NHS London

Clinical Reference Guide: Post COVID Syndrome Pathway

Pan-London Guidance for Standardised Referral, Assessment and Onward Access to Rehabilitation Services

The evidence regarding the Post COVID Syndrome is rapidly emerging and the proportion of individuals requiring support following COVID-19, the rehabilitation needs of this patient cohort, and the time period for which they continue to experience symptoms are not yet fully known. This document is based on the available evidence at the time and expert consensus. It will be continuously reviewed to ensure alignment with the evolving data.

Executive Summary

This commissioning guidance has been developed in collaboration with stakeholder representatives from across the five London ICSs, both through a clinical reference group and a series of task & finish (T&F) groups held across November 2020. The Clinical Reference Group and the three task & finish subgroups covered referral and assessment, the designated assessment clinic and follow on services. Each subgroup held up to three workshops with diverse clinical and patient representation.

This *Post-COVID Syndrome Pathway Commissioning Guidance* is a curation of those workshop contributions, available evidence, national and regional existing guidance and the experience of post-COVID-19. vanguard services in London.

Post-COVID syndrome, colloquially known as 'Long COVID', is a novel sequela and therefore there is minimal robust research evidence available at this time. Therefore, this guidance will be a 'living document' with the expectation that an iterative approach will be required as innovation and evidence emerge. This guidance should be regarded as a starting point for the region with respect to the post-COVID syndrome pathway.

Executive Summary

Primary care will be the key gatekeeper for this pathway, initially identifying, investigating and managing patients through acute, ongoing symptomatic and into post-COVID syndrome stages. There will also be a need to undertake proactive case finding, particularly for communities where there is existing evidence in disparity in COVID-19 outcomes and risk (e.g. BAME communities, people with learning disabilities) which could involve Social Prescribers and outreach teams/initiatives.

The definition of post-COVID syndrome by NICE is based on duration of symptoms but takes no account of severity and complexity – which will vary between patients (likewise during the acute and ongoing symptomatic phase).

Where there is not a clinical need for a patient to access the specialist assessment clinic, a primary care team may determine a patient may instead need to be referred directly for rehabilitation. In that case, the Single Point of Access service would receive this referral and provide care navigation into local rehabilitation assets. This may include an initial assessment / triage. The Single Point of Access may be led by therapists, likely be community or primary care based which could work across Primary Care Networks (PCNs).

Where a patient attends the Specialist Assessment Clinic, the Single Point of Access service would accept the personalised care plan from the specialist assessment clinics as a trusted assessment and provide navigation into the local rehabilitation assets.

Clinical Case Definition: Post COVID-19 Syndrome

Signs and symptoms that develop during or following an infection consistent with COVID-19, continue for **more than 12 weeks** and are not explained by an alternative diagnosis.

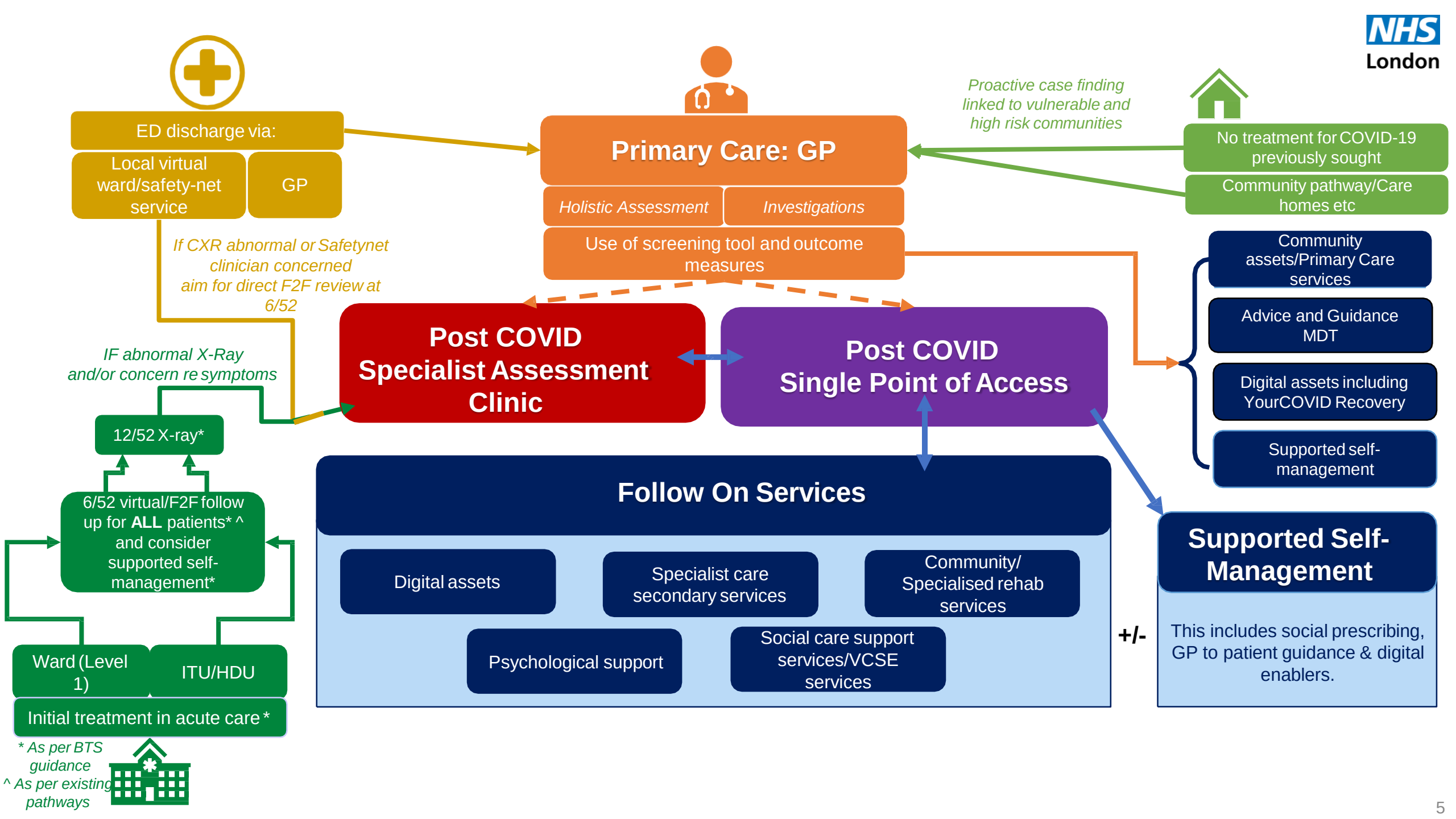
It usually presents with clusters of symptoms, often overlapping, which can fluctuate and change over time and can affect any system in the body.

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

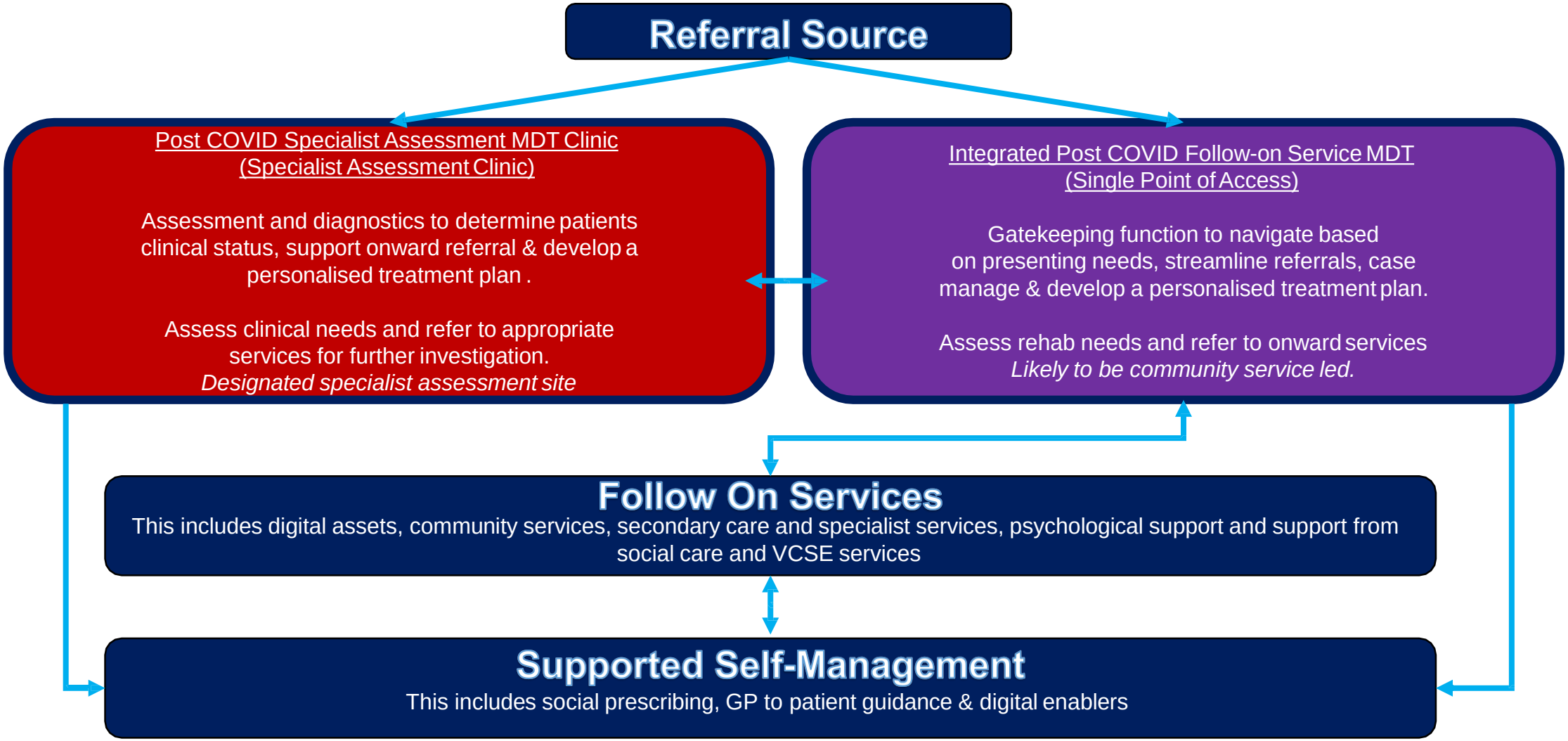
NICE, 2020

The NICE guidance, sets out three different phrases to define the effects of COVID-19 at different time points. These are “acute COVID-19 infection”, ongoing symptomatic COVID-19” and “Post COVID-19 Syndrome”. Definitions of these can be found in the glossary.

The NICE guidelines [NG188]: COVID-19 rapid guideline: managing the long-term effects of COVID-19 was published on 18th December 2020


NHS London
ED discharge via:
Local virtual ward/safety-net service
GP
Primary Care: GP
Holistic Assessment
Investigations
Use of screening tool and outcome measures
Proactive case finding linked to vulnerable and high risk communities
No treatment for COVID-19 previously sought
Community pathway/Care homes etc
If CXR abnormal or Safetynet clinician concerned aim for direct F2F review at 6/52
IF abnormal X-Ray and/or concern re symptoms
12/52 X-ray*
Post COVID Specialist Assessment Clinic
Post COVID Single Point of Access
Community assets/Primary Care services
Advice and Guidance MDT
Digital assets including YourCOVID Recovery
Supported self-management
6/52 virtual/F2F follow up for ALL patients* ^ and consider supported self-management*
Follow On Services
Digital assets
Specialist care secondary services
Community/ Specialised rehab services
Psychological support
Social care support services/VCSE services
+/-
Supported Self-Management
This includes social prescribing, GP to patient guidance & digital enablers.
Ward (Level 1)
ITU/HDU
Initial treatment in acute care *
* As per BTS guidance
^ As per existing pathways

Post COVID Syndrome Pathway



Primary Care Assessment

Consider adapted assessments for those with learning disabilities & additional consideration for those with language requirements

Background

COVID-19 Diagnosis: Confirm if/when the patient previously had a positive COVID-19 swab
History: Take the patients' history including potential fluctuating symptoms and trends
Patient baseline: Gain an understanding of the patient's functional baseline prior to contracting COVID-19
Examination: Conduct a patients' examination (including Neurology)

Investigations

Bedside Investigations: Pulse, oxygen saturations, sitting/standing blood pressure, sit-to-stand test (1 minute version to assess for any desaturation)
Mental Health: Screen for anxiety/depression
Blood Tests (within 4 weeks of referral to clinic): COVID-19 serology, FBC, U&E's, LFT's, CRP, Ferritin, BNP, Vitamin D and Cortisol* if patient is fatigued**
Additional Tests: Chest X-Ray, ECG (if possible) ***, Rockwood Frailty Tool where appropriate, use of a screening tool (Newcastle post-COVID Screening Tool/ COVID-19 Yorkshire Rehabilitation Screening (C19-YRS) tool in alignment with the national specification)****

Social Assessment

Understand the patients' social needs: Impact of condition on family, occupation etc.

** Only if done at 09.00 – this should not be a random cortisol*
*** Do **not** include d-dimer or troponin as routine tests. This should only be used in secondary care to diagnose VTE/ACS*
**** Do **not** include echoes due to delays in access from primary care*
***** Use as a decision aid.*

Inclusion and Exclusion Criteria for the Specialist Assessment Clinic

Inclusion Criteria

- Suspected or confirmed diagnosis of COVID-19
- Persistent signs and symptoms consistent with COVID-19, that are not explained by an alternative diagnosis for 12 weeks or more.
- Persistent signs and symptoms consistent with COVID-19, for less than 12 weeks if other possibilities of an alternative underlying disease are excluded.

Exclusion Criteria

- Never had a positive COVID-19 test and low index of suspicion for COVID-19.
- Other causes for symptoms or symptoms resolve once this cause has been treated (i.e. Vitamin D deficiency causing fatigue).

Standardised Assessment

A summary of the investigations which should be undertaken as a minimum for patients attending the Specialist Assessment Clinic.

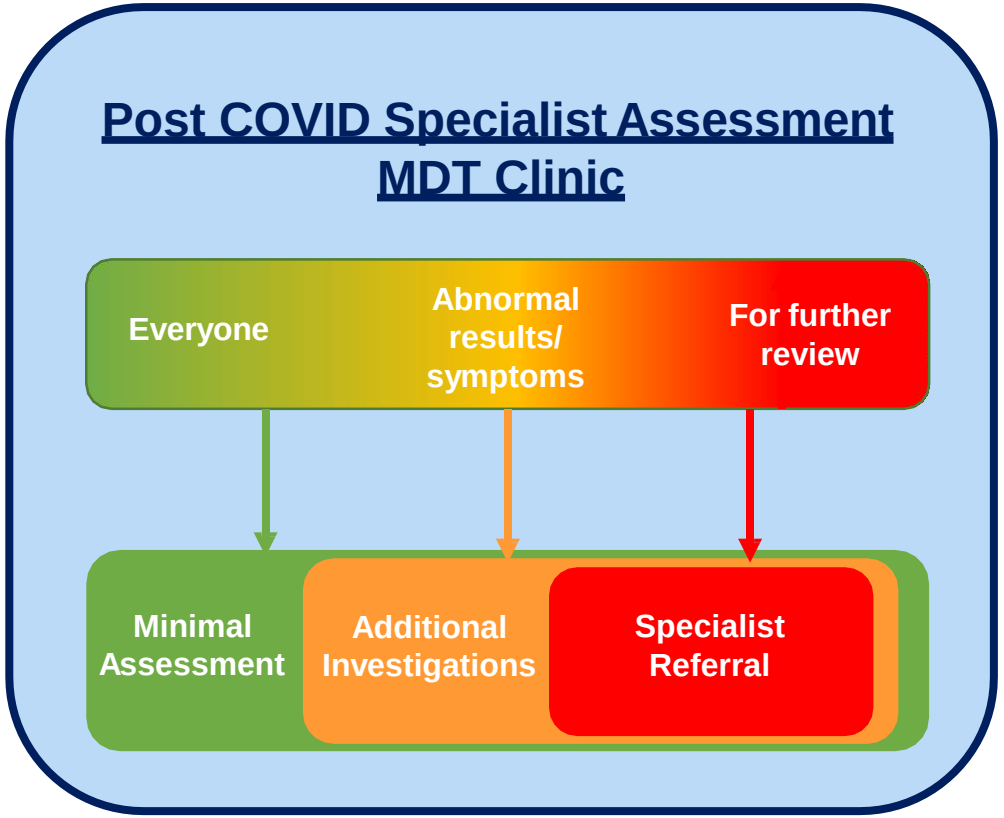
The pathway outlines the subsequent actions that are recommended as a result of abnormal results or symptoms.

The detailed assessment undertaken within the clinic should support understanding of the patients trajectory. In addition to the clinical assessment, a social assessment of the patient should also be incorporated.

Patients must be appropriately screened in Primary Care and during the Specialist Assessment Clinic to ensure nothing is overlooked before they are referred to follow on services.

Furthermore, there is a clear need to collect data on the patients being referred to the Assessment Clinic to develop understanding of the condition and its impacts as well as inform future service provision. Tools, indicated for use in the national specification are included within this guidance.

The following pages contains guidance regarding the assessment that should be undertaken based on clinical need. It is important that assessments and tests conducted should inform clinical management.



Summary of assessments to be undertaken at the Post COVID clinic

Extended Bloods

	Troponin	D-dimers	CK	Liver function tests	Ferritin	BNP or NT-proBNP	CRP	Vitamin D	Cortisol
Minimal Assessment	IF elevated*	IF concerns/desat on transfer*	IF abnormal*	IF abnormal*	IF abnormal*	*if BNP > 400 or NTpro-BNP > 2000* / *BNP>100 or NTpro-BNP>400*	IF abnormal*	IF abnormal*	IF high fatigue score
Additional Investigations	Virtual review and CMR	CTPA	Watch trend	Ultrasound and or Liver Screen	Watch trend & ensure no other cause		Watch trend & ensure no other cause	Supplementation if low	
Onward Referral	Refer to cardiology	Action according to clinical judgement*	Action according to clinical judgement*	Refer to Hepatology	Action according to clinical context and judgement*	2/52 / 6/52: Cardiology heart failure team	Action according to clinical judgement*		Refer to endocrinology service

Assessment (Some of the questionnaires can be sent to the individual and completed prior to the clinic appointment)

	Sit to Stand/6 minute Walk Test	GAD	PHQ4	Modified PTSD (2 questions)	Cognitive Assessment (6 CIT)	MRC or BPAT**	FACET	ECG	VAS Scores
Minimal Assessment	Desaturation ≥4% SpO2% from baseline				≥8 significant	≤2 / ≥ 4		Judged by physician to be of concern	
Additional Investigations	CTPA/HRCT/LFT	0-5= mild, 6-10 =moderate,11-15= mod severe, 16+=severe		≥ 6	MOCA (requires license)	Action accordingly	Action according to clinical judgement		Watch trends
Onward Referral	Referral to cardiology/ respiratory	Refer to psychology based on clinical judgement			Should not be used to exclude brain fog given fluctuations in presentation	Consider validation with 6MWT if abnormal		Referral to cardiology	

*The Specialist Assessment Clinic should have multi-speciality input to support the determination of subsequent action

** Should be observed by a physiotherapist to determine breathing pattern disorder.

Additional Investigations for consideration based on clinical need

Abnormal symptoms/ results	CXR abnormal	Desaturations	HRCT abnormal or concerns*	Abnormal BP (+ concerns)	Previous PE/ Disproportionate desaturations*	Concern about PHT or significant breathlessness	Suspected asthma
Additional test	HRCT/CTPA		Lung Function Test	Echo	VQSpect	CPET	Peak Flow Diaries
Onward Referral	*Desaturating and normal CT* → Referral to cardiology/respiratory*					*Consider w/ discretion if available*	

Additional investigations for consideration based on clinical need

Abnormal symptoms/ results	CT findings/aid decisions on steroids	Suspected autonomic dysfunction	Suspected hypertension w/ intermittent dizziness or postural intolerance		Abnormal ECG OR echo OR troponin/ strong clinical suspicion
Additional test or onward Referral	Lung function	Compass 31	Referral to Specialist clinic	24hr BP	24hr ECG
Onward Referral	Refer to cardiology*				

If young

If other tests have indicated normal results

Incidental findings – refer down appropriate pathway e.g. 2WW

*The Specialist Assessment Clinic should have multi-speciality input to support the determination of subsequent action. Onward referrals may be needed dependant on expertise at the clinic or additional patient need

MDT Workforce

Optimal Workforce

Minimum workforce for Specialist Assessment Clinic

- Consultants (consider respiratory, cardiology, gastro and neurology representation)
- Physiotherapist with expertise in breathing pattern and breathlessness assessment
- Occupational Therapist with expertise in cognitive and fatigue assessment/management
- Clinical Psychologist (may not see everybody)

Minimum workforce for Single Point of Access

- Physiotherapist with expertise in breathing pattern and breathlessness assessment
- Occupational Therapist with expertise in cognitive and fatigue assessment/management
- Mental health expertise e.g psychologist/IAPT
- Other roles as determined by local systems

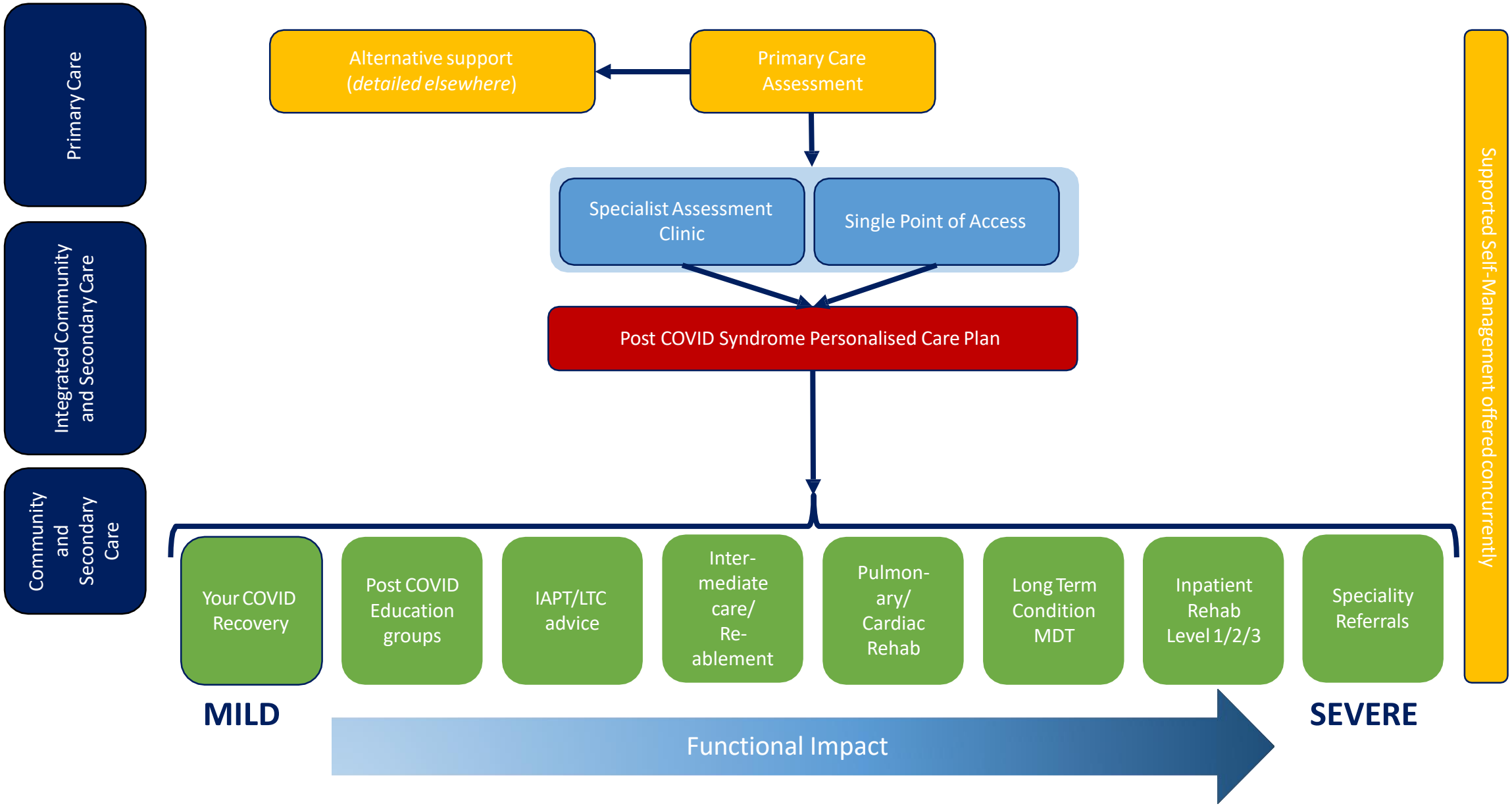
Care Coordinator and admin support

Social Prescribing Link Worker

Additional clinic workforce for consideration

- Neurologist
- Dietician
- Speech and Language Therapist
- Respiratory Physiologist
- MSK Expertise
- Neuro-cognitive and neuro-psychiatry expertise
- Nurses
- Nursing and Healthcare Assistants
- Learning Disability Liaison Nurses
- Proactive case finders
- Consideration for new roles

Onward Referral



Supported Self-management

Supported self-management is of critical important to support people living with Post COVID Syndrome and other long-term conditions during the pandemic.

Approaches including health coaching, self-management education and peer support which are important to help these individuals ‘build their knowledge, skills and confidence to manage their own health and care’, as well as improve outcomes and experiences of care. Those playing a vital role in this include, link workers, care co-ordinators and health coaches which, as of April 2020, Primary Care Networks have been able to recruit to. The delivery of this will require close working within primary care and the Post COVID Syndrome Integrated Service should seek to establish relationships with, ensuring representation within the MDTs where possible. However the demand on these roles within existing capacity is acknowledged and the use of other resources should also be considered for each patient.

Other tools to aid supported self-management during this time (and beyond) include social prescribing and digital enablers as well as the advice and guidance given by clinicians to patients.

Where these are offered, it is important to consider accessibility for people with learning disabilities, language barriers and digital inequalities which may impact an individuals ability to benefit from the offer.

Learning and Development

Specialist services alone will not have the capacity to see all Post COVID Syndrome patients, so where appropriate, it is important to upskill and offer advice for clinicians throughout the pathway. Close working between clinicians diagnosing Post COVID Syndrome and those leading on the management of long-term conditions would help support some patients to self-manage.

Post COVID Syndrome patients are often highly complex and can relapse quickly. Clinicians need a strong understanding of the condition before making decisions about management of patients. In particular, this includes knowledge around the risks around setting exercise goals need to be considered as this can make Post COVID Syndrome patients more unwell if not carefully managed.

Staff across the pathway would also benefit from training around support planning, delivering personalised care, and managing fatigue, breathlessness, and low-acuity cognitive issues.

It is paramount that clinicians across the health and care spectrum have a clear understanding of what Post COVID Syndrome is so that they can readily identify when an individual may be experiencing it and respond appropriately. Post COVID Syndrome is a new condition so learning and best practice must be shared effectively across the region. Academic Health Science Networks (AHSNs) and other networks will be key enablers in this. Clinicians would also benefit from support to help them stay abreast of the latest research and guidance on management of Post COVID Syndrome patients. Clinicians should seek opportunities to partake in QI and research activity to contribute to understanding of the disease and its impacts. Internal communication plans should include consideration for how information and resources for clinicians is disseminated and accessible to staff working at all levels within their organisations.

Evaluation and future work

Post-COVID colloquially known as ‘Long COVID’, is a novel sequela and therefore there is minimal robust research evidence available at this time. Therefore, this guidance will be a ‘living document’ with the expectation that an iterative approach will be required as innovation and evidence emerge. We will periodically convene CRG meetings as new information/evidence becomes available.

This guidance should be regarded as a starting point for the region with respect to the post-COVID syndrome pathway.

Phase 2

There is likely to be a second phase for this piece of work to consider the longer-term needs of patients and the ongoing role of the NHS across primary, secondary and community care. This will include the work to address patients who may not recover from post COVID and include further discussions with other stakeholders including social care.

Learning Health Systems

Learning Health Systems

As part of the ongoing evaluation that will take place, opportunities will be identified to enable this at a regional level, implementing a learning health system that supports development, transformation and improvement of Post COVID Syndrome linked services. ICSs should also enable local evaluation to support knowledge mobilisation and employ quality improvement methodologies to support the systematic improvement of clinic and pathway design.

This should include consideration of the following areas: