) to ensure optimal communication between all agencies and individuals involved in providing care and optimal communication with the patient.
- Individualised rehabilitation of the patient requires repeated needs assessments and goal setting. Rehabilitation needs and goals should be assessed as soon as possible and must involve the patient and teams that take on the responsibility for their ongoing care at every transfer point along their care pathway.
- ICSs must focus on health inequalities; ensuring that all those affected by COVID-19 have equity of access to rehabilitation care. Service planning, delivery and ongoing evaluation will need to be based on a clear understanding of the needs of diverse communities.
- Patients should receive ongoing rehabilitation delivered by the most appropriate service/team for their needs. A Multidisciplinary team (MDT) approach is advocated.
- Providers should participate in data collection across the Network to help inform rehabilitation service needs, patient outcomes and quality improvement measures for the programme

13.4 Methodology and Outputs

UCLPartners worked with NHS England and NHS Improvement London to set out evidence-based core standards for an Integrated Care System with regard to COVID-19 rehabilitation service, which include provision for patients:

- discharged from ICU to hospital wards
- discharged from hospital wards to the community
- who have been managed within a community setting but still have rehabilitation needs

This paper is intended to support commissioning of rehabilitation services from NHS providers across London and provide guidance to NHS providers on the requirements of this service and how it might be delivered in conjunction with social care.

A review of the literature on rehabilitation following critical care and COVID-19 was undertaken to identify documents that had made recommendations on provision of rehabilitation services.

Three clinical reviewers analysed these documents to each produce an independent draft of consensus statements. The reviewers then agreed on a single list of consensus statements with references to where the statements originated from. The reviewers did not give personal opinions, but where there were discrepancies in evidence or gaps in evidence this was documented

On reviewing the literature, it became very clear that:

- much of the recommendations related to patients who had been critically ill and did not consider rehabilitation of patients coming from a community setting or ward-based environment
- the needs of patients and the provision of services required for community and ward-based patients are likely to be largely significantly different to those who had been critically ill and will be tested with the patient group.

For these reasons two separate tables were produced:

A. Non-Critical Care patient COVID-19 rehabilitation
This document focuses on post COVID-19 rehabilitation recommendations for those patients who, required care primarily at home (never attending hospital) and also for those patients who were admitted to a hospital ward, but never required critical care.

B. Critical Care patient COVID-19 rehabilitation
The second part (critical care), includes recommendations for the rehabilitation of those patients who were critically ill with COVID-19 infection requiring part of their care to be undertaken in critical care. Recommendations for critical care rehabilitation are presented across five distinct transition points of the patient pathway:

1. During Critical Care
2. Before discharge from Critical Care
3. During ward based care
4. Before discharge to home or community care
5. After discharge from hospital

Sections 13.8, 13.9 and 13.10 provide additional recommendations proposed by the London expert reference group in May 2020 and through the consultation on the consensus statement with the patient reference group and healthcare professional survey. These recommendations were not identified in guidance or literature reviewed to formulate the consensus statement. These have yet to be to be fully considered and are therefore listed separately in sections 13.8, 13.9 and 13.10 for consideration by ICSs.

13.5 Professional bodies and documents reviewed for recommendations

The consensus statement includes recommended core standards for the provision of rehabilitation services for adults, over 16 years old, who have suffered with COVID-19 infection. They incorporate existing national guidance and recommendations on rehabilitation following critical illness, which are equally applicable and relevant to COVID-19 patients who required admission to critical care during their hospital admission.

Recently published guidelines and recommendations from professional bodies and societies regarding rehabilitation from COVID-19 infection include the following:

- **Public Health England (PHE)**

https://www.gov.uk/government/publications/wuhan-novel-coronavirus-infection-prevention-and-control/COVID-19-personal-protective-equipment-ppe

- **National Institute of Clinical excellence (NICE)**

https://www.nice.org.uk/guidance/cg83
https://www.nice.org.uk/guidance/qs158

- **Faculty of Intensive Care (FICM)**

https://www.ficm.ac.uk/sites/default/files/ficm_rehab_provisional_guidance.pdf
Intensive Care Society (ICS)
https://www.ics.ac.uk/ICS/ICS/GuidelinesAndStandards/Framework_for_assessing_early_rehab_needs_following_ICU.aspx

- **British Thoracic society (BTS)**

https://www.brit-thoracic.org.uk/about-us/COVID-19-information-for-the-respiratory-community/

- **British Thoracic Society Guidance on Respiratory Follow Up of Patients with a Clinico-Radiological Diagnosis of COVID-19 Pneumonia**.

https://www.brit-thoracic.org.uk/document-library/quality-improvement/covid-19/resp-follow-up-guidance-post-covid-pneumonia/

- **Chartered Society of Physiotherapist (CPS)**

https://www.csp.org.uk/system/files/publication_files/001745_COVID-19%20Rehab%20Standards.pdf

- **British Psychological Society (BPS**)

https://www.bps.org.uk/coronavirus-resources/professional/psychological-needs-recovering-severe-coronavirus

- **NHS England (NHSE)**

https://www.england.nhs.uk/coronavirus/publication/after-care-needs-of-inpatients-recovering-from-COVID-19

- **Royal College of Occupational Therapist (RCOT)**

https://www.rcot.co.uk/files/guidance-quick-guide-occupational-therapists-rehabilitation-people-recovering-COVID-19-2020

- **British Society of Rehabilitation Medicine (BRSM)**

https://www.bsrm.org.uk/downloads/COVID-19bsrmissue1-published-27-4-2020.pdf National Outreach Forum – Quality and Operational Standards for the Provision of Critical Care Outreach Services (Consultation Version, Chapter 6)

- **The National Outreach Forum**

https://norf.org.uk/resources/Documents/QOS%20CCOS%20NOrF%202019/NOrF%20QOS%2011%202019.pdf

- **Royal College of Speech and Language Therapists: COVID-19 speech and language therapy rehabilitation pathway**

https://www.rcslt.org/-/media/rcslt-COVID-19-slt-rehab-pathway.pdf?la=en&hash=B59AD546C6E368A34D7AA63165DC568C65428B2C

The following documents have been reviewed and incorporated in this consensus statement:

2009	NICE *Clinical guideline 83*
2017	NICE *Quality Standards 158: Rehabilitation after critical illness in adults* *This quality standard covers adults with rehabilitation needs as a result of critical illness that required level 2 or level 3 critical care. It describes high-quality care in priority areas for improvement*
2 June 2019	Faculty of Intensive Care (FICM) and Intensive Care Society (ICS): *Guidelines for the provision of intensive care services Edition*
April 2020	Royal College of Occupational therapist: *A quick guide for occupational therapists: Rehabilitation for people recovering from COVID-19*
13 May 2020	Chartered Society of Physiotherapy: *CSP COVID-19 Rehabilitation Standards Rehabilitation of adults who are hospitalised due to COVID-19: physiotherapy service delivery.*
5 June 2020	NHS England: *After-care needs of inpatients recovering from COVID-19*
16 April 2020	British Psychological Society: *Meeting the psychological needs of people recovering from severe coronavirus (COVID-19)*
11 May 2020	British Thoracic Society: *Guidance on Respiratory Follow Up of Patients with a Clinico-Radiological Diagnosis of COVID-19 Pneumonia*
19 May 2020	FICM: *Recovery and Rehabilitation for Patients Following the Pandemic*
3 June 2020	ICS: *Responding to COVID-19 and beyond: A framework for assessing early rehabilitation needs following treatment in intensive care*
18 June 2020	Public Health England: *Guidance Reducing the risk of transmission of COVID-19 in the hospital setting*
	Public Health England: *Recommended PPE for healthcare workers by* ***secondary care inpatient*** *clinical setting, NHS and independent sector*
	Public Health England: *Recommend PPE Recommended PPE for* ***primary, outpatient, community and social care*** *by setting, NHS and independent sector*

13.6 Table A: COVID-19 patients managed on ward or in community only (non-critical care)

No.	Recommendation (non-ICU pathways)	Source
1	Infection Prevention and Control: PPE guidance is available from PHE for different clinical settings, inclusive of the following - Primary care - Ambulatory care - Non-emergency outpatient and other clinical settings e.g. optometry, dental, - maternity, mental health - Individuals own home (current place of residence) - Community and social care - Care home, - Mental health inpatients - Other overnight care facilities e.g. learning disability, hospices, prison healthcare	PHE/NHS E/I
Needs assessment		
2	Diagnosis of COVID-19 when the patient is at home A diagnosis of COVID-19 pneumonia is established based on clinical and radiological findings. The COVID-19 swab status of patients is not relevant.	BTS
3	A single co-ordinator is required for all patients recovering from COVID-19 infections. It is suggested that the GP should be the single care co-ordinator for ALL patients managed ONLY in the community and never admitted to hospital. Whereas, the respiratory team conducting the 'post COVID-19 clinic' follow-up for patients admitted to the ward are suggested as the single care co-ordinator up until the patient is discharged from the clinic.	
4	The education and training needs of primary and community staff will need to be reviewed with the potential for signposting to existing or commissioning new resources where appropriate.	NHSE/I
5	Stratification of the diagnosis of COVID-19 pneumonia to mild or moderate disease includes anyone who did not require ICU or HDU care – typically cared for on the ward or in the community. This group includes those discharged directly from the emergency department or medical assessment unit and not admitted despite a diagnosis of COVID-19 pneumonia.	BTS

No.	Recommendation (non-ICU pathways)	Source
6	Individualised rehabilitation of the patient cared for only on the ward, requires repeated assessments and goal setting. Rehabilitation needs and goals should be assessed as soon as possible on the ward Effective communication must involve the patient and responsible teams for their ongoing care at every transfer point along their care pathway. Patients should receive ongoing rehabilitation delivered by the most appropriate service/team for their needs. Multidisciplinary team (MDT) approach advocated.	CPS CPS NHSE/I/CPS
7	Confirmed COVID-19 infection without radiological evidence of viral pneumonia or those whose radiology normalises by the time of hospital discharge do not need routine CXR follow-up and do not require face to face or telephone contact from the respiratory team.	BTS
8	Rehabilitation following COVID-19 infection for patients cared for in the community and/or a hospital ward only should be holistic and encompass consideration of both 'Physical' and 'Non-physical' domains (see below) **Physical:** Pulmonary versus Non-pulmonary - Cardiology - Urology - Neuromuscular - Neuropathy - Endocrine - General function: Dietary/nutrition, pressure ulcers, fatigue, oral health and hygiene, speech and language, **Non-physical: Psychological and neuro-psychological (cognitive impairment):** - Delirium - Cognitive impairment - Mental health - Sleep disturbance **Social** - Impaired activities of daily living	NHSE/I NHSE/BPS

No.	Recommendation (non-ICU pathways)	Source
Respiratory follow-up		
9	It is recommended that a clinical review at 4-6 weeks post discharge is required for patients with persistent breathlessness, oxygen requirements, rehabilitation needs, palliative care/symptom management and psychosocial needs which can be addressed by either hospital or community teams. They need to be assessed for serious and potentially life limiting complications of COVID-19, which include pulmonary fibrosis and pulmonary vascular disease. It is recommended that a robust follow up and management algorithm is followed were appropriate.	BTS
10	Patients recovering gradually in the community from mild-moderate COVID-19 pneumonia with no features of malignancy on a chest x-ray (CXR) require a routine follow-up CXR at 12 weeks from hospital discharge with review ideally via a virtual clinic. A 6 week CXR is required if any features suggestive or suspicious for lung malignancy where identified on the initial CXR or breathlessness is persistent.	BTS
11	If the 12-week follow-up CXR demonstrates complete resolution (or minor insignificant changes e.g. atelectasis) please send a standard discharge letter to patient and GP.	BTS
12	If there are persisting CXR abnormalities at 12 weeks, consider requesting: full pulmonary function tests and arrange to see the patient in a face to face outpatient setting with results or arrange initial telephone consultation.	BTS
13	If more than 6 weeks has passed since the 1st CXR, consider repeating the CXR on arrival to the outpatient setting as in some patients the abnormalities may have resolved between these two time points. If the 2nd CXR has cleared or has non-significant findings, radiological follow up ends. Consider discharging the patient if well and manage any pulmonary function test abnormalities. Reassess the need for referral to rehabilitation services.	BTS
14	Patients with persistent abnormalities on the 2nd CXR and/or abnormal pulmonary function tests and/or significant unexplained breathlessness may require further investigations which might include; - pre-contrast high resolution volumetric CT and a CT pulmonary angiogram (CTPA) to assess for the presence of both Interstitial lung disease (ILD) and pulmonary embolus (PE). - Walk test with assessment of oxygen saturation - Echocardiogram In the event that specific abnormalities such as Interstitial lung disease (ILD) i.e. pulmonary fibrosis or Pulmonary hypertension (PH) are identified, patients should be considered for referral to regional specialist services. Patients diagnosed with PE de novo during follow up should be treated as per protocols and followed up in local services.	BTS

No.	Recommendation (non-ICU pathways)	Source
15	Cardiac, renal and neurological complications may be prevalent and so consideration of dedicated specialist follow up should be considered and where joint clinics exist, these should be utilised to streamline the patient pathway.	BTS
Scope of services		
16	The Royal College of Occupational Therapist (RCOT) is calling for access to good quality, person-centred rehabilitation for those that need it. The 1.7 million people that have had to self-isolate are the immediate priority, as well as the significant numbers of people that have had the virus itself.	RCOT
17	Key asks of system leaders and policymakers when it comes to rehabilitation: - Commit to the Right to Rehab as a fundamental element of our health and care system. - Continue to maintain rehabilitation services during the lockdown to minimise the negative impact on people who do not have COVID-19 and to help people recovering from COVID-19 to recover after discharge from hospital. - Prioritise the 1.7 million people who have had to self-isolate for the (minimum) 12 week period, many who will be unable to access rehabilitation in their conventional way and will need new support. - Expand and retain the multi-disciplinary rehabilitation workforce to deliver ongoing rehabilitation. - Ensure parity of rehabilitation for mental and emotional health issues with physical health conditions.	RCOT
18	Services should be available for patients who never get admitted to hospital, but who still have on-going needs for rehabilitation. Some patients may present with long-term sequelae at a later stage and should be able to access services as those needs arise. This will require networking with general practice so that patients who present with late rehabilitation needs are identified.	FICM BRSM
19	Community health services – working together with other providers of physical and mental health care – will need to support the increased number of patients who have recovered from COVID-19 and who, having been discharged from hospital, need ongoing health support that rehabilitates them both physically and mentally. Meeting these challenges will be a joint endeavour, working seamlessly together including through, for example, multidisciplinary teams and/or virtual ward arrangements.	NHSE/I

No.	Recommendation (non-ICU pathways)	Source
20	Key rehabilitation recommendations after COVID-19 for community or hospital ward patients - Online resources for web based, self-directed rehabilitation at home - Use of existing services is advocated with good communication between secondary care and community services regarding the rehabilitation assessment and goals - Ensure there is a designated single care co-ordinator to ensure minimising the number of steps in the rehabilitation pathway - Use of voluntary and care sector organisations	BTS NHSE CPS BPS

13.7 Table B: Critical care

No.	Recommendation (ICU pathways)	Source
1	Infection Prevention and Control: - All staff, at all stages of the pathway, should have access to PPE and adhere to the latest PHE guidance on infection control - There should be both COVID protected and COVID risk managed areas, in the hospital environment, supported by appropriate COVID testing	PHE NHSE/I BRSM CPS
During critical care		
2	Rehabilitation on critical care should begin as soon as possible Within 4 days of admission or before discharge from Critical care 2-3 days of admission to acute care service	NICE CG83/CPS NICE QS158/ GPICS2 FICM BRSM
Scope of service		
3	Commissioners (clinical commissioning groups, NHS England and NHS Improvement) must ensure that they commission critical care services which use a comprehensive clinical assessment to identify adults at risk of morbidity and establish their rehabilitation goals. They should monitor the providers to ensure that this is done within 4 days of critical care admission or before discharge from critical care, whichever is sooner, reviewed and updated throughout rehabilitation	NICE QS158
4	Rehabilitation services should be planned and delivered in coordinated networks with collaborative commissioning. There should be close links and collaboration between: - Level 1, 2 and 3 services - Acute hospitals (critical care/acute medical/specialist rehabilitation teams) - General Practice - Community and social services - Voluntary sector organisations (including through social prescribing)	GPICS2 NHSE/I FICM BRSM

No.	Recommendation (ICU pathways)	Source
5	There is a need for increase capacity at all levels along the rehabilitation pathway starting within critical care and continuing out into the community	BRSM GPICS2 FICM ICS RCOT
Needs assessment		
6	The recovery and rehabilitation after critical illness for the majority of patients can be met by local multidisciplinary teams to facilitate discharge home. Occasionally, patients require ongoing rehabilitation within a local general (level 3) rehabilitation service before discharge home.	FICM BRSM ICS RCOT
7	A smaller proportion of patients will have a recovery that has complex needs requiring specialist rehabilitation in a Level 1 or 2 facility.	BRSM/ICS
8	Many rehabilitation services are commissioned for single conditions, such as stroke and pulmonary rehabilitation, rather than reflecting need – people living with more than one long term condition.	RCOT
9	Within critical care, rehabilitation goals can be short, medium or long term and will change throughout the patient's recovery from critical illness. The development of rehabilitation goals should, where possible, involve the patient.	NICE 83 NICE QS158 GPICS2 FICM BSRM CPS BPS NHSE

No.	Recommendation (ICU pathways)	Source
10	The sequelae and recovery from critical illness associated with COVID-19 will encompass physical (pulmonary and non-pulmonary sequelae) and non-physical domains e.g. cognitive impairment, psychological and social impacts. 'Post intensive care syndrome' encompasses physical, cognitive and psychological sequelae after critical illness. An holistic approach to rehabilitation after critical illness within and after discharge from critical care is required.	NICE CG83 NICE QS158 GPICS2 FICM CPS NHSE ICS BSRM
11	A stepped, needs-based, approach to providing psychological care is recommended. This consists of provision of information and psychological care by ward staff in hospital, and early follow-up after hospital discharge, to provide a structured rehabilitation package and referral to specialist psychological services where appropriate	BPS
12	Critical illness recovery has an individualised trajectory for each patient that is unpredictable and requires continual input from the multi-disciplinary team (MDT) to tailor the rehabilitation process.	NICE CG83 NICE QS158 GPICS2 FICM ICS BRSM CPS BPS RCOT

No.	Recommendation (ICU pathways)	Source
13	The range of healthcare professionals required to conduct the assessments and interventions can include: - Nursing (ICU and rehabilitation) - ITU Consultants and junior doctors - Rehabilitation Medicine Consultants - Specialist Medical Consultants (Neuro, Renal, Respiratory, ENT) - Physiotherapist - Occupational Therapy - Speech and Language Therapy (SALT) - Dietician - Pharmacist - Psychologist - Neuro/liaison psychiatrist - Social worker - Administrative support	NICE CG83 NICE QS158 GPICS2 FICM ICS BRSM CPS BPS RCOT
14	Patients with on-going rehabilitation needs after the immediate early rehabilitation phase should have a Rehabilitation Plan or Prescription (RP) outlining their physical, cognitive, neuro-behavioural and musculoskeletal rehabilitation needs and should outline how/where they will be met.	ICS FICM BRSM CPS
15	Rehabilitation outcomes should be monitored, and progression made using outcome measures appropriate for the stage of recovery, individual therapy, and dependent on local resources (including personnel, equipment, and finance).	GPICS2 CPS BRSM BTS RCOT
16	The size of the workforce required to delivery these services will depend on the outcomes after COVID-19 and will need to be assessed and most likely increased in order to deliver these services	BRSM FICM RCOT
17	For high-risk/complex patients, capturing the experience for the patient and family in a manner that they can reflect upon and engage with during the time spent in hospital should be considered. This may take the form of diaries, either paper or electronic, and may include photos, videos and written information. This material may be collected prospectively or retrospectively depending on the desire of patient and family.	GPICS2 FICM

No.	Recommendation (ICU pathways)	Source
Before discharge from critical care		
18	Infection Prevention and Control: - All staff, at all stages of the pathway, should have access to PPE and adhere to the latest PHE guidance on infection control - There should be both COVID-19 protected and COVID-19 risk managed wards supported by appropriate routine COVID-19 testing	PHE
19	Adults at risk of post intensive care syndrome (critical illness related morbidity) must have a formal handover of care, including their agreed individualised structured rehabilitation plan when they transfer from critical care to a general ward.	NICE CG83 NICE QS158 GPICS2 ICS BSRM CPS
Needs assessment		
20	Patients with complex needs requiring specialist rehabilitation should be referred into specialist services e.g. stroke and trauma rehabilitation. There is trial-based evidence to demonstrated improved outcomes and for it to be cost-effective.	BSRM
21	Patients with severe disabling illness/injury should have access to appropriate rehabilitation to optimise their recovery, including early rehabilitation while still in acute hospitals, specialist inpatient rehabilitation and longer-term community-based support. Patients should be provided with on-going, multi-agency support and services should provide life-long access to specialist nursing home care (including neuro-palliative care if required) with input from specialist outreach rehabilitation teams.	FICM BRSM RCOT
22	Patients who have (or are likely to have) on-going complex needs for requiring specialist rehabilitation should be assessed by a Rehabilitation medicine (RM) Consultant prior to discharge from the acute unit. The RM consultant (or their designated deputy) is responsible for confirming category A or B needs, and for expediting referral and transfer for on-going specialist rehabilitation as soon as they are fit enough.	BRSM RCOT

No.	Recommendation (ICU pathways)	Source
23	RM consultants should be involved from an early stage in the patient's acute care pathway to assess patients with complex rehabilitation needs and participate in the planning and execution of their interim care and rehabilitation. Within each network an identified RM Consultant (or consultants) should be an integral part of the acute care pathway team.	BRSM
24	Where patients lack capacity, *best interests* decision-making should guide treatments including life sustaining treatment, neuro-palliative and end of life care.	NICE CG83 NICE QS158 GPICS2 BRSM CPS
During ward-based care		
Scope of service		
25	The individualised, structured rehabilitation programme should be developed and delivered by members of a multidisciplinary team and should include appropriate referrals.	NICE CG83 NICE QS158 GPICS2 BRSM ICS FICM RCOT
26	Critical Care Outreach services should follow up all patients who have been discharged from critical care after a stay of more than 24 hours within 1 day after discharge or sooner if required. The purpose of these reviews includes: • Supporting patients recently discharged from critical care to prevent at-risk patients from being re-admitted to critical care • Support alternative pathways of care through advanced care planning. • Input into the multi-disciplinary review of post-critical care ward patients' goal setting and recovery care plans	NoRF
27	Care co-ordination is important and limiting the number of steps in the pathway (including step-down discharge within hospital) and number of professionals involved should be minimised (i.e. making every contact count) as is clinically appropriate to reduce the number of times patients are moved and to reduce the risk of infection.	FICM NHSE

No.	Recommendation (ICU pathways)	Source
Needs assessment		
28	For patients with symptoms of stress related to traumatic incidents and/or memories then initiate appropriate preventative strategies. A stepped, needs-based, approach to providing psychological care is recommended. This consists of provision of information and psychological care by ward staff in hospital, and early follow-up after hospital discharge, to provide a structured rehabilitation package and referral to specialist psychological services where appropriate	NICE CG83 BPS RCOT
Before discharge home or to community care		
Scope of service		
29	A significant number of issues can complicate a patient's recovery from COVID-19 and these may present on discharge from hospital. These issues should inform the patient's new or amended personalised care and support plan, including what they will be able to do for themselves to manage their needs, and what wider support they will need from services including social care and the voluntary sector. These should be considered in the context of either immediate or longer-term needs, and be further categorised as physical, neuro-psychological and social, though patient needs and symptom management should always be considered holistically.	NICE CG83 NICEQS158 GPICS2 NHSE FICM ICS BRSM CPS BPS RCOT
30	Patients should be supported through adapting or strengthening existing local arrangements: - Existing critical illness recovery (post ICU follow-up) clinics - Cardiopulmonary rehabilitation - Sports and exercise medicine - Vocational rehabilitation - Transplant/Dialysis - Stroke neurorehabilitation- Neurorehabilitation - Neurological disability services	NHSE/I ICS FICM BRSM RCOT

No.	Recommendation (ICU pathways)	Source
31	Patients who are ready to go home should have supported discharge and early community-based rehabilitation, with access to a range of services according to their individual needs	GPICS FICM ICS BRSM RCOT
Needs assessment		
32	Patients who are ready to leave hospital but require long-term care should be discharged to an appropriate care setting under the "Discharge to Assess" programme, where their on-going requirements for health and social care can be planned in close integration	FICM ICS BRSM
33	If continuing rehabilitation needs are identified from the functional assessment, ensure that before the patient is discharged: • discharge arrangements, including appropriate referrals for the necessary ongoing care, are in place before completing the discharge •all discharge documents are completed and forwarded to the appropriate post-discharge services and the patient •the patient, and/or the family and/or carer as appropriate, is aware of the discharge arrangements and understands them	NICE CG83 NICE QS158
34	Equality and diversity considerations: People who do not speak or read English well may be at a disadvantage, particularly because of the complex language used in critical care. Translators should be available if needed to ensure that people understand the information given to them. Arrangements should be made to account for the extra time that this may require.	NICE QS158

No.	Recommendation (ICU pathways)	Source
After discharge from hospital		
Scope of service		
35	Infection Prevention and Control: PPE guidance for different clinical setting clearly defined. This includes non-emergency outpatients and other settings: - Primary care - Ambulatory care - Maternity - Mental health - Individuals own home (current place of residence) - Community and social care - Care home, - Mental health inpatients - Other overnight care facilities e.g. learning disability, hospices, prison healthcare	PHE/ NHSE
36	ALL patients rehabilitating from COVID-19 and discharged from critical care require a single care co-ordinator. This should be a member of the critical care team associated with the local critical care follow-up service e.g. critical care nurse or allied health professional. If no local critical care follow-up service exists then the respiratory team should provide this single care co-ordinator role.	FICM
Needs assessment		
37	A remote or telephone consultation by either a respiratory health care or critical care professional should be conducted in the first instance. A face to face clinical assessment by a respiratory health care professional can then be arranged should a virtual consultation not be deemed sufficient or suitable to assess specific needs of the patient. This 'Post-COVID-19' appointment should include an holistic assessment, especially if a critical illness recovery (post-ICU) clinic service is lacking. This should 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 and onward referral where required - Assessment and management of anxiety - Assessment and management of dysfunctional breathing - Consideration of a new diagnosis of venous thromboembolic disease (VTE)	BTS FICM BPS

No.	Recommendation (ICU pathways)	Source
38	If there is evidence of clinically significant interstitial lung disease (ILD) such as organising pneumonia or pulmonary fibrosis, patients should be considered for referral to Regional Specialist ILD services.	BTS
39	If there is evidence of significant pulmonary hypertension (PH) during follow up, patients should be considered for referral to a specialist PH service.	BTS
40	Pulmonary rehabilitation (PR) should be started early (within 30 days) to maximise benefit. However, specifically for COVID-19 patients, the British Thoracic Society and several equivalent societies internationally recommend waiting 6-8 weeks post-discharge, particularly due to unknowns about the patient's infectiousness	BTS
41	Fatigue and ongoing respiratory problems are common, and there is an emerging suggestion, that the high inflammatory burden associated with the virus can induce vascular inflammation and cardiac problems. Current occupational therapy practice recognises that such physical problems have a severely limiting impact on people's ability to function. A significant number of people experience cognitive and mental health difficulties following the acute illness and this needs assessment by an occupational therapist.	RCOT
42	All patients recovering from severe COVID-19 should be proactively followed up a hospital based critical illness recovery clinic to assess their psychological needs or such a service does not exist then their GP should assess and refer as required. It is recommended that this assessment includes brief screening for the following elements (the use of brief standardised measures can be helpful, examples are given below). • Daily routines including sleep/wake routine • Evidence of returning to normal activities • Impact on family or other social relationships • Anxiety issues (e.g. GAD-2 or GAD-7) • Low mood (e.g. PHQ2 or PHQ-9) • Post-traumatic stress symptoms (e.g. Trauma Screening Questionnaire, TSQ) • Cognitive difficulties (e.g. MOCA).	BPS

No.	Recommendation (ICU pathways)	Source
43	Key psychosocial aspects of the rehabilitation package would include: • Provision of information • Psychological education to normalise symptoms and explain causes • Support for emotional distress • Cognitive-behavioural approaches to recovery • Interventions to increase confidence in, and overcome fear of, resuming normal activities • Advice on compensating for cognitive problems • Peer support and integration with patient and family-led organisations such as ICU Steps • Involvement of relatives. These psychological aspects could be delivered remotely via the internet (including contact with other patients) but should be integrated within the overall MDT support package (exact arrangements will be dependent on the current isolation restrictions). Those with clinically significant difficulties with mood, anxiety, post-traumatic stress or other psychological difficulties, should be referred to local psychological therapy services or specialist psychological services in physical health, critical care or trauma, where available. Those with significant cognitive difficulties should be referred to specialist neuropsychiatric, neuro-rehabilitation and/or neuropsychology services e.g. local memory clinics.	BPS
44	There is a need to ensure there is equal access to high-quality community rehabilitation services for all, the 'Right to rehab'	RCOT
45	Community respiratory teams will play an important part in the early care of patients discharged from hospital, for example when considering ongoing oxygen requirements, identification of rehabilitation needs, diagnosis of dysfunctional breathing and mental health assessment. Please liaise where possible.	BTS
46	It is not intended that follow up appointments will be offered within 'post COVID-19' follow up clinics. Where further investigations are requested, a virtual review and onward referral to appropriate services should be considered. If investigations are normal consider discharge. If onward care is required consider discharge back to GP, utilising community respiratory clinics where possible or transfer into usual general respiratory clinics where needed.	BTS
47	Where possible teams should opt for remote or virtual working with pre-ordering of tests prior to clinical reviews.	BTS FICM

No.	Recommendation (ICU pathways)	Source
48	COVID-19 associated cardiac, renal and neurological complications may be prevalent and so consideration of dedicated specialist follow up should be considered and where joint clinics exist, these should be utilised to streamline the patient pathway.	BTS FICM
49	Rapid follow-up assessment and intervention where high risk speech and language therapy (SALT) needs are identified with timely access to SALT specialist assessment based on urgency of need. S&LT input within specialist secondary and tertiary care joint MDT clinics as needed e.g. voice, tracheostomy, airways. Access to joint ENT and SALT clinics to identify interventions required for persistent voice, tracheostomy and emergent complex laryngeal/airway issues SALT input within relevant MDTs	RCSLT
50	To avoid duplication of work streams, liaison between respiratory and local critical care teams is recommended to coordinate respiratory follow up with dedicated critical illness recovery follow up which some units provide. Where a face-2-face 'post COVID-19' respiratory team clinic exists, ALL in-hospital investigations should be performed in one visit, where possible, to enable multi-morbidity assessment. Critical illness recovery (follow-up) services led by a multi-disciplinary team can be conducted virtually initially, if a 'post-COVID-19' respiratory clinic exists.	BTS FICM BPS
51	Patients discharged from the critical care unit must have access to critical illness recovery follow-up programme to assess recovery. Adults who stayed in critical care for more than 4 days and are at risk of morbidity should be reviewed 2 to 3 months after discharge from critical care. Additional criteria for follow-up include: - length of mechanical ventilation - ICU delirium - Referral by another clinician, self or family.	NICE CG83 NICEQS158 GPICS FICM NHSE/I BPS

No.	Recommendation (ICU pathways)	Source
52	'Post-COVID-19' critical illness recovery should be evaluated with a thorough, holistic functional assessment of both physical and non-physical sequelae of critical illness. This should be undertaken by a multi-disciplinary team (MDT) linked to the critical care and may include any or all of the following allied healthcare professionals (AHPs) (occupational therapy and psychology are key members of the MDT): - ICU consultant/nurse - Physiotherapist - Occupational therapist - Psychologist - Psychiatrist - Pharmacist - Dietician - Speech and language therapist. - Social worker - Administrator support If a critical illness recovery clinic does NOT exist then COVID associated pulmonary and extra-pulmonary complications should/can be evaluated in a 'post COVID-19' respiratory led clinic	NICE CG83 NICEQS158 GPICS2 FICM NHSE/I BTS BPS
53	People who have a stay in critical care for 3 days or more, less than one third will have returned to their baseline function after 6 months A number of people will struggle to return to work or to return to their previous job role / salary. Nearly a third of people with post intensive care syndrome (PICs) does not return to work, a further third does not return to their previous income. Occupational therapy is a key member of the MDT in hospital and outpatient critical illness recovery service to address these issues	RCOT FICM
54	Critical illness recovery services should have a designated lead clinician. There should be a clear governance structure and audit and service evaluation should be embedded from the outset. Patients should be involved in the design of these services and patient experience evaluation and feedback processes should be also be built into the service.	FICM

No.	Recommendation (ICU pathways)	Source
55	Outpatient clinics should have access to equipment that facilitate face-2-face and virtual clinics attendances. Face-2-face clinic attendance should have equipment to enable: - Physiological measurements e.g. oxygen saturations, pulmonary function tests, heart rate, blood pressure, 6 minute walk tests - IT equipment e.g. tablets, PCs, telephone - Accessibility equipment - Clinical e.g. phlebotomy, local anaesthetic and wound packs - Electronic assistive technology e.g. tablets, iPads - Orthotics - Resuscitation equipment - Oxygen Virtual: Software that interfaces with electronic booking processes e.g. Attend Anywhere®	FICM BRSM
56	Critical illness recovery clinics should incorporate a pre-clinic team meeting to briefly discuss all patients, identifying key recovery needs and individual nuances/challenges. There should also be a post-clinic debrief to share findings, address discrepancies and agree interventions. These briefs should also serve as educational, supportive and iterative service improvement exercises.	FICM
57	The establishment of a critical care patient and relatives support group should be encouraged.	NICE CG83 NICE QS158 GPICS FICM
58	Patients and relatives should be surveyed regularly, and this information should be utilised to assess rehabilitation and follow-up services.	GPICS FICM
59	Privacy and connectivity will dictate the best environment for virtual clinics, and they should be supported by appropriate IT infrastructure.	FICM
60	There should be clear links and information sharing between primary care and secondary/tertiary care.	FICM

No.	Recommendation (ICU pathways)	Source
61	The changes to the NHS Standard Contract for 2017-19 define the responsibility of the provider of commissioned services and these are key for any provider of an outpatient service to ensure good practice for patient care and to maintain a good working relationship with local GPs e.g. any condition related to the ICU admission should be managed directly by the clinician in the outpatient clinic	FICM
62	Domiciliary, personal assistants and care homes may need to be included in multidisciplinary support for people recovering from COVID (at home or in a care home).	NHSE/I
63	Staff should have free access to psychological and practical support, in line with NICE guidance.	NHSE/I
64	Data on patient-centred outcomes is required.	FICM BRSM ICS BTS
65	Respiratory services should where possible collate data on all patients assessed to allow participation in forthcoming nationally coordinated audits and research studies. More information regarding relevant data points will be released in the near future. It is important that the respiratory community rapidly learn as much as possible about COVID-19 and iterate the follow up guidance to maximally support patients, optimally use NHS resources and provide high quality care.	BTS
66	The education and training needs of primary and community staff will need to be reviewed with the potential for signposting to existing or commissioning new resources where appropriate.	NHSE/I

13.8 Part 1: Key recommendations from the London ICU reference group in May 2020, not identified in the consensus statement, to be considered

This list of recommendations comprises proposals from the London expert reference group in May 2020, that were not identified in the consensus statement (nor have identified sources in reviewed guidance or literature). These have yet to be to be fully considered and are therefore listed separately in the section before the two tables. If they fill a gap in the consensus statements where a need is identified, we will agree an appropriately robust governance process to test and approve them.

TBC-1. A single care co-ordinator role is required for all patients recovering from COVID-19 infections whether managed in hospital (ward and/or critical care) or the community.

a. Community patient (never admitted to hospital) - GP acts the single point-of-care co-ordinator
b. Ward ONLY (never admitted to critical care) OR Critical care patient WITHOUT access to a 'Critical illness recovery' or 'Post ICU' clinic
    i. The respiratory team conducting the 'post COVID-19' respiratory clinic act as the single point-of-care co-ordinator until discharged from the clinic.
    ii. 'Post COVID-19' respiratory clinic team refer to a multi-disciplinary 'Critical illness recovery' or 'Post-ICU' clinic acting as a 'hub' (see 2. Below)
c. Critical care (ALL patients recovering COVID-19) – a critical care nurse or therapist (occupational therapist or physiotherapist) **linked** with a 'Critical Illness Recovery' or 'Post-ICU' clinic should act as the single point-of-care co-ordinator.

TBC-2. Develop a 'hub' and 'spoke' model for critical care after care services across integrated care systems in London to enable multi-disciplinary 'Critical illness recovery' or 'Post-ICU' clinics to act as a 'hub' to less resourced critical care units 'spokes' with limited after care services i.e. no occupational therapy, psychology/liaison or neuropsychiatry services available. This would ensure equitable access for ALL patients especially those with more complicated features of post intensive care syndrome.

TBC-3. Funding of critical illness after care services needs urgent review. A national or pan-London tariff for each patient discharged from critical care needs to be considered to enable consultant intensivist led multidisciplinary critical care outpatient services to be established sustainably ensuring patients receive equitable patient-centred rehabilitation across London to facilitate patient recovery.

TBC-4. To enable the highest quality post COVID patient-centred care further improvements to the collaboration between secondary and primary care need to be realised:

a. Digital notifications to GPs for ALL post-COVID critical care AND hospital discharges need to be available AND associated with electronic checklists that focus on key clinical, psychological, cognitive and social sequelae of COVID-19.

b. GPs need to be able to easily access 'post COVID respiratory' AND 'Critical illness recovery' or 'Post-ICU' clinics via the electronic referral service (ERS) or an equivalent digital referral system.

TBC-5. Community therapies, inclusive of occupational therapy, physiotherapy, pulmonary rehabilitation, talking therapies and social services, need to be prioritised following redeployment of staff into secondary care to prevent delays in delivery of care after hospital discharge e.g. only one physiotherapist in a London CCG is prioritising patients based on chronological order of referral rather than on a needs assessment.

TBC-6. The development of regional critical illness rehabilitation programmes, similar to evidence-based pulmonary rehabilitation should be considered.

13.9 Part 2: Key recommendations from a COVID-19 patient forum, not identified in the consensus statement, to be considered

Twelve people who have had COVID-19 joined a patient forum facilitated by UCLPartners on 20 July. With permission from UCLPartners the full report is included Appendix 7 – Testing Rehabilitation Consensus Statements with people affected by COVID-19.

Attendees described a wide range of symptoms including fatigue, headaches, brain fog, gastro, breathing difficulties, chest pains, numbness, dizziness, joint pains, rapid heartbeat. For some the symptoms were continuous, although the majority described a relapsing-remitting pattern with '*everyday a lottery – I don't know what I'm waking up to'.* People expressed fears they might never get better and that they might be at higher risk of contracting a wide range of infections, due to the impact of COVID-19 on their immune system.

Most participants had experienced what they referred to as 'gas lighting' – professionals in primary and secondary care not believing they had had COVID-19, being '*dismissive*' of their symptoms, refusing to make referrals for specialist assessments for ongoing cardiac, neurological or respiratory symptoms. When seeking support, people had been referred for an anti-body test which took place several weeks after initial symptoms and often came back negative.

Participants expressed concern that one health care professional, such as a GP, might be the sole 'gate-keeper' to someone accessing rehabilitation services. This concern was due to the apparent lack of understanding amongst health care professionals about COVID-19 and variable experiences regarding support and access to services. One participant felt a sole 'gate keeper' might result in a 'postcode lottery' due to the high demand on GP practices in some parts of London.

Participants were supportive of many of the statements, particularly: involving patients, having a dedicated multi-disciplinary team, infection control measures, virtual consultations, effective coordination across care services, personalised assessment and holistic care.

The following were emphasised:

TBC 7. With regard to involving patients, it was highlighted that an increasing number of people were sharing their experiences (eg: LongCovidSOS, SLACK) and that actively involving and listening to people would provide a rapid route for

health care professionals to learn about the virus and expand research efforts. In addition it was recommended that learning be taken from other conditions that had similar widespread effects (eg: The Sepsis Trust).

TBC-8. Provide information and training materials and videos for patients and carers to explain COVID-19 (eg: how it presents, its pathology) and provide guidance on a range of topics including diet, infection prevention and control, management of respiratory symptoms, step guides to support people returning to daily activities, legal and benefits advice etc.

TBC-10. Offer people with relevant symptoms an assessment of their medical fitness including cardiac, respiratory, joint/ muscle pain. People want reassurance that they are medically fit before they feel safe to start exercising again and actively participating in rehabilitation.

TBC-11. Provide ongoing training and guidance for care coordinators so that they: understand COVID-19 and the various ways it can present; facilitate access to services in response to an individual's needs; reduce the need for people to retell their story to every new professional etc.

TBC-12. Commit to investing in rehabilitation and recovery services and acting quickly.

A patient survey on the consensus statement is also currently open. Findings will be shared with London ICSs.

13.10 Part 3: Key recommendations from a healthcare professional survey regarding the consensus statement, not identified in the consensus statement, to be considered

A survey was circulated on 7–14 July 2020 to a representative sample (commissioners and providers, members of the MDT, geographical spread across London) of health and social care professionals to capture feedback on the consensus statement. Forty-seven responses were received. The professional healthcare respondents are listed by profession, clinical area and ICS/STP in Appendix 3 – Respondents to survey on the Consensus Statement.

Respondents agreed with the Consensus Statement document, highlighting the need for this guidance and standardisation of care services across London.

Some respondents requested more detail and direction by specifying, for example, which data collection tools to be used, the frequency/ intensity of rehabilitation interventions, the particular referral pathway for patients with concerns about their recovery, the role of 'hot sites' and the plans for sustainability modelling. This level of detail is not available in the reviewed guidance documents, although it likely to be for consideration by ICSs

A number of comments were made regarding the GP acting as a Care Coordinator including, the need to clarify the role, to ensure patients have a consistent 'named' GP and the need for care coordinator training. One respondent suggested alternative care coordinators (eg: senior physiotherapists) be considered.

Comments regarding specific statements included:

Table A:

Point 8: Consider addition of 'neurology', 'hair loss' and 'sexual dysfunction' under physical domains. Consider prevention (eg: flu /COVID-19 vaccination), identifying areas where prevention of second sequalae could impact rehabilitation.

Point 9: Consider whether a clinical review at 4 – 6 weeks might be too long

Table B:

Point 37: Consider addition of 'fatigue'

Point 51: Consider standardising length of stay criteria due to the current variation

Point 52: Consider additions to MDT members namely, neurology, respiratory ICU consultant and an ICU nurse

The following additional recommendations were made by survey respondents

- Addressing health inequalities
- Increasing rehabilitation capacity
- Ensuring access for all care professionals to patient records

TBC -13. Equality and Health Inequalities - None of the documents reviewed set out detailed guidance on addressing equality and health inequalities but one notes that work is underway to understand the relationship between health inequalities and COVID-19.

Clinical Commissioning Groups (CCGs), NHS England and NHS Improvement have legal duties in respect of equality and health inequalities, as employers and as local and national system leaders, in creating high quality care for all. At a service level, consideration should be given to:

- The local and regional demographics pertinent to health inequalities
- Inclusion of social circumstances in holistic assessments
- Location of services
- Provision of patient information resources in accessible formats
- Provision of translators
- Preventing digital exclusion where services are carried out remotely
- Inclusion of family members and carers
- Outreach to high risk or vulnerable groups
- The role of patient feedback, patient involvement groups and of co-production in shaping services.
- Staff awareness of local services and voluntary organisations to which they can refer patients
- Involvement of public health doctors in the development or improvement of services

The above list is not exhaustive, and each service will need to develop its own plan to address these issues.

14 Appendix 3 – Respondents to survey on the Consensus Statement

The following lists shows the groups of respondents to the survey on the consensus statement, broken down by profession, clinical area and ICS/STP.

14.1 Professional group

Answer choices:	**Number of responses:**
Clinician	26
Commissioner	7
Operational Manager	6
Social Care	4
Other (CSU, Chair, COVID renewal programme manager)	3
Academics	2
Total respondents: 47 (1 with dual role)	

14.2 Clinical area.

Responses:	**Number of responses:**
Critical Care	5
Intensive Care / anaesthetics	2
GP	2
Physiotherapy	2
Critical Care Psychiatry	1
Acute speech and language therapy	1
Adult Social Care	1
Corporate nursing	1
Liaison Psychiatry	1
Neurological infection	1
Neuro rehabilitation	1
Occupational therapy	1
Reablement	1
Rehabilitation medicine	1
Respiratory medicine	1
Total respondents: 23	

14.3 London ICS

ICS /STP	**Number of responses:**
SWL	13
NEL	9
SEL	8
NCL	3
NWL	6
Other: (West Essex, Essex, Herts & West Essex, University of Liverpool, NHSE/I)	5
Total respondents: 44	

15 Appendix 4 - Case Studies

15.1 Development of a Multidisciplinary Post-Critical Care Clinic at Guy's & St Thomas' NHS Foundation Trust (NICE shared learning entry)

15.1.1 Post Intensive Care Syndrome

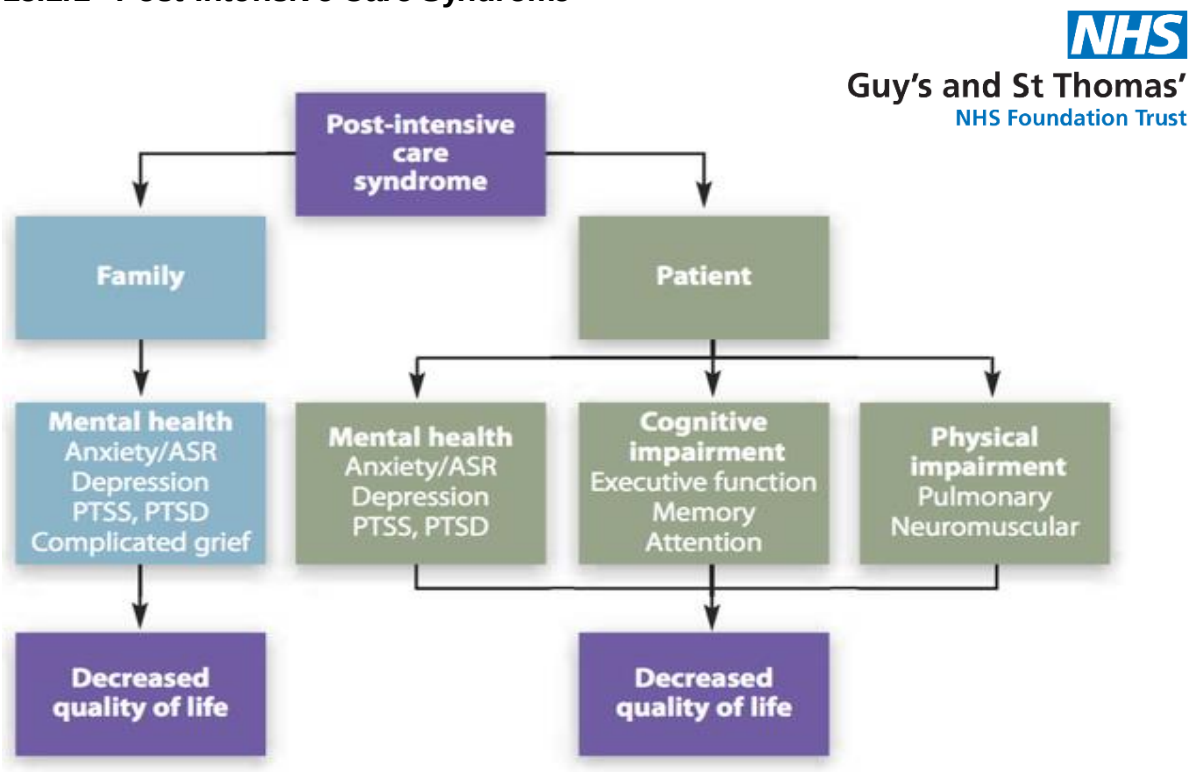


Figure 5: Post Intensive Care Syndrome

15.1.2 National benchmarking

The service is unique in providing a comprehensive face-to-face multi-professional assessment.

The data below from the **2016 national critical care non-medical workforce survey data** demonstrates the relative scarcity of MDT member participation in post critical follow up services:

	No of units surveyed	% in follow up clinic
Psychology	135	13.0%
OT	146	5.5%
Neuropsychiatry		? not asked
Physiotherapy	126	29%

15.1.3 Patient Pathway

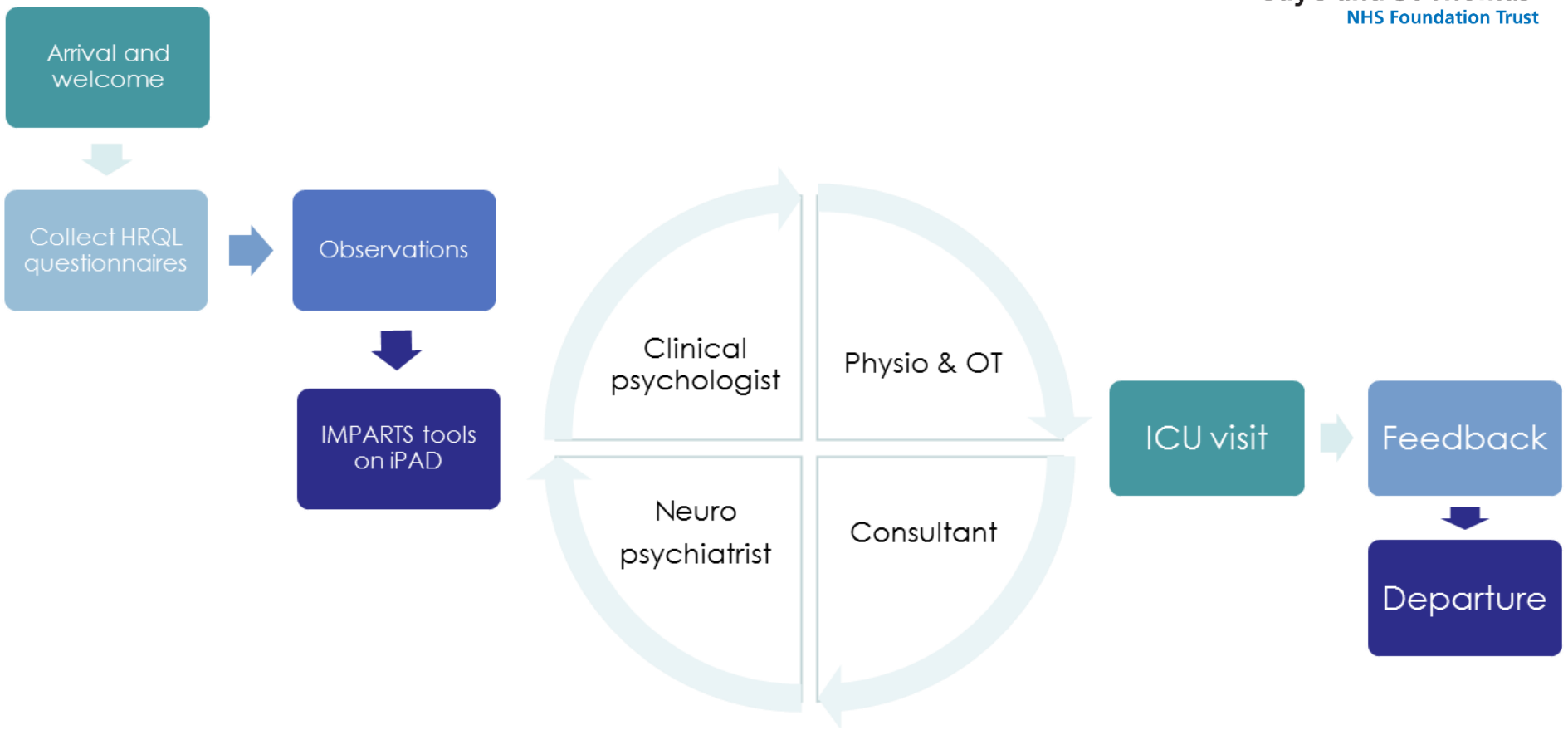


Figure 6: GSTFT post critical care clinic process map

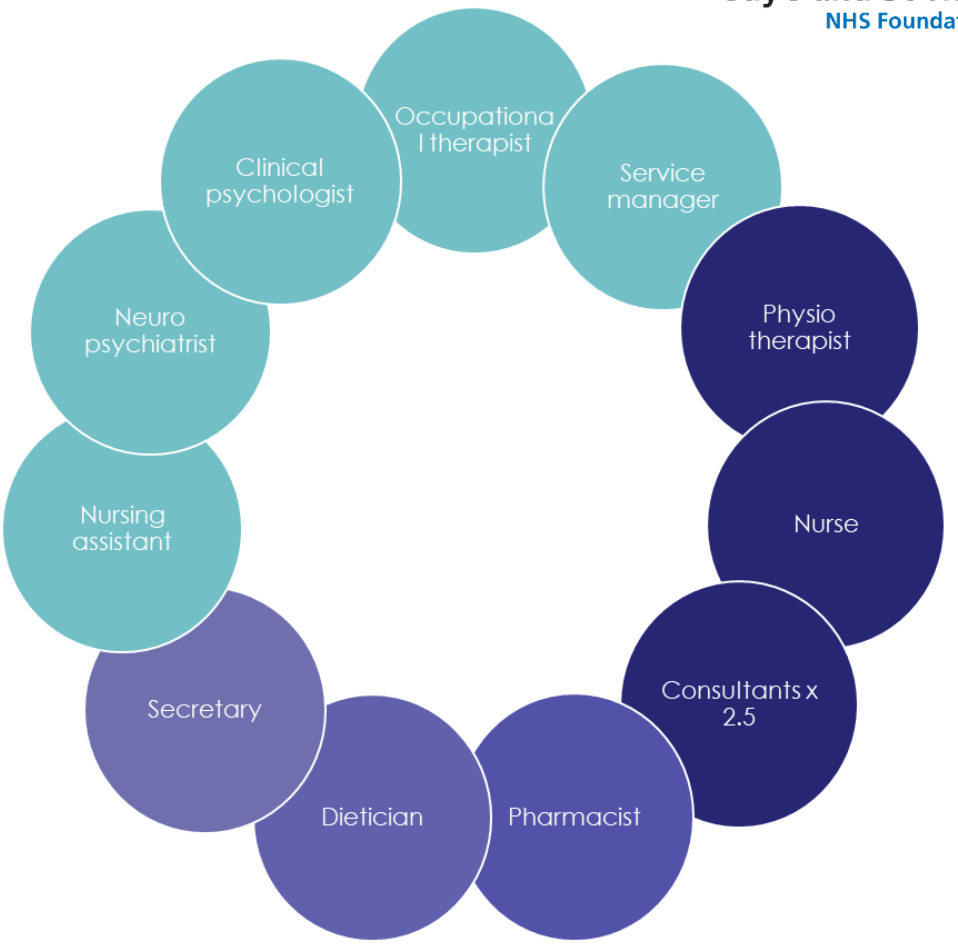
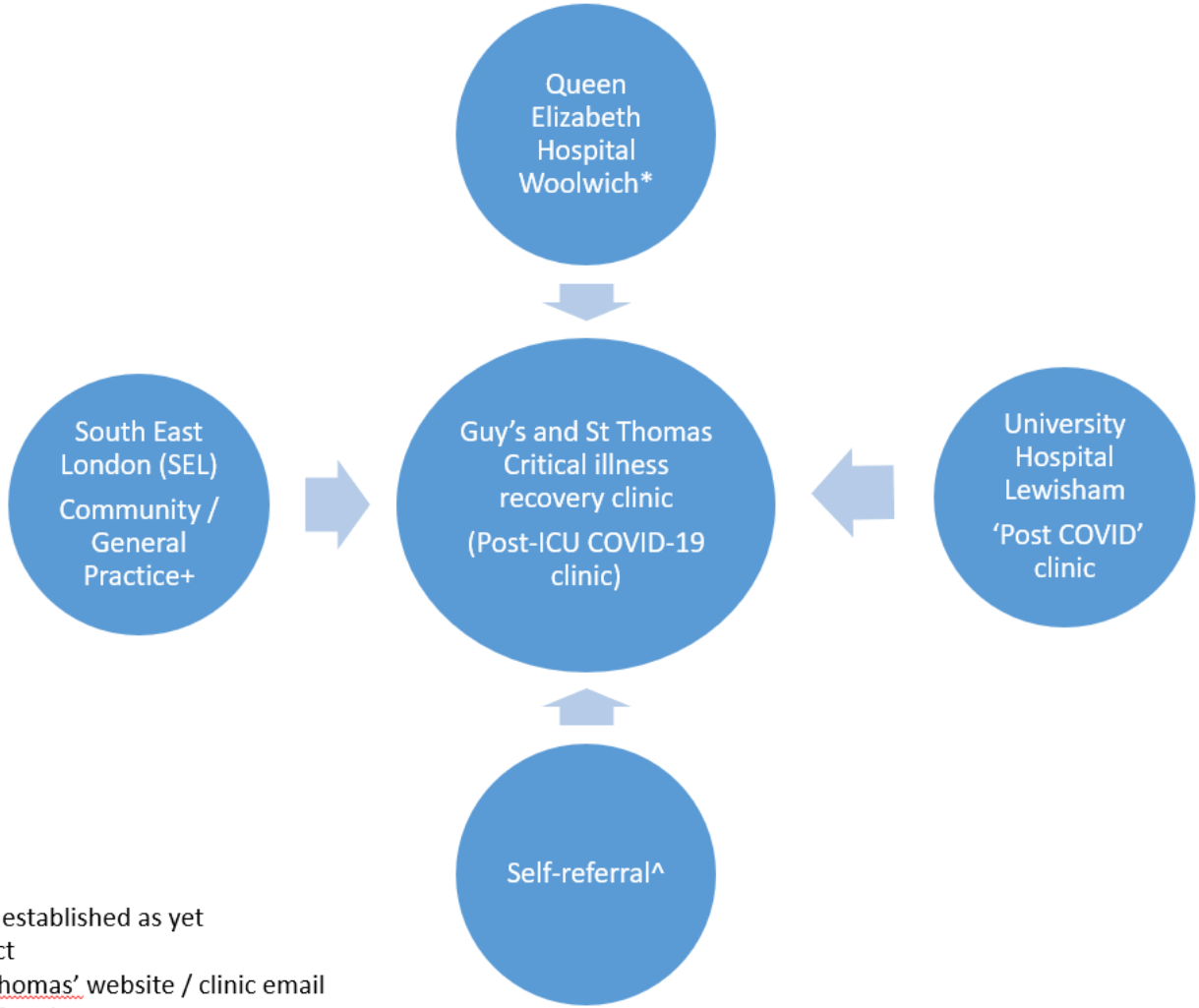


Figure 7: Multidisciplinary structure

Inclusion criteria	Exclusion criteria
Patients discharged from critical care are invited to clinic 2-3 months post discharge if they meet meet any one or more of the following criteria:	Patients with any of the following features are considered for exclusion if deemed unlikely to benefit from the service:
Duration of mechanical ventilation > 72 hours	Palliative care or progressive disease
ECMO	Neurorehabilitation pathway
Significant ICU delirium	
Appropriate self-referral or colleague referral	

15.1.4 Guys and St Thomas' NHS Foundation Trust Hub and Spoke Model

Guy's and St Thomas'
NHS Foundation Trust



* No direct referral established as yet
+Consultant connect
^Via Guy's and St Thomas' website / clinic email address then GP referral

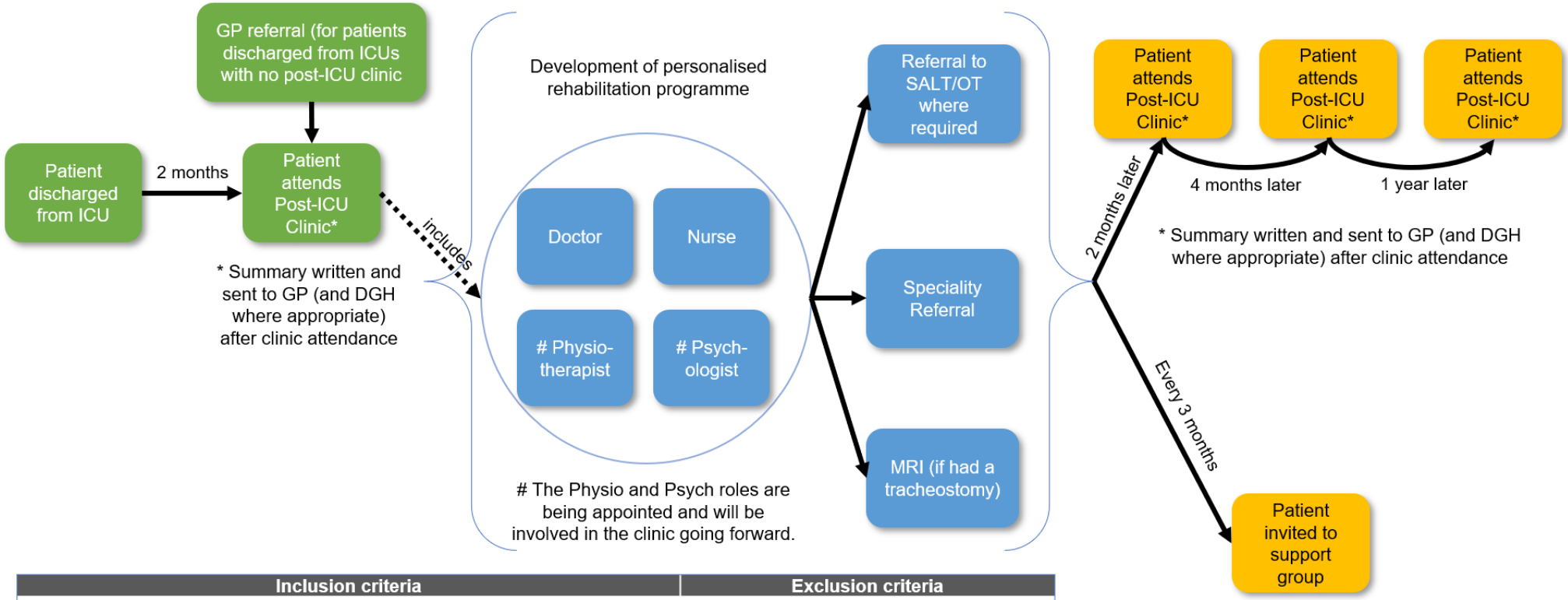
15.1.5 Functional assessment matrix

NICE CG83 statement 1.23 recommends a functional assessment of health and social care needs, to include sexual dysfunction. The guideline specifies the physical and non-physical dimensions that ought to be assessed. The following matrix shows how we achieve this in our clinic.

NICE CG 83 dimensions	Assessed by	Details of assessment
Physical dimensions		
• Physical problems	PT, OT, Consultant, dietician, pharmacist	6MWT Grip strength Chelsea Critical Care Physical Assessment Tool (CPAX) Functional Independence Measure (FIM FAM) Vital signs, weight, height Food diary & MUST score Medicines reconciliation and review Spirometry
• Sensory problems	Consultant, PT	Pain assessment Berg balance
• Communication problems	Nurse, OT, neuropsych, consultant	
• Social care or equipment needs	OT, PT, nurse, consultant	EQ5D SF36
Non physical dimensions		
• Anxiety, depression & PTS-related symptoms	Clin psych, neuropsych	Specialist psychiatric risk assessment Completion of PHQ9, GAD7, PTSS14 scales Visit to ICU
• Behavioural and cognitive problems	Neuropsych, OT, clin psych	Montreal cognitive assessment (MoCA) Referral to neuropsych clinic if required
• Other psychosocial or psychological problems	Nurse, Clin psych, OT	
Other		
• Sexual dysfunction	Consultant	SCSM questionnaire Referral to psychosexual service if required
• Driving	Consultant, OT	DVLA driving assessment if required
• Flight safety	Consultant	Aviation consultant referral if required

15.2 Royal Berkshire NHS Foundation Trust

15.2.1 Patient Pathway



Inclusion criteria	Exclusion criteria
Patients discharged from critical care are invited to clinic 2 months post discharge if they meet any one or more of the following criteria:	Patients with any of the following features are considered for exclusion:
Length of admission to ICU > 4 days	Short stay ICU patients with the exception of those at risk from maternal sepsis
Patients in ICU < 4 days if: • they have been in ICU with problems around the delivery of their baby, or • have had a sudden unexpected admission to ICU such as anaphylaxis	Patients with specialised rehabilitation or complex psychiatric needs

Contact details:
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Nurse Consultant Mekanie Gager
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16 Appendix 5 - Commitments for ICS/STP commissioners & providers

	The ICS/STP Commissioners will:	Providers will:
Analyse	Ensure analysis of met and unmet need and identify gaps in provision, used to inform commissioning decisions	Ensure services have access to data that indicates the needs of the population
		Share data with commissioners which will inform commissioning priorities
Plan	Inform commissioning decisions and service specifications based on the best available evidence and best practice	Work with commissioners, NHS England and NHS Improvement (London) to develop a service that will effectively and efficiently achieve the desired outcomes
	Produce clear service specifications with clearly defined outcomes to be achieve	Work with commissioners, NHS England and NHS Improvement (London) to develop targets that measure and reflect good performance
	Ensure equality of opportunity for providers ensuring that the distribution of services maintains accessibility for the population	
	Undertake equality impact assessments	
Do	Monitor and evaluate improvement to ensure continuous improvement and the achievement of target outcomes	Provide the service as set out in the service specification to achieve prescribed outcomes, ensuring alignment with core standards
	Share progress with commissioners and NHS England (London)	Work with commissioners, NHS England and NHS Improvement (London) to examine ways to improve quality and performance
Review	Evaluate achievement of outcomes	Provide performance data according to the service specification
	Make decisions about the future of the service and decommissioning when appropriate	

17 Appendix 6 - Psychological and Neuro- Psychological follow-up

As people recover from COVID-19, some of whom have been hospitalised and even admitted to ICU during the COVID-19 pandemic are perhaps at higher risk than usual of experiencing psychological distress, it is recommended that a brief screen for emotional distress takes place.

Possible psychological difficulties resulting from critical illness, hospitalisation, and / or a combination of pre- and post-illness factors (such as previous trauma, significant loss of functioning, poor social support, loss of a loved one due to Covid-19, widespread media coverage of the pandemic) could influence the development of a range of difficulties including Post Traumatic Stress Disorder, Health Anxiety, Depression etc. There are effective treatments available for these difficulties, and screening and signposting is a vital part of any follow-up programme.

Brief screening questionnaires which are self-report and easy to administer, include:

- **Generalized Anxiety Disorder 2-item (GAD-2)**
- **Patient Health Questionnaire-2 (PHQ-2)**
- **Trauma Screening Questionnaire**

If a person scores 3 or higher on either the GAD-2 or the PHQ-2 screening questionnaires, it is likely that they may benefit from further assessment and support, and details of how to access this should be given.

The Improving Access to Psychological Therapy (IAPT) initiative, which commenced on 2008, provides primary care talking therapies services across England (there may be national variations for Scotland and Wales). IAPT services provide a range of stepped-care interventions following NICE guidance. This is predominantly cognitive behavioural therapy (CBT) for anxiety disorders and depression, and also includes other therapeutic modalities such as Eye Movement Desensitisation Reprocessing or counselling.

A referral to an IAPT service can be made in a variety of ways:

- **Self-referral** (online self-referral forms, telephone and email contacts can be found by doing an internet search for IAPT and the local borough or town, or via: https://www.nhs.uk/service-search/find-a-psychological-therapies-service/
- **GP referral**
- **referral from another health care professional or care service** (some but not all IAPT services accept tertiary referrals)

Once referred, if the IAPT service does not consider their service to be suitable (at screening or assessment), they will have details of their local secondary care services (Community Mental Health Teams) and will be able to redirect a referral, if appropriate. Examples of reasons for declining a referral include active ongoing risk (to self/ others), existing psychological support being offered by another relevant service or a

primary diagnosis of a psychiatric illness, such as Schizophrenia or Personality Disorder, that is not currently well managed.

IAPT services in England have taken part in an extensive programme of training in the wake of the pandemic in order to further upskill their staff to adapt to online working, as well as on Covid19 relevant topics, such as PTSD following an Intensive Care stay. These webinars have been delivered by experts in the field.

The role of liaison psychiatry should also be considered in the context of delivering post-COVID-19 rehabilitation support to patients. Liaison Psychiatry services provide the assessment and treatment of mental health problems within emergency departments and on the wards, with a key role in facilitating safe and timely discharges. They can also be appropriately placed to follow up patients within one day of discharge from critical care. It is recognised however that the provision of such a service remains variable across London and not all Trusts provide the service. Some existing liaison psychiatry services also offer outpatient support and services within community settings which should be considered where possible for patients with complex mixed physical and psychiatric symptoms.

18 Appendix 7 – Testing Rehabilitation Consensus Statements with people affected by COVID-19

Core standards VS consensus statements

Introduction

Thirteen documents published by national bodies and professional societies that made recommendations for rehabilitation services were reviewed to produce a draft of Consensus Statements that lay out a set of 78 core standards for COVID-19 rehabilitation services in London.

To facilitate patient feedback on the Consensus Statements, the 78 standards were categorised into a set of principles to test with people affected by COVID-19, patients and carers. The principles were described as follows:

1. Assessment of rehabilitation needs and coordination of care
2. Involvement of people who have experienced COVID-19
3. Infection prevention and control
4. General recommendations to commissioners and providers of rehabilitation services

The principles were tested with people who had lived experience of COVID-19 through:

- **A Patient and Public Involvement and Engagement (PPIE) Forum:** On 20 July, twelve people recovering from COVID-19 participated in a video conference. The first 60 minutes involved an open discussion to understand the participants' recovery and rehabilitation experiences and to identify areas of alignment with the principles. During the remaining 30 minutes, the principles were presented and participants were asked for comment.
- **A corresponding online survey:** From 17– 24 July, a survey was strategically circulated to patients and carers, asking for comments on the principles. The survey had a response rate of 58%, with 176 responses received.

PPIE Forum

Attendees described a wide range of symptoms including fatigue, headaches, brain fog, gastro, breathing difficulties, chest pains, numbness, dizziness, joint pains, rapid heartbeat. For some the symptoms were continuous, although the majority described a relapsing-remitting pattern with 'everyday a lottery – I don't know what I'm waking up to'. People expressed fears they might never get better and that they might be at higher risk of contracting a wide range of infections, due to the impact of COVID-19 on their immune system.

Most participants had experienced what they referred to as 'gas lighting' – professionals in primary and secondary care not believing they had had COVID-19, being 'dismissive' of their symptoms, refusing to make referrals for specialist assessments for ongoing cardiac, neurological or respiratory symptoms. This was sometimes the case with romantic partners, family, and friends. When seeking support, people had been referred for an anti-body test which took place several weeks after initial symptoms and often came back negative. For those participants who had not received a COVID test initially, it is not possible to say if the negative result for antibodies was a result of late antigen testing or an indication that their initial illness had not been COVID.

Participants expressed concern that one health care professional, such as a GP, might be the sole 'gate-keeper' to someone accessing rehabilitation services. This concern was due to the apparent lack of understanding amongst health care professionals about COVID-19 and variable experiences with support and access to services. Many people reported frustration and feeling defeated with their GPs, given how care is currently set up so that GPs are the gateway to accessing further specialist support. One participant felt a sole 'gate-keeper' might result in a 'postcode lottery' due to the high demand on GP practices in some parts of London.

Participants were supportive of many of the standards, particularly: involving patients, having a dedicated multi-disciplinary team, infection control measures, virtual consultations, effective coordination across care services, personalised assessment and holistic care.

Finally, people wanted to feel 'safe'. They wanted to know if they were still contagious with COVID-19, and whether they could, when they had the energy, re-enter the world. People worried that they had low- to poorly-functioning immune systems, which meant they would be highly susceptible to catching COVID-19 again, or the upcoming seasonal flu. They needed to know more about their own respective conditions, and sought reassurance on their current health experiences.

Recommendations

Forum participants made the following recommendations:

- **Actively involve and listen to people** as this will provide a rapid route for health care professionals to learn about the virus and expand research efforts. It was highlighted that an increasing number of people are sharing their experiences online (e.g.: LongCovidSOS, SLACK). In addition, it was recommended that learning be taken from other conditions that had similar widespread effects (e.g.: The Sepsis Trust).
- **Provide information, training materials and videos** for patients and carers to explain COVID-19 (e.g.: how it presents, its pathology) and provide guidance on a range of topics including diet, infection prevention and control, management of respiratory symptoms, step guides to support people returning to daily activities, legal and benefits advice etc.
- **Offer people with relevant symptoms an assessment of their medical fitness** including cardiac, respiratory, joint/ muscle pain. People want reassurance that they are medically fit before they feel safe to start exercising again and actively participating in rehabilitation.
- **Provide ongoing training and guidance for care coordinators** so that they: understand COVID-19 and the various ways it can present; facilitate access to services in response to an individual's needs; reduce the need for people to retell their story to every new professional.
- **Commit to investing in rehabilitation and recovery services** and acting quickly.

Following the meeting, four individuals contacted the PPIE lead seeking addition to the contact list of people to update on this work programme.

Survey

Distribution

The link to the survey was put up on the UCLPartners website. It was advertised to, or asked to circulate by, numerous sources including:

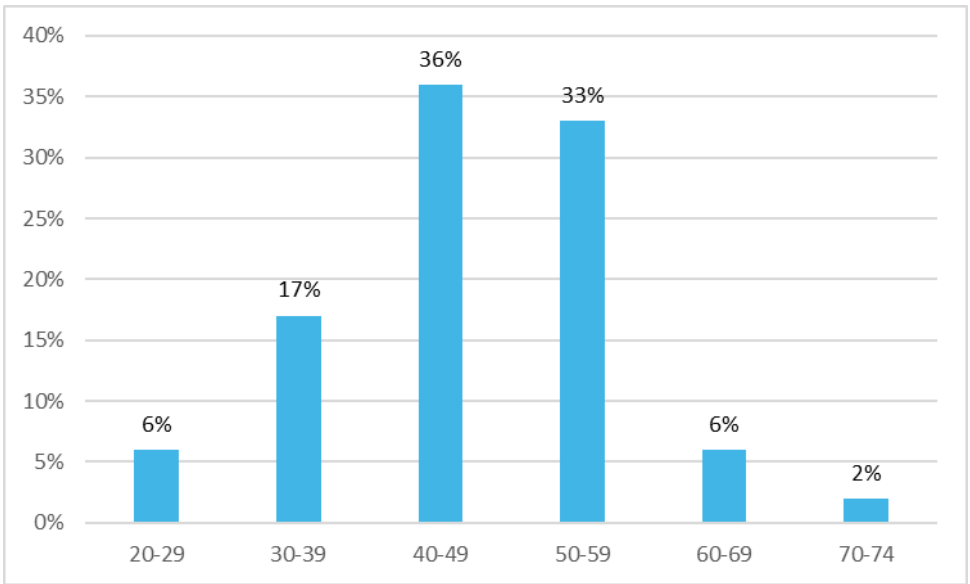
- **The staff at UCLPartners**

- **The Barts Health PPIE team, which includes people interested in health research across their hospitals, including Newham Hospital which have a link for people interested in COVID-19**
- **The UCLPartners patient and public pool**
- **The head of Patient Experience at Luton and Dunstable NHS Foundation Trust**
- **The LongCovidSOS team, which includes thousands of people experiencing Long Covid**
- **The PPIE leads at the other London AHSNs, Imperial College Health Partners and the Health Innovation Network in South London**
- **A Facebook group associated with the symptoms app run by Kings College London**
- **Specific handles on Twitter, including:**
    - **Michael Rosen**
    - **BMJ Patient Editor**

Respondents profile

176 people responded to the survey.

- The majority of respondents managed their COVID-19 out of hospital (went to A&E but were not admitted to hospital; were cared for in the community by their GP or self-isolated). The remainder were carers (6%), were admitted to hospital (6%) or to ICU (1%).
- Of those who provided their gender (n = 101) 84% were female.
- For those who provided their age (n = 98) the range was 23 – 74 years. Figure 1 shows the age categories of survey respondents. *Please note this sample is not representative of the full age distribution of those known to have contracted COVID or to have had the most severe infections.*



- Figure 1: Age of survey respondents
- Of those who provided their ethnicity (n = 96), one respondent described him/herself as Black British, one as Caribbean, one as Indian; two as of mixed ethnic background and other respondents described themselves as white.

Responses to principles

The following responses were shared by survey participants:

> *"I need to feel that people are interested in recovering me and I won't be left on some sort of forgotten heap as I caught it at lockdown stage. We are the people that others have learnt from but I don't want that to be my legacy. I need caring professional personalised help. I feel let down by my GP service and think if I'd had had the support early, I wouldn't be chronically ill now"*
>
> *"Thank you for understanding the severity of the fatigue! And the combination - physically making the journey to hospital, walking down corridors, sitting on chairs, and cognitively for explaining symptoms and disease picture, recalling previous stages of the illness etc. This often generates significant word-finding difficulties for me, which would mean that I couldn't maximise the benefits of the consultation"*

Assessment and care coordination

Respondents were presented with the following principles relating to rehabilitation assessment of needs and care coordination

- There should be a single co-ordinator of care (in hospital or out of hospital) for every person recovering from COVID-19
- People's needs and goals should be assessed as soon as possible, and assessments should be repeated as people's needs and goals may change over time
- Rehabilitation should cover physical, social, psychological, emotional and cognitive needs and goals
- There should be effective communication and collaboration between GPs, community services, hospitals, social services and voluntary sector organisations

Ninety-one percent of respondents agreed with these principles. Seventy-four percent of respondents responded that there was nothing missing against these core principles.

The following needs and gaps around the 'Assessment and care coordination' category were highlighted:

- **Listening and acknowledgement:** Commitment from care professionals (particularly care coordinators) that people's symptoms will be carefully considered, that referrals for specialist support will be made and that honest conversation will be held about the lack of knowledge regarding COVID-19 recovery and rehabilitation. Respondents referenced being dismissed, refused onward referral and assumptions made – without assessment – regarding the causes of their symptoms and trajectory of recovery. One respondent recommended patients being able to change specialist/supporting clinician easily if they feel they are not being listened to. To make this possible, it was recommended that care professionals be provided with guidance, training and adequate resources.
- **Personalised care:** A personal approach, continuity of care and repeated holistic assessments (including the needs of carers and dependents) as symptoms can change over time.
- **Rapid access to specialists:** Many respondents requested that the dedicated rapid-access multi-specialty (e.g.: cardiology, ENT, GI, neurology, renal, respiratory, physiotherapy,

psychotherapy) clinics be established as a priority to provide medical and psychological assessment (face to face and virtual options) to identify treatable causes of symptoms and provide assurance about fitness to resume exercise and/or start rehabilitation.

- **Regularly updated information**: This was requested for patients and health care professionals on COVID-19 symptoms, available rehabilitation services, access and referral routes and advice (e.g.: diet, boosting of immune system).
- **Information for employers**: Along with financial, employment, benefits support for people recovering from COVID-19 including their dependents.
- **Minority/vulnerable groups:** Inclusion of standards for: children experiencing post COVID-19 symptoms, people with disabilities, people who are symptomatic but did not test positive for COVID-19 because they became unwell before testing was available or were tested too late, perhaps through a symptom-based diagnosis; and those living outside of London.
- **Further research:** Many respondents highlighted the importance of further research to better understand what COVID-19 recovery and rehabilitation, to understand if people remain infectious and to alleviate anxiety and stigma.
- **Access to notes**: It was recommended that patients be able to access their test results and notes.

Infection protection and control

Respondents were presented with the following principles relating to infection protection and control:

- The number of steps in a person's rehabilitation pathway and number of professionals involved should be kept to a minimum to reduce the risk of infection.
- Where appropriate, remote or virtual appointments should be offered unless this is deemed unsuitable.
- Dedicated follow up clinics should be considered, where specialists (e.g.: cardiac, renal, neurological) run a joint clinic to reduce the number of visits a person needs to make to hospital.

Seventy-five percent of respondents agreed with these principles. Eighty-six percent of respondents responded that there was nothing missing against these core principles.

The following needs and gaps around the 'infection protection and control' category were highlighted:

- **Rapid access to professionals:** Respondents recommended that the main principle be ensuring that people can rapidly access those professionals essential to their recovery even if this results in multiple visits, and they should see them through the most appropriate and/or preferred mechanism (face to face or virtual)
- **Importance of face to face consultations:** Concerns were raised by some respondents regarding over reliance on virtual (phone or video) consultations, highlighting the absence of physical examinations, potential delays to treatment, detrimental impacts on care, feeling overlooked and personal difficulties in discussing symptoms over the phone. It was recommended that at least some appointments, with appropriate infection control measures, be face to face, particularly the initial multi-speciality assessment.
- **Virtual appointments and combined clinics:** Some respondents supported the offer of virtual appointments and combining clinics due to their level of fatigue and anxiety about transmitting the virus to others and being exposed to viruses whilst suffering lowered immune system. It was also highlighted that some people may need support getting to

hospital appointments as they are unable to drive due to symptoms or not having access to a car.

- **Family support:** Allowing a member of the family to sit in on consultations was raised as helpful, particularly for people with disabilities.

Involving people

Respondents were presented with the following principles relating to involving people affected by COVID-19:

- Translators should be available if needed to ensure that people understand the information given to them.
- The establishment of a critical care patient and relatives support group should be encouraged.
- Patients and relatives should be asked for feedback regularly, and this information should be utilised to assess rehabilitation and follow-up services.

Eighty-nine percent of respondents agreed with these principles. Eight-six percent of respondents responded that there was nothing missing against these core principles.

The following needs and gaps around the 'involving people' category were highlighted:

- **Listening to experiences:** Listening to patient and carer experiences is essential, including those who are withdrawing and dropping out of services. No decisions should be taken about the design of rehabilitation services without the meaningful involvement of patients with this condition and their carers/ families. Easy ways to provide feedback and/or complain should be established and communicated. It is important to recognise that people are experiencing brain fog, which hinders interaction with the support and provision of feedback.
- **Support groups**: These were highlighted as important for all patients, not just for those who went to critical care, and also for relatives and carers. Services should link to well-established groups already formed. It was also highlighted that support groups would be of value for people experiencing the same clusters of symptoms (e.g.: breathlessness, fatigue etc.) and may provide an opportunity to raise awareness of services not endorsed directly by the NHS, such as, osteopaths, supplements, meditation, acupuncture.

General recommendations for commissioners and providers

Respondents were presented with the following principles relating to recommendations for commissioners and providers:

- Patients should receive ongoing rehabilitation delivered by the most appropriate service/team for their needs. A multidisciplinary team approach is advocated.
- Providers should participate in data collection to help inform rehabilitation service needs, patient outcomes and opportunities for quality improvement.
- Existing rehabilitation services should be reviewed, standardised and expanded where necessary.
- There should be online resources for web-based, self-directed rehabilitation at home.

Eighty-seven percent of respondents agreed with these principles. Eight-four percent of respondents responded that there was nothing missing against these core principles.

The following needs and gaps around the 'general recommendations for commissioners and providers' category were highlighted:

- **Data collection**: This was highlighted as paramount due to the virus being novel. It was felt that accumulating data would put providers in a better position to give evidence-based advice. However, concern was expressed about a private company collecting and storing data.
- **Online resources but not in place of testing**: Online resources were highlighted as useful for some people. However, for some patients this was felt to be less important than face-to-face support. The risk of care coordinators referring to online resources/ websites rather than offering follow up or testing was raised. Reference was also made to signposting to existing online resources (e.g. the Homerton hospital's guide for people with COVID-19) with a recommendation to direct people to existing resources rather than duplicate.

Concern was expressed around how the NHS will manage workload – meeting the needs of existing patients without COVID-19 alongside the additional demands of people recovering COVID-19.

At the end of the survey, 70 individuals left their names and contact details seeking to be updated on this work programme.

Conclusion

This document reports on what people who have had COVID-19, and a few carers, consider is important to them in the development of a rehabilitation service after COVID-19. If rehabilitation services are to genuinely help people post-COVID-19, their development must be informed by the experiences of those who have had COVID-19.

People who took part in the PPIE forum, and online survey, were passionate about being included in this work. They recognised the power of their voices yet were desperate to be heard, and have their opinions and experiences included in development of rehab services. Some reported that taking part in this work gave them hope for the first time in months.

It must be acknowledged that reporting on gender, ethnicity, and age were characterised by significant missing data. We are in the process of circulating the survey to, and possibly having another PPIE forum with, more men, older people, and people who are not White.

We thank all those who were involved in the PPIE forum, and those who completed the survey, we are very grateful for all your insights.