



A guideline to supporting the recovery and rehabilitation of adults with confirmed or suspected COVID-19 in Greater Manchester

Version 2.5

January 2021

VERSION	OUTLINE	GOVERNANCE		
V1.1	Based on wave 1 – pre national guidance	Shared with PCC, CCC, Hospital Gold Command and shared widely (June 20)		
V2.1	Revised with national guidance on COVID-19 acute virtual wards	Shared with CCC, Hospital Gold Command and Joint Working Co-ordination Group (Oct 20)		
V2.3	Updated further with national guidance on post acute COVID-19 clinics			
V2.4	Updated further following early sight of the new guidance: National Guidance for post- COVID syndrome assessment clinics	Shared with GM stakeholders Nov 2020		
V2.5	Minor modifications to reflect service specifications	Shared with CCC, Hospital Gold Command and Joint Working Co-ordination Group (Jan 21)		

Revisions from v2.4 to v2.5

Minor wording changed in fig 1.

Revised fig 2 in accordance with service specification v4.

Revised wording under section 4.0 and 4.1.

This guideline is intended for the Greater Manchester (GM) locality leads involved in the shaping of services to support the recovery and rehabilitation of COVID-19.

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1.1 RATIONALE

At present, it is recognized that:

- COVID-19 is a new condition of which the consequences are not yet fully known, nor fully understood.
- Timeliness of access to services is crucial: some clinicians report patients presenting late to services due to some of the limitations in current pathways with a potential risk to patient safety and clinical outcomes.
- Patients considered high risk of deteriorating, and developing severe disease from COVID-19, require follow up of the acute illness, especially in the first 14 days. Measurement of patient oxygen saturation is key to detecting deterioration early and ensuring patients care is escalated quickly. Early access to oxygen and treatment, including dexamethasone, is known to be associated with reduced mortality and better clinical outcome (Group, 2020).
- COVID-19 virtual ward care models have continued to evolve alongside our understanding of COVID-19, key markers in health deterioration, and treatment. The latest model advocated by the national COVID expert consensus reference group recommends using NEWS2 scoring, oxygen saturations and risk stratification as part of the initial assessment. This is followed by using pulse oximetry and a patient diary of symptoms to enable remote monitoring and escalation to secondary care in the event of deterioration.
- Where COVID-19 virtual wards are not in place for the acute phase, there is a risk of rapid deterioration, particularly silent hypoxia, which is a concerning feature of the disease.

Given the lack of clinical symptoms associated with profound hypoxia, this may not be recognised in some, until it is too late.

• The importance of COVID-19 virtual wards has been recognised by the GM Primary Care cell, the GM Community Co-ordination cell and the GM Gold Command Hospital Cell. The GM Winter planning Group felt the adoption and delivery of virtual wards across GM would be key to supporting plans to tackle the unpredictable demand for the forthcoming winter (2020/21).

1.2 THE PRINCIPLES

The following guideline has been developed to support clinicians within GM localities to follow up and monitor patients with confirmed or suspected COVID-19. The guideline does this by:

Offering a **systematic and robust approach to triaging and monitoring** patients in different clinical settings, and

Proposing a **tested and existing methodology to escalate**, **and de-escalate** patients recovering from confirmed or suspected COVID-19 in a way that:

- Is timely
- Considers the wider health needs of the patient
- Promotes **easy access**, to diagnostics and treatment
- Enables the follow up and safe discharge of a patient back to routine care, and
- Promotes **remote monitoring** (where possible) to ensure the continued **safety of GM clinicians**

The guideline also proposes a system for the **collation of ongoing research and intelligence**.

1.3 OBJECTIVE

It is important to note:

The guideline being proposed is **intended to support GM localities**; to ensure their own processes, where they have them, are robust, optimise emergent learning and best practice from centers of excellence in GM and where they may not yet have them, have an agreed foundation on which to develop an approach.

This guideline **builds on existing processes**, and **utilizes existing resources** to enable localities, where need be, to shape their clinical response.

This work supports both the GM Gold Command Hospital cell and the Primary Care cell by:

- Having an early escalation process for those rapidly deteriorating,
- Having a monitoring process for those who may else return to secondary care,
- Proposing a supporting system that **links directly to other agreed pathways** such as the GM discharge pathway, Care home pathway, and assessment pathways, and
- Promotes the recording of continued **research and intelligence**

1.4 THE PATHWAYS

The following pathways (figures 1-6) offer a high-level guide to support the short, medium, and long-term recovery and rehabilitation for people with confirmed or suspected COVID-19.

Figure 1 broadly describes the acute phase of COVID-19 and the mechanisms that may be offered to support recovery within the first 4 weeks. This includes a high-level description of COVID-19, a virtual ward (or equivalent) to support those with an increased risk of acute deterioration.

Figure 2 broadly describes the process for following up patients >4 weeks post presentation. This outlines an approach to supporting longer symptoms using post-acute assessments and management strategies that include post-acute COVID-19 clinics¹.

Figure 3 outlines the post-acute COVID-19 clinic pathway using MDT input for those people with suspected post COVID-19 syndrome (typically >12 weeks).

Figure 4 outlines the considerations to support longer-term recovery. It should be noted the rehabilitation referred to should not be confused with complex rehabilitation recommended as part of the ICU step down process although some components may be similar.

Figure 5 broadly describes the process for monitoring patients in the acute phase (first 14 days) through the mechanism of a virtual ward (or equivalent). This process outlines more detail to that described in the bottom left of figure 1 and is based on the national pathways in appendix C

¹ National Guidance for post-COVID syndrome assessment clinics

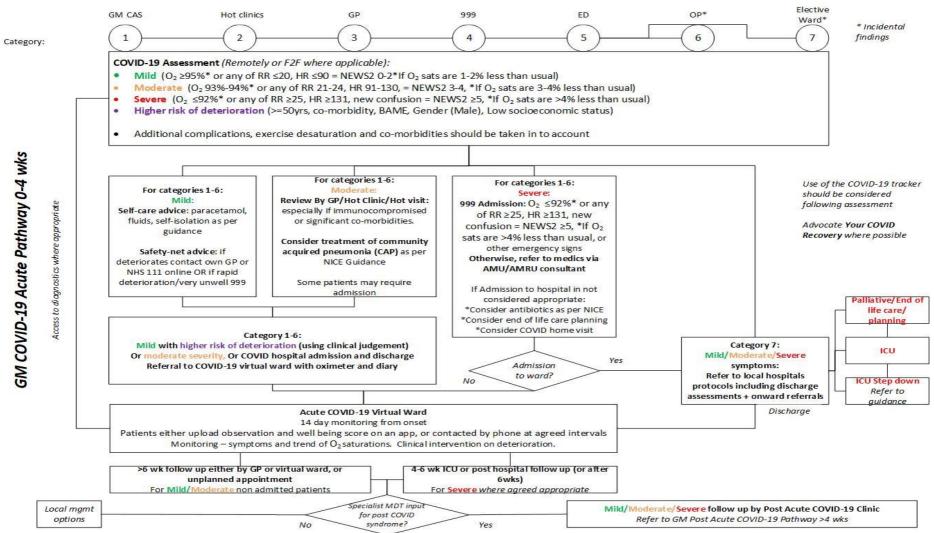
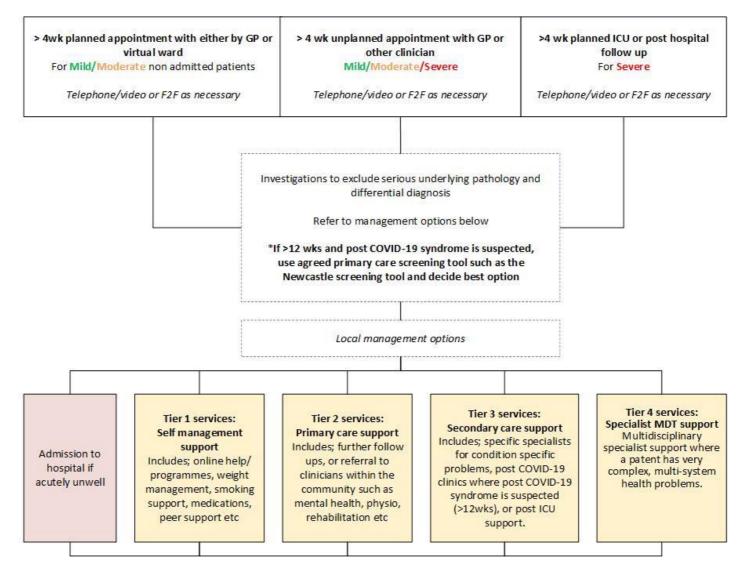


Fig. 1. A structured approach to following up patients with confirmed or suspected COVID-19 in GM (acute phase 0 – 4 weeks)

Timelines are from onset of symptoms, although clinical decision is advised as some patients may present late of have a lengt hy stay in hospital.





Refer to the appendices for the Newcastle Screening Tool.



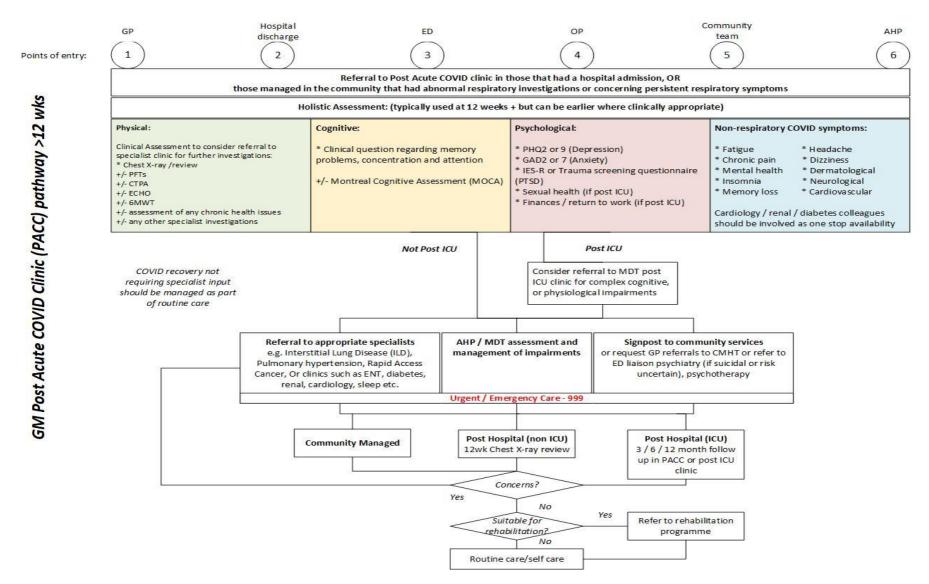
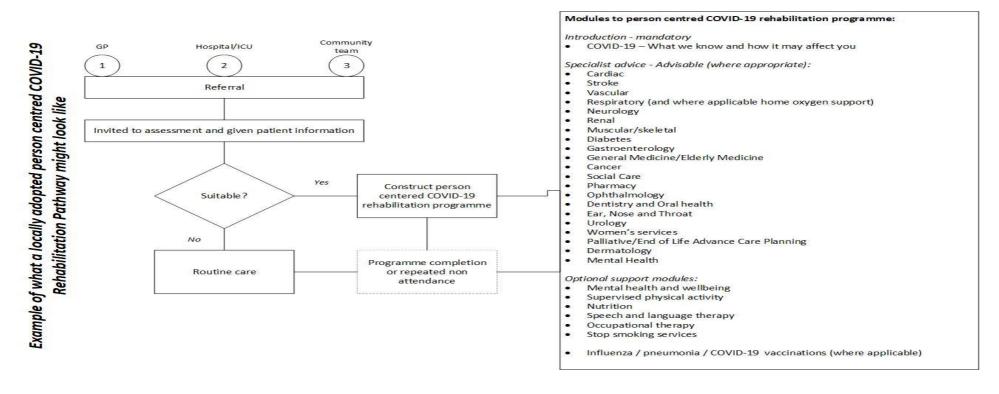


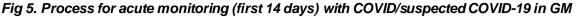
Fig. 4. Further considerations to support long term COVID-19 recovery

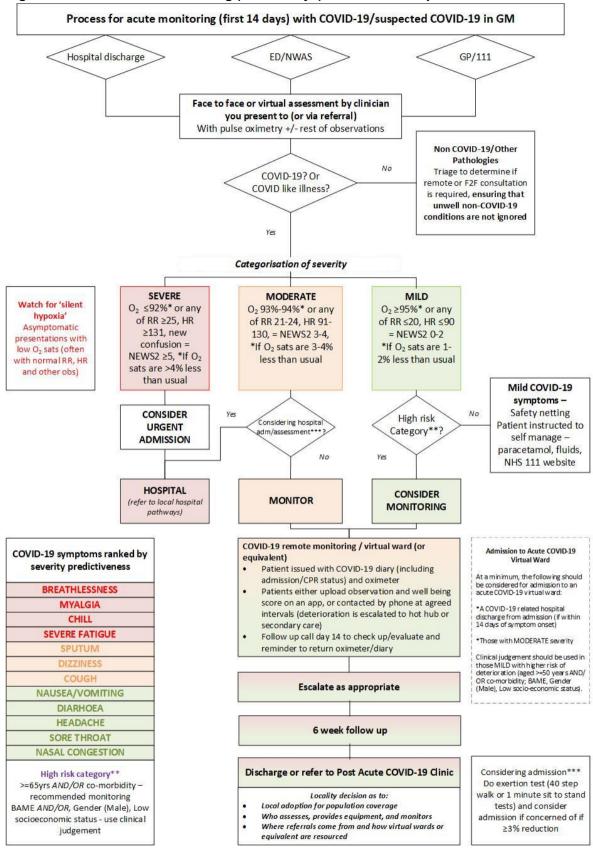
Your COVID-19 Recovery – an online rehabilitation service to provide personalized support to patients https://www.yourcovidrecovery.nhs.uk/

BTS Guidance on Delivering rehabilitation to patients surviving COVID-19 using an adapted pulmonary rehabilitation approach - <u>https://www.brit-thoracic.org.uk/about-us/covid-19-information-for-the-respiratory-community/#pulmonary-rehabilitation-resource-pack</u>

A locally adopted person centered COVID-19 rehabilitation pathway (see example illustration)







2.0 SUPPORTING THE ACUTE PHASE: A VIRTUAL WARD SERVICE (OR EQUIVALENT)

2.1 Definition of a virtual ward service

A virtual ward service can be defined as a service that reviews the health and care requirements of those recently experiencing COVID-19 symptoms and relative complications predominantly using non-contact means, such as telephone, video calling etc. However, face to face follow ups, may occur if deemed necessary where these facilities exist, to see patients safely.

The aim of a virtual ward service is to monitor patients within the community deemed to be at high risk of deterioration.

An acute COVID-19 virtual ward is primarily concerned with addressing the acute phase of illness, especially in the first 14 days. This involves the measurement of patient oxygen saturation and other observations in order to detect deterioration early and escalate care as quickly as appropriate.

However, the virtual ward concept should also be used to support follow ups at 4 - 6 weeks, and at 12 weeks, where the locality deems it appropriate. Some localities may choose to combine the function of the virtual ward teams, others may want to run them as separate parts of the pathway.

2.2 Benefits of an acute COVID-19 virtual ward

The main benefit of the acute COVID-19 virtual ward is to monitor, escalate and treat deteriorating people in the community in a way that is timely and prevents avoidable health complications and death. Those acutely unwell will be actively monitored and treated in their homes, where possible, negating the need for unnecessary clinical appointments and presentations. Also, avoiding complications in those unaware of the dangers being posed by a deterioration in their health.

The day to day monitoring of patients does not necessarily need to be done by a clinician. Clinicians will only be involved in the initial assessment, deterioration and where treatment is needed. Therefore, the demand on primary care and secondary care clinicians should not be significantly increased compared to routine care at present. The difference being those who currently present to primary care for the first time, either symptomatic or through testing, will have an assessment to determine if they require monitoring. And those that have deteriorated will have clinical input, in most cases before they present to unplanned care with significant health issues.

The monitoring will either be automatic (passive) or through appointment (active). Automatic monitoring will see patients uploading their observations and wellbeing score on an approved app. If these remain within the mild range during the period, then there is no need for clinical intervention or advice. Clinical input is only sought through deterioration of concern. In virtual wards that apply automated monitoring, less input is needed from the resources overseeing it. Appointment monitoring is where staff contact the patients at agreed intervals for their observations and wellbeing score. Appointment monitoring is more applicable to an infrastructure that does not have suitable digital platforms to enable automatic monitoring or monitoring certain cohorts of patients that may struggle using an app (e.g. those with dementia, learning disabilities, impairments, stroke etc). As with automatic monitoring, clinical input may only be sought should there be a concern regards deterioration.

2.3 Setting up a service

How a virtual ward service is set up is left to the discretion of each locality. The service should be primarily concerned with:

- Reviewing the health and well-being of a patient with confirmed or suspected COVID-19 by using observation tools to assess the severity of COVID-19 related symptoms, and where applicable,
- Taking in to account the broader health picture, such as higher risk factors of deterioration, or complications that can result in a deterioration of health and admission.

Therefore, careful consideration needs to be given as to who is involved, and how the service links to other specialists, and care co-ordinators. Services can be formed from existing resources but will require oversight from senior clinicians.

Further supportive information can be found on: <u>https://future.nhs.uk/</u>

Refer to section 3 – Considerations in setting up a virtual ward (or equivalent)

Procedures will have to be put in place to ensure discharges from hospital out of area, are carried out by the appropriate team.

2.4 Recording of virtual ward information

The recording of the data as part of the virtual ward process is at the discretion of each locality, but it would help to have consistent fields for comparative purposes such as those outlined in appendix a.

Data captured as part of the virtual ward process would likely include that outlined in the referral, plus, the risk category, oxygen saturation and NEWS2 score, admissions, and home visits during the process. In addition, complications and co-morbidities may be recorded.

Information would be stored using appropriate data protection means.

3.0 CONSIDERATIONS IN SETTING UP VIRTUAL WARDS (OR EQUIVALENT) IN A LOCALITY

The following are some options for consideration in setting up a virtual wards (equivalent) in a locality. Where choices feature exclusions, assurances will be sought to ensure localities consider the recovery of all patients concerned.

Categories	Options
Funding	A. Use of internal hospital resources and budgets
	B. Use of both hospital/community budgets
	C. Use of community budgets
	D. Specific COVID-19 fund, where available
	E. Innovation funds, where available
	F. Charitable funds, where appropriate and available

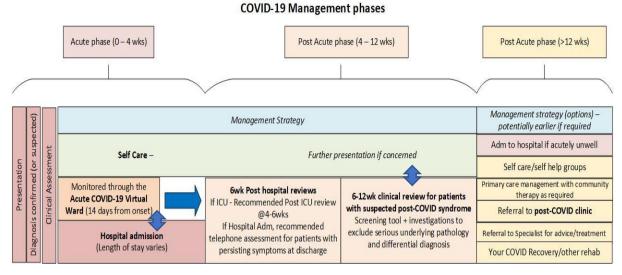
Scope	 A. Confirmed COVID-19 only B. Confirmed and suspected COVID-19/COVID-19 like illness C. All high-risk cohorts >=65yrs, co-morbidity, BAME, Low socioeconomic status or gender (male). D. Specific high-risk cohorts only E. Referrals from specific sources (e.g. hospital discharges (acute and MH trusts), ED, care homes, NWAS, community etc)
Population coverage	 A. One virtual ward (or equivalent) per locality B. Multiple virtual wards or equivalent (e.g. one hospital ward and community level wards(s))
Resources	 A. Hospital led/community led? B. Respiratory led/General medicine led/generalist /Multi- disciplinary/ Led by other discipline C. Who will staff the virtual ward? (e.g. clinical, non-clinical with clinical supervision) D. The days and times it functions (including OOH cover) E. Appointed leads F. Links to other specialists / pathways
Assessments and observations	 A. Who will carry out the initial assessment? B. Who will provide the oximeters and diary? C. Have enough oximeters been ordered to cover your population? (recommendations are for 30 per Primary Care Network, and 1 per 1000 hospital resident population – see appendix b for estimates) D. Who will collect and chase returning oximeters and diaries? E. How will non COVID health issues be recorded and escalated where necessary? F. Automatic and/or appointment monitoring (defining which cohorts may need appointment monitoring e.g. delirium, stroke, dementia, leaning disabilities etc)
Technologies and data links	 Home visits should be considered when technologies are not available or suitable. A. Telephone only B. Telephone/video C. Telephone/video/telemedicine's/home equipment/apps Other technologies required on top of patient administration systems may include Graphnet, Winscribe, Medisec, the COVID tracker and business intelligence tools/research tools to ensure data linkage and to support continued ongoing research A. How will you refer to the virtual ward (or equivalent)?

	B. How will observations be fed to the virtual ward (or					
	equivalent) e.g. verbally, through an app, or using other tools etc?					
	C. How will the virtual ward (or equivalent) staff know which patients to contact/discharge etc?					
	D. Will/can the virtual ward (or equivalent) records be shared?					
Interdependencies	Consideration should be given to leads in the following areas:					
	 Primary care (GP lead/community lead/Hot clinic lead) Information technology Home oxygen 					
	Business intelligence and/or research					
	GovernanceLong term recover programmes					
	Community teams (where not already included)					
	 Specialists not part of the follow ups (for a broad list of potential specialists refer to figure 3: An illustration to help structure COVID-19 person centred rehabilitation and longer term recovery) 					
Data collection and	Localities need to agree the data to be collected as part of the					
evaluation	process to evaluate the effectiveness of virtual wards (or equivalent), and to inform a cycle of continued learning. Considerations as to:					
	A. The data fields to be collected					
	B. The business intelligence tools to extract them					
	C. The frequency of reporting					
	D. Data quality					
	Examples as to what data can be collected can be found in appendix a.					

4.0 SUPPORTING PEOPLE IN THE POST ACUTE PHASE: FOLLOW UPS / CLINICAL ASSESSMENTS

The presentation and management of COVID-19 can be broken down in to 2 main phases; the acute phase (0-4 weeks) and the post-acute phase (>4 weeks); the latter featuring 'post COVID syndrome' which is typically symptoms lasting 12 weeks or more. Management within these phases should be seamless (refer to fig. 6).

The post- acute phase between 4 and 12 weeks is characterised by patient reviews that may feature further investigation and a clinical assessment to determine further management options. Such options may include referral to a post-acute COVID-19 clinic, if post COVID syndrome is suspected.



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

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

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

Clinical judgement will be used during planned or unplanned post COVID-19 clinical appointments, as to what services and treatments are offered. Clinical judgement will take in to account the patient's overall health, diagnostics, any new or persistent symptoms and health trajectory.

As per figure 2, a number of options remain open to clinicians at any given time that include:

Tier 1 services: Self-management strategies - such as online help/programmes, weight management, smoking support, medications, peer support etc

Tier 2 services: Primary care support – referral to clinicians within the community such as mental health, physiotherapy, occupational therapy, rehabilitation etc

Tier 3 services: Specialist support from secondary care – either specific specialists for condition specific problems, post COVID-19 clinics where post COVID-19 syndrome is suspected (>12wks), or post ICU support.

Tier 4 services: And multidisciplinary specialist support where a patent has very complex, multisystem health problems.

4.1 Post-Acute COVID Clinics for post COVID-19 syndrome (>12wks)

A post acute COVID clinic for post COVID-19 syndrome is typically a tier 3 service, although, tier 2/3 hybrid models may be used where agreed appropriate.

The service needs to be clearly identified within a locality, with primary care and other secondary care services made aware, enabling referrals can be made and received.

On receipt of a referral, a patient needs to be triaged, and appropriate patients assessed. This includes the holistic assessment outlined in figure 3. Assessments can either happen prior to an appointment that determines a treatment plan, or within the same appointment depending on the service being provided.

The assessment by the clinic should be led by a clinician who is able to ascertain the extent of rehabilitation needs and is aware of the service options available to the patient within the locality. Many existing post-acute COVID-19 clinics are led by respiratory consultants with referral to other teams as needed. Localities may wish to consider other innovative approaches to how their clinics are led and the workforce. It is suggested other members of the MDT including physiotherapists can provide strong support for assessment of respiratory function, strength and exercise tolerance. Additionally, occupational therapists can provide a personalised and occupation-focused approach to assessment such as cognition, delirium, mental health (fear, anxiety and mood), and functional outcome, independence and activity measures, including support for self-management and social prescribing.

The 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 as soon as possible.

Outcomes from the assessment are to 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
- Specialist intervention through referral as appropriate
- 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).

Local Post Acute 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

Health inequalities - clinics should be supportive to those with learning disability and autism and be aware of diagnostic overshadowing (*refer to appendix D*).

How these clinics are provided is to the discretion of the locality. 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).

4.2 Post-ICU Clinics for COVID-19

It is recommended there be a collaboration between post-acute COVID-19 clinics and Post-ICU clinics (where they both exist) to determine who takes responsibility for the rehabilitation of post-COVID-19 ICU patients that are discharged from hospital.

Where transfers occurred between ICU's there needs to be an agreement as to which post ICU clinic takes on the responsibility for the Post-ICU clinic assessment. National guidance suggests 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.

Following admission for severe COVID (ICU or requiring CPAP) an initial 4-6 week telephone or virtual follow up is recommended.

As with post-acute COVID clinics guidance advocates an assessment within 4-6 weeks of a patients discharge from hospital. Referrals before this timeframe should occur if significant symptoms are evident.

The assessment should be led by a clinician who is able to ascertain the extent of rehabilitation needs and is aware of the service options available to the patient within the locality. The 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 as soon as possible.

Outcomes from the assessment are to 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
- Specialist intervention through referral as appropriate
- 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).

Various post ICU recovery clinic services exist, from 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). How these clinics are provided is to the discretion of the locality.

For further details refer to COVID-19: Guidance for the commissioning of clinics for recovery and rehabilitation.

AMU BTS	Activities of Daily Living Acute Medical Unit British Thoracic Society Clinical Assessment Services
BTS	British Thoracic Society Clinical Assessment Services
	Clinical Assessment Services
CAS	
0/10	Continuous Positivo Airwov Processo
CPAP	Continuous Positive Airway Pressure
CTPA	Computed Tomography Pulmonary Angiogram
CXR	Chest X-Ray
ECG	Echocardiogram
ED	Emergency Department
GM	Greater Manchester
GP	General Practitioner
HDU	High Dependency Unit
HR	Heart Rate
HRCT	High Resolution Computed Tomography
ICU	Intensive Care Unit
ILD	Intestritial Lung Disease
LTOT	Long Term Oxygen Therapy
MDT	Mulit-disciplinary Team
NEWS	National Early Warning Score
02	Oxygen
OP	Outpatient
PCN	Primary Care Network
PE	Pulmonary Embolism
PFTS	Pulmonary Function Test
PH	Pulmonary Hypertension
PHE	Public Health England
PPE	Personal Protective Equipment
RAC	Rapid Access Clinics
RR	Respiratory rate
SOB	Shortness Of Breath
VW	Virtual Ward

GLOSSARY OF TERMS

5.0 APPENDICES

APPENDIX A – INFORMATION RECOMMENDED FOR COLLECTION

Core information	Essential information captured	Desirable information to be captured
Core information Unique reference Name Age Gender Ethnicity Post code GP Practice code Episode of care Co-morbidity	Essential information captured Diagnosis code COVID-19 confirmed/suspected - Test positive (Y/N/No test/awaiting result) Severity Episodic care Presentation (service e.g. GP, ED, OP etc) Presentation date Follow up dates Number of follow ups Diary + oximeter readings NEWS2 Scores, other observations such as Heart Rate, respiratory rate Follow up contact (face to face or phone) Contact by professional 999 Admission (hospital)	Co-morbidites (long term conditions/mental health/cancer/other relevant diagnosis) Related Complications (subsequent diagnosis codes e.g. Pneumonia, Pulmonary Embolism, Renal problems, Gastroenterology etc) Treatments Continuous positive airway pressure (CPAP), Oxygen, Long Term Oxygen Therapy (LTOT), Max flow rate etc) Diagnostics (Chest X-ray (CXR), Computerised tomography pulmonary angiogram (CTPA), Electrocardiogram (ECG), Echocardiogram, Renal function, High Resolution Computerised Tomography (HRCT), Pulmonary Function Test (PFT)) Rehabilitation referral Rehabilitation attendance
	Admission date Admission method	Rehabilitation attendance Rehabilitation completion
	Finished consultant episode (dates) Finished consultant episode (speciality) Ward	

Hospital discharge (date) Discharge destination	

Useful comparative information

Demand

- Where patients present in each locality,
- How often,
- The average number of follow ups,
- Referrals,
- Oximeter demand,

Behaviours and illness

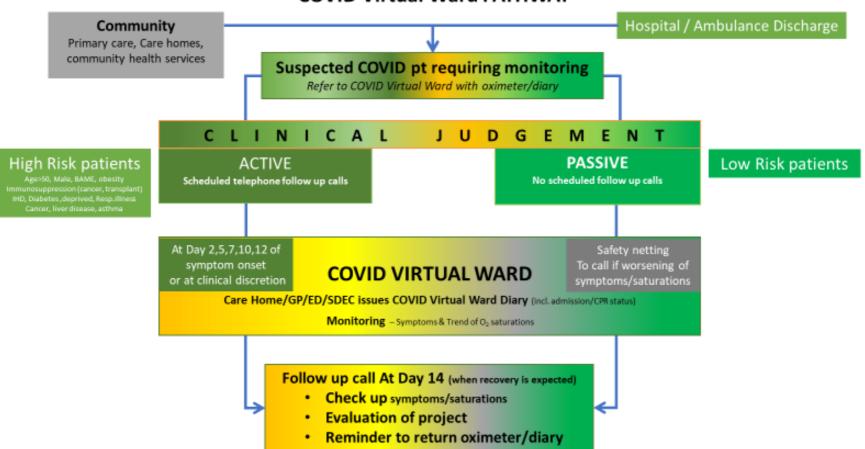
- Severity
- Health upon presentation and early detection
- Outcomes improvement/deterioration (by severity, high risk / non high risk groups, admission or hospital presentation avoidance),
- Mortality (by severity, high risk / non high risk groups)

APPENDIX B – ESTMATED OXIMETERS REQUIRED FOR VIRTUAL WARDS (OR EQUIVALENT) – BASED ON GUIDANCE

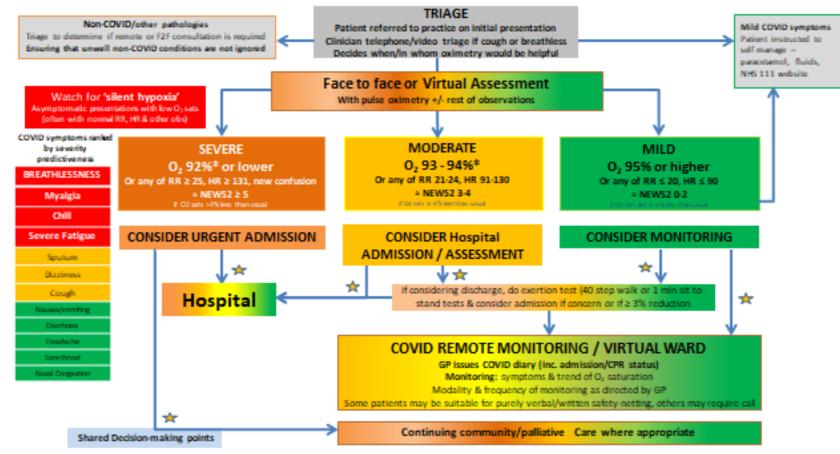
	Populations *	No. of PCN's	Approximate no. of community oximeters required for VW's (based recommendations of 30 per PCN)	Hospital Trusts	Approximate no. of Trust pulse oximeters required collated (based recommendatio ns of 1 per 1000)	Approximate no. of Trust pulse oximeters required collated (based recommendatio ns of 1 per 1000)	Total require d to cover locality
NHS Bolton	287,550	9	270	Bolton	288	288	558
NHS Bury	190,990	4	120	Pennine	191		311
NHS Heywood, Middleton and Rochdale	222,412	6	180	Pennine	222	650	402
NHS Oldham	237,110	5	150	Pennine	237	1	387
NHS Trafford	237,354	5	150	Manchester	237	790	387
NHS Manchester (Nrth, Sth, Central)	552,858	14	420	Manchester	553	790	973
NHS Salford	258,834	5	150	Salford	259	259	409
NHS Stockport	293,423	7	210	Stockport	293	293	503
NHS Tameside and Glossop	260,063	5	150	Tameside and Glossop	260	260	410
NHS Wigan Borough	328,662	7	210	Wigan	329	329	539
		67	2010		2869	2,869	4879

Populations* - resident populations based on 2019 office of national statistics estimates

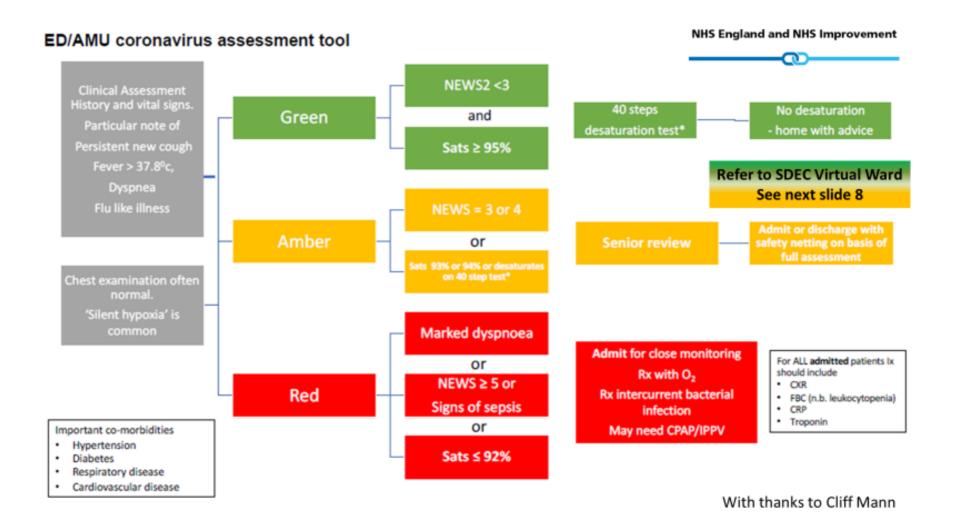
APPENDIX C – NATIONAL PATHWAYS

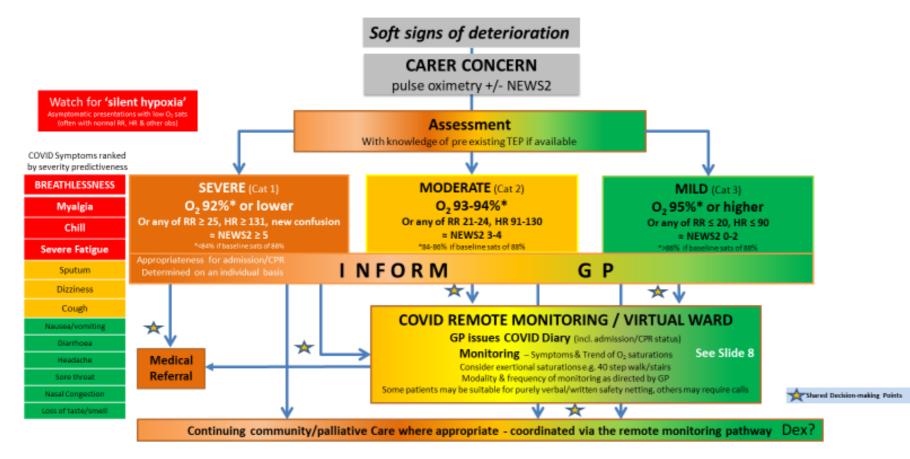


COVID Virtual Ward PATHWAY



ADULT PRIMARY CARE COVID ASSESSMENT PATHWAY





CARE HOME/COMMUNITY COVID ASSESSMENT PATHWAY

APPENDIX D: Guidance for post-acute COVID-19 Clinics: Information on learning disability and autism

- Think about your initial communications with anyone who may have a learning disability or is autistic and ensure these are reasonably adjusted consider the need for using augmentative communication methods (e.g. easy read) and determining the preferred method for communication.
- Include an expectation that the physical environment of clinics is suitable for people with a disability including location, accessibility, low sensory environments for autistic people (please think about lighting, noise level etc)
- An expectation that providers, when setting up the clinic, will co-produce the care pathway with patients with a learning disability, particularly ensuring that there are good, accessible referral routes into the service from GPs, community learning disability teams, acute hospitals, care and nursing homes
- Importance of proactively asking about the need for and making reasonable adjustments, a requirement under Equalities legislation, to care for people with a disability: for people with a learning disability this may include easy read or accessible written information/ information in other formats such as spoken word or film, people needing to be accompanied at appointments by family or a carer, having a quiet waiting room for autistic people, information captured on Care Summary Record and Reasonable Adjustments Digital Flag (where available)
- An expectation that providers will have ways to capture information about who is using the service including identifying people with a learning disability and autistic people/people with protected characteristics and having mechanisms for reviewing this data to check that people are accessing the service in line with expected demography. People with a learning disability are at least as likely to become ill with Covid-19 as the general population and the presence of co-existing conditions may in fact make them more vulnerable, therefore providers need to be proactive in reaching out to people with a learning disability and autistic people
- Need to include an expectation that providers of clinics will have an explicit strategy for ensuring that the service is accessible to people with a learning disability and autistic people which includes: recognition that people with a learning disability might not have the health literacy to recognise that they have long Covid or be able to describe the symptoms or that the symptoms might look different for a person with a disability. It is particularly important that the clinical ask the key question of the person/family/carer- how are you compared to life before Covid-19? There's a campaign #KnowYourNormal to help autistic people describe what they feel like when they are well compared with when ill https://www.ambitiousaboutautism.org.uk/what-we-do/youth-participation/youth-led-toolkits/know-your-normal
- We would expect providers to have an easy read version of what long Covid is. We would expect clinicians to know how it might be different for a person with a learning disability including a reference to diagnostic overshadowing that includes information and support for GPs in terms of identifying that a person with a learning disability or autistic person is experiencing long Covid rather than an issue related to their disability
- Consider the needs of individuals who may need support and how the service can be reasonably adjusted to ensure individuals can have a carer or supporter with them if they need this which may be contrary to usual processes for Covid-19 attendance at health appointments

Information about people with a learning disability and autistic people

In 2018/19 at least 41% of people with a learning disability who died, died as a result of a respiratory condition. There is therefore, strong reason to suspect that people with a learning disability may be significantly impacted by the coronavirus pandemic.

People with a learning disability have higher rates of morbidity and mortality than the general population and die prematurely. They have a higher prevalence of asthma and diabetes, and of being obese or underweight in people; all these factors make them more vulnerable to coronavirus. There is evidence that people with autism also have higher rates of health problems, both physical and mental health, throughout childhood, adolescence, and adulthood, and that this may result in elevated risk of morbidity and early mortality.

People with a learning disability might be dependent on others for support in activities of daily life, and some will live in communal residential settings - which adds to vulnerability and their needs in relation to long term debilitating symptoms.

Approach to supporting people with a learning disability and people with autism

- Be aware of diagnostic overshadowing: This occurs when the symptoms of physical ill health are mistakenly either attributed to a mental health/behavioural problem or considered inherent to the person's learning disability or autism diagnosis. People with a learning disability have the same illnesses as everyone else, but the way they respond to or communicate their symptoms may be different and not obvious. Their presentation with long Covid may be different from that for people without a learning disability.
- Pay attention to healthcare passports: Some people with a learning disability and some people with autism may have a healthcare passport giving information about the person and their health needs, preferred method of communication and other preferences. Ask the person and/or their accompanying carer if they have one of these.
- Listen to parents/carers: The family or carer will have a wealth of information about the individual and how they have been, including any other comorbidities and the medication the person is taking. Listen to them as well as the person you are caring for. They know the person who is unwell best. They also know how the person's current behaviour may differ from usual, as an indication that they are unwell. The family or carer may have short videos of the person to give you an idea of their usual self. But remember the carer they come in with may not be their usual carer at this unusual time.
- Make reasonable adjustments: This is a legal requirement and is important to help you make the right assessment decisions for an individual. You can ask the person and their carer/family member what reasonable adjustments should be made. Adjustments aim to remove barriers, to do things in a different way, as well as to provide something additional to enable a person to receive the assessment and treatment they need. Examples include: allocating a clinician by gender, taking blood samples by thumb prick rather than needle, providing a quiet space to see the patient away from excess noise and activity.
- Communication: Communicate with and try to understand the person you are caring for. Check with the person themselves, their family member/carer or their hospital/communication passport for the best way to achieve this. Use simple, clear language, avoiding medical terms and 'jargon' wherever possible. Some people may be non-verbal and unable to tell you how they feel. Pictures may be a useful way of communicating with some people, but not all.

- Understanding behavioural responses to illness/pain/discomfort: A person with a learning disability and some people with aut ism may not be able to articulate their response to pain in the expected way: eg they may say that they have a pain in their stomach when the pain is not there; may say the pain is less acute than you would anticipate; or not say they are in pain when they are. Some may feel pain in a different way or respond to it differently: eg by displaying challenging behaviour; laughing or crying; trying to hurt themselves; or equally may become withdrawn or quiet. People who are wheelchair dependant may have chronic pain. Understanding what is 'normal' for that person by talking to them, their family and carers, is crucial to helping with assessment and diagnosis. You can use pictures to help establish whether a person is in pain and where that pain is.
- Mental Capacity Act: People with a learning disability and people with autism do not automatically lack capacity. Assess capacity in line with the person's communication abilities and needs, and remember the principle of the Mental Capacity Act in making appropriate efforts and adjustment to enable decision making wherever possible.
- Ask for specialist support and advice if necessary: e.g community learning disability team/acute hospital liaison nurse can help you with issues of communication, reasonable adjustments, assessment of pain.
- Mental wellbeing and emotional distress: It is estimated that 40% of adults and 36% of children and young people with a learning disability and or with autism experience mental health problems. Change in routine can have a big effect on their emotional and mental wellbeing. In a clinic setting, masks and protective clothing may frighten them, make them more anxious and lead to adverse behaviours, such as hurting other people, hurting themselves and destroying property. Do not assume that this is an indication of mental illness and do your best to work with the person who is unwell, their carer or family member to find out how best to keep them calm and relaxed.

Useful links

Speciality guidance on caring for people with a learning disability and autistic people: <u>https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/C0031 Speciality-guide LD-and-coronavirus-v1 -24-March.pdf</u>

My pain profile helps you identify the signs that someone is in pain: <u>https://www.dyingmatters.org/sites/default/files/user/images/pain%20assessment%2</u> 0tool%20Notts%20final%20doc.pdf

The Disability Distress Assessment Tool (DisDAT) is based on the idea that each person has their own 'vocabulary' of distress signs and behaviours: https://www.wamhinpc.org.uk/sites/default/files/Dis%20DAT_Tool.pdf

Non-Communicating Adults Pain Checklist (NCAPC) is an 18-item checklist that helps you assess chronic pain in non-communicating adults. <u>https://cpb-use1.wpmucdn.com/wordpressua.uark.edu/dist/9/300/files/2017/04/NonCommunicating-Adult-Pain-Checklist.pdf</u>

Wong and Baker's FACES Pain Rating Scale uses pictures of faces to help people communicate pain intensity from 'no hurt' to 'hurts worst': <u>https://wongbakerfaces.org/instructions-use/</u>

Information on the Mental Capacity Act:

• <u>https://www.nhs.uk/conditions/social-care-and-support-guide/makingdecisions-for-someone-else/mental-capacity-act/</u> • <u>https://www.mencap.org.uk/advice-and-support-guide/makingdecisions-for-someone-else/mental-capacity-act/</u>

Mental wellbeing: https://theconversation.com/how-coronavirus-could-affect-thewellbeing-of-people-with-intellectual-disabilities-133540

APPENDIX E: Newcastle post-COVID syndrome Follow-Up Screening Questionnaire

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

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

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

Most patients who experienced severe symptoms during the acute phase will have residual problems such as fatigue, breathlessness, and poor sleep quality for several weeks. For the majority, these symptoms will resolve, albeit slowly. Unless there are very unusual features, the most appropriate course of action early in the post-acute phase may be advice on graduated physical rehabilitation and the passage of time.

A small proportion of patients however will go on to have symptoms that persist beyond 12 weeks, a condition commonly known as 'Long COVID'. Such individuals require more detailed investigation and are likely to need more intensive and specialist support.

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

Section 1 (to be completed pre call)

Name.....

NHS number

Date of Positive Swab.....

Date of Onset of symptoms.....

Date of Discharge (for hospital admissions)

Date of call _____

Person phoning _____ Role _____

Level of respiratory support during acute Illness:

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

Supplemental oxygen Managed in the community

Section 2

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

Symptoms Full Recovery

2. Are you more breathlessness than you were before you COVID illness?

a. Is this more than you would have expected by now?

or

b. Do you think you're on your way back to full fitness?

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

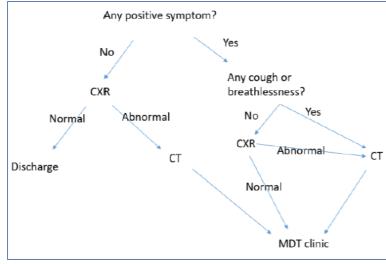
a. Is this more than you would have expected by now?

Or

- b. Do you think you're well on your way back to full fitness?
- 4. Do you have a cough (different from any cough you may have had before COVID-19)? Yes No
- 5. Do you get any palpitaions (sense that you can feel your heart pounding or racing) Yes No
- 6. How's your physical strength? Do you feel so weak that it still limiting what you can do (more than you were pre your COVID illness)? Yes No
- 7. Do you have any myalgia ('aching in your muscles')? Yes No
- 8. Do you have Anosmia ('no sense of smell')? Yes No

- 9. Have you lost your sense of taste? Yes No
- 10. Is your sleep disturbed (more than it was pre-COVID)? Yes No
- 11. Have you had any nightmares or flashbacks? Yes No
- 12. On your mood
- c. Is your mood low/do you feel down in the dumps/lacking in motivation/no pleasure in anything? Yes No
- d. Do you find yourself feeling anxious/worrying more than you used to? Yes No
- 13. Have you lost weight (> 1/2 stone, 3 Kg) since your COVID illness? Yes No
- 14. Any other symptoms (list)





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