

**NHS Standard Contract - Service Specification**

<b>Service Specification</b>	<b>V4.0. 18th Jan 2021</b>
<b>Service</b>	<p><b>Post-Acute COVID-19 services and clinics to support and manage ‘post COVID-19 syndrome’ in adults</b></p> <p><i>Includes detail on:</i></p> <p><i>Tiers 1-4 services</i></p>
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<b>Provider Lead</b>	<p>Manchester NHS Foundation Trust (MFT) to act as lead provider with Northern Care Alliance (NCA) as key provider for the GM System.</p> <p>SROs – Professor Jane Eddleston and Dr Chris Brooks on behalf of the GM Partnership Medical Executive</p>
<b>Period</b>	<b>December 2020 onward</b>
<b>Date of Review</b>	<b>April 2021</b>

**1. The acute and post-acute phase of COVID-19**

The presentation and management of COVID-19 can be broken down in to 3 main phases;

- Acute COVID-19: signs and symptoms of COVID-19 for up to 4 weeks.
- Ongoing symptomatic COVID-19: signs and symptoms of COVID-19 from 4 to 12 weeks.
- Post-COVID-19 syndrome: signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis (NICE 2020).

It is expected, management across these phases should be seamless

In addition to the above, the term “Long COVID” has been commonly used to describe signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more).

The post- acute phase (>4 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 secondary care service (tier 3), if post COVID-19 syndrome is suspected.

This service specification outlines the approach to supporting those with confirmed or suspected COVID-19, in the post-acute phase >4 weeks; with particular attention to those between 4 and 12 weeks and greater than 12 weeks.

## 2. Rationale and Population Needs

### 2.1 National context

At present, it is recognised that:

- Many people experiencing ongoing health effects following COVID-19 infection managed their condition independently at home while acutely infected. It is also recognised that not all patients seriously impacted in the longer term were hospitalised or had a positive Severe Acute Respiratory Syndrome by Corona Virus 2 (SARS-CoV-2) test.
- The number of patients who need post-COVID syndrome management focusing on recovery and rehabilitation is likely to grow as COVID-19 infection rates continue to rise.
- People with post-COVID syndrome have reported that whilst GPs have been sympathetic, some have been unsure how to refer into treatment services.
- 67% of GPs surveyed reported that they are looking after patients with COVID-19 symptoms lasting longer than 12 weeks.
- There is increasing evidence that COVID-19 has a disproportionate impact on those in deprived populations and people in black and ethnic minority groups, and thus exacerbates existing health inequalities.
- In patients discharged from hospital with COVID-19, 34% had cough and 69% had fatigue. 14.6% had depression following follow up for a median average of 54 days (Mandal. Thorax 2020). Based on figures from this study, and others; it is reasonable to assume that around 10% of those admitted will need long term input for ongoing symptoms (<https://www.bmj.com/content/371/bmj.m3981>)
- Academic publications have estimated that 10-20% of people are still unwell after 3 weeks and 1-3% are still significantly unwell after 12 weeks (Tenforde et al. MMWR 2020).
- This is supported by a prospective study using the COVID Symptom Study app (yet to be published), that found around 4.5% had symptoms lasting more than 8 weeks and 2.3% longer than 12 weeks (Carole H. Sudre 2020).
- NHS England / Improvement are looking to ensure the rapid establishment of clinics to manage post COVID-19 syndrome, by publishing commissioning guidance, and allocating funds to local health systems.
- NHS England / Improvement have allocated funds to General Practices to support seven objectives. The third objective is: *First steps in identifying and supporting patients with Long COVID.*

### 2.2 Local context

- GM has additional challenges that impact on population health. These include areas of deprivation and vulnerable population demographics such as multiple occupancy homes, high prevalence of chronic lung, cardiac and diabetic conditions known to lead to more serious consequences of infection.
- Taking into account the GM population and the results from the above studies, estimates suggest anywhere between 600 and 2400 patients diagnosed in October 2020 will experience symptoms that may require multidisciplinary specialist support January/February 2021 (refer to appendix one). However, it should be noted, these are crude estimates and accurate predictions remain difficult due to a number of variables.

## 3. Pathways, guidance and approach

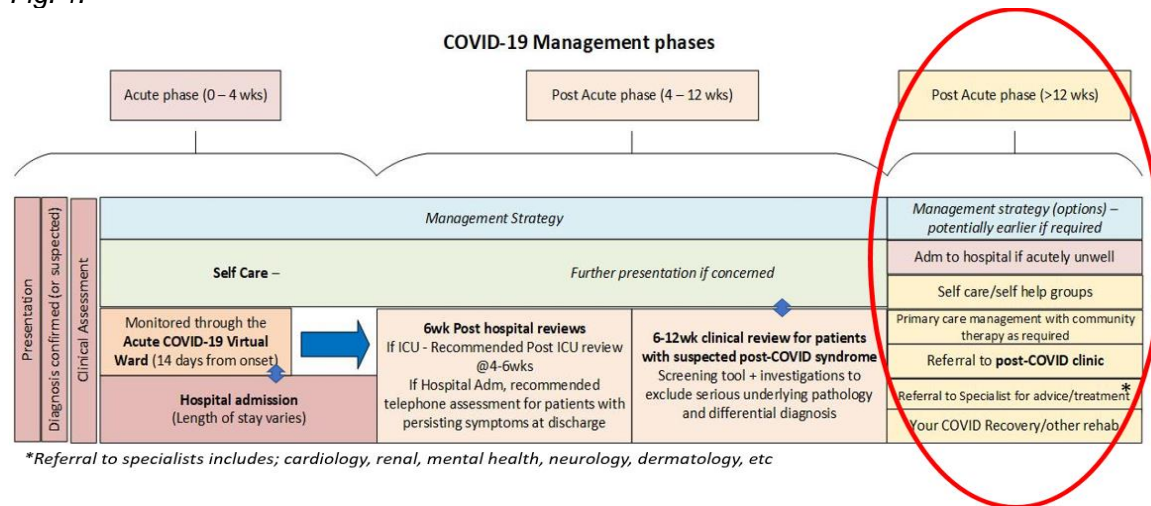
### 3.1 Pathway and guidance

There are four main routes to supporting people with confirmed or suspected COVID-19 during the post acute phase:

- Self management support (with information and available tools)
- Support using primary care services
- Support using secondary care services, and
- Hospital admission where appropriate

As highlighted in section 1 and in the following figure, the process is fluid, with escalation and de-escalation where necessary.

Fig. 1.



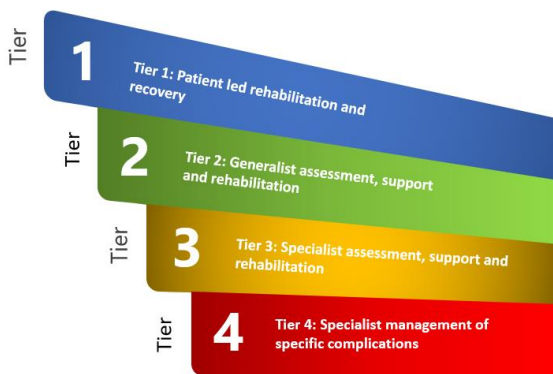
In the delivery of this service, the provider will adhere to the latest *guideline to supporting the recovery and rehabilitation of adults with confirmed or suspected COVID-19 in Greater Manchester (2021)*.

### 3.2 Tiered approach to the management of Post-Acute COVID-19

Whilst the pathway in fig.1 outlines a linear approach to managing COVID-19, the following figure outlines a management model weighted by the level of intervention necessary (see fig.2).

Typically, the higher the tier, the more resource intensive. Comparatively, it is likely the higher the tier, the fewer patients requiring it.

Fig. 2



The tiers can be summarised as follows:

**Tier one:** Self-management support (with information and available tools)

**Tier two:** Support using primary care services

**Tier three:** Support using secondary care services, and

**Tier four:** Highly specialist input and rehabilitation for complex patients

The interventions carried out in each tier are as follows:

#### **Tier 1 (Self-management as advised by primary care)**

- ✓ Information and Education/material provided about the disease and recovery and options for self-management, this should include advice to carers and family's where available.
- ✓ Referral to Your COVID recovery
- ✓ Self-monitoring and reporting back to GP with worsening and low mood. symptoms such as breathlessness, fatigue, chest pain
- ✓ Voluntary sector and social support

**Tier 2 (primary care)**

- ✓ Therapeutic relationship with a generalist clinician (e.g. GP, Advanced Nurse Practitioner, Physiotherapist, Occupational Therapist) who takes responsibility for the patient's overall care and helps them navigate the system
- ✓ Full history, clinical examination including functional and psychiatric assessments
- ✓ Confirm that Post COVID-19 syndrome is likely (even in the absence of a positive test); or, if not, other possible diagnosis and document in the medical record
- ✓ Basic tests (e.g. bloods, X-rays, exercise tolerance tests, blood pressure, pulse oximetry etc) if appropriate to exclude alternative diagnoses (e.g. sepsis) and rule out serious complications. Note: not all patients will need such tests
- ✓ Rehabilitation support (remote or face to face - examples include; referral to community based pulmonary rehabilitation, cardiac rehabilitation, smoking support, weight management programmes)
- ✓ Ongoing monitoring and support (e.g. by telephone, video, or in-person check-ups) as needed
- ✓ Management of other long-term conditions (e.g. diabetes, asthma)
- ✓ Offer advice and guidance to tier 3 of what services are locally available
- ✓ Referral to Tier 3 as appropriate
- ✓ Referral to Improving Access to Psychological Therapies or psychiatric services as appropriate (see mental health service guide)
- ✓ Use of validated screening tools for cognitive/mental health identification and triage
- ✓ Use of social prescribing

**Tier 3 (Secondary care/ MDT)**

- ✓ Dedicated COVID-19 service/clinic (usually respiratory but sometimes neuro- and/ or cardiac)
- ✓ Personalised rehabilitation plan with (e.g.) breathing exercises, supervised pacing and psychological support
- ✓ Referral to other specialties as appropriate e.g. cardiology, neurology, haematology, psychiatry or Multidisciplinary (MDT) approach within clinic itself
- ✓ Testing according to specialist guidelines (e.g. Computerised Tomography (CT), Magnetic Resonance Imaging (MRI))
- ✓ Dialogue and agreed division of responsibility between specialties, Intensive Care Unit (ICU) and primary care.
- ✓ Offers advice and guidance to tier 2 services

**Tier 4 (Tertiary care/ MDT)**

- ✓ Management of specific conditions (Interstitial Lung Disease (ILD)/ Chronic thromboembolic pulmonary hypertension (CTEPH)/ Transplant)
- ✓ Tertiary neuro-rehabilitation and neuropsychology
- ✓ Chronic Fatigue syndrome services
- ✓ Access to other Mental Health (MH) services

**4. Clinical Coding**

**SNOWMED-CT Coding**

- Acute COVID-19 infection (1325171000000109)
- Ongoing symptomatic COVID-19 (1325181000000106)
- Post-COVID-19 syndrome (1325161000000102)

**5. Tier 1 services**

Tier 1 will include services and tools to enable and support self-management. Information may also include contact details should symptoms change or worsen.

These are signposted by tier 2 services (and where necessary tier 3) for patients who do not require ongoing support from primary and secondary care.

Tier 1 services will include:

1. The provision of general information and advice about COVID-19 that encompasses:
  - a) Information about new or continuing symptoms of COVID-19 that the person can share with their family, carers and friends.
  - b) ways to self-manage their symptoms, such as setting realistic goals,
  - c) details of existing local services that accept self-referral,
  - d) sources of advice and support, including support groups, social prescribing, online forums and apps, social care, housing, employment/return to work, and advice about financial support
2. The provision of educational material, like leaflets, on self-help tools that are available locally, and
3. The offer of referral to Your COVID Recovery (if appropriate).

Rehabilitation in tier 1 pertains to personalised self-help goals that are accessible through self-referral where available or via GP's. Examples include; online Cognitive Behavioural Therapy (CBT) programmes, smoking support services, active lifestyle management courses, weight loss programmes, or social / peer support groups.

Appropriate coding needs to be entered within the Electronic Patient Record (EPR) or equivalent digital systems.

## 6. Tier 2 services

Tier 2 services are provided throughout the COVID-19 recovery pathway:

- During the acute phase / post-acute phase when a patient remains in the community under the care of their GP or other primary care service
- During the post-acute phase when a patient either undergoes a clinical review or self presents, and
- During the post-acute phase to support the management of ongoing symptomatic COVID-19 (>4 weeks), or post COVID-19 syndrome (>12weeks) where secondary care intervention is not deemed necessary.

The primary aim of tier 2 services is to identify and support patients with post-acute COVID-19; and where possible those with post COVID-19 syndrome (in accordance with the 7 priorities outlined by NHS England / Improvement).

Tier 2 services are mainly primary care-led services that:

- 1- Offer an initial consultation for those concerned about Post COVID-19 syndrome (>4 weeks). This can be either face to face, via telephone, or via video.
- 2- Review cases where post COVID syndrome is likely and assess as per locality agreement
- 3- Provide initial assessments, diagnostics, and advice and treatment.
- 4- Link to expertise from within primary and social care
- 5- Link to expertise within secondary care capitalising on existing routes like advice and guidance or Consultant Connect
- 6- Triage patients into the most appropriate care pathway; including initiating urgent referrals to appropriate specialist services (i.e. chest pain clinics, oxygen service, multi-system inflammatory syndrome services in children)

### 6.1 Assessments and Follow ups

Assessments and/or follow ups by an appropriately skilled clinician (Doctor/Nurse/Allied Health Professional (AHP)) within primary care for:

- A planned review of a non-hospitalised patient following referral from home oximetry/virtual ward models of care (>4 weeks post diagnosis/first symptoms) as appropriate
- A planned review of a hospitalised patient where locally agreed >4 weeks post discharge
- An unplanned review of a patient experiencing post-acute COVID-19 symptoms either through self-presentation or referral from another service, at any point (usually >4 weeks)

Assessments will include:

- Full history, clinical examination and functional assessment
- Basic tests:

- a) Offering blood tests, which may include a full blood count, kidney and liver function tests, C-reactive protein test, ferritin, B-type natriuretic peptide (BNP) and thyroid function tests.
  - b) If appropriate, offering an exercise tolerance test suited to the person's ability (for example the 1-minute sit-to-stand test). During the exercise test, recording the level of breathlessness, heart rate and oxygen saturation.
  - c) For people with postural symptoms, for example palpitations or dizziness on standing, carrying out a lying and standing blood pressure and heart rate recordings (3-minute active stand test, or 10 minutes if suspected postural tachycardia syndrome, or other forms of autonomic dysfunction).
  - d) Offering a chest X-ray by 12 weeks after acute COVID-19 if the person has not already had one and they have continuing respiratory symptoms. *Chest X-ray appearances alone should not determine the need for referral for further care.*
  - e) Offering other tests where appropriate and available such as an Electrocardiogram (ECG), spirometry, an Echocardiogram, pulse oximetry, and standing blood pressure to exclude alternative diagnoses (e.g. sepsis) and explore COVID-19 complications. *Note: not all patients will need all these tests*
- The use of a standardised screening tool to determine if post COVID-19 syndrome diagnosis is likely (an example being the Newcastle post-COVID syndrome Follow-Up Screening Questionnaire; others are available – see appendix 3). This assessment is typically done >10 weeks post diagnosis or initial symptoms but can be done earlier or later.
  - Use of psychiatric assessment tools like the Psychiatric Health Questionnaire version 9 or the Generalised Anxiety Disorder Assessment version 7 at regular intervals

Assessment of cognitive function using validated tools like the “6 Items Cognitive Impairment Test”, which can be applied over the phone (<https://patient.info/doctor/six-item-cognitive-impairment-test-6cit>), or the “Addenbrooks Cognitive Examination” (<https://www.sydney.edu.au/brain-mind/resources-for-clinicians/dementia-test.html>)

Below are examples of outcomes from this assessment:

- Offer referral to rehabilitation services or exercise on prescription
- Offer ongoing monitoring and support (e.g. by telephone, video, or in-person check-ups) as needed
- Support the management of other long-term conditions (e.g. diabetes, asthma)
- Request further diagnostics as appropriate and as available within primary care localities
- Referral to other primary care services such as IAPT, psychiatric services (as per MH pathway currently under discussion), physiotherapy, smoking support services, as appropriate
- Referral to secondary care specialist services, where appropriate (i.e. direct referral to heart failure services for example). Some of these referrals maybe of an urgent nature based on clinical need.
- Referral to the post COVID-19 secondary care services (tier 3) as appropriate (either for clinical review or for advice and guidance). Some of these referrals maybe of an urgent nature based on clinical need.
- In some cases, facilitate urgent referral for a psychiatric assessment if there is an identified risk to the individual (like self-harm)

It is worth noting the following when post COVID-19 syndrome is suspected (NICE 2020):

- Clinical judgement will be used to determine the appropriate support for patients with post COVID-19 syndrome.
- Symptoms vary, and patient decisions need to be taken into account alongside clinical need.
- Not all patients with post COVID-19 syndrome will require tier 3 input. Referral to other primary care services will be considered where appropriate and available.
- Clinical advice will be sought by the locally identified post COVID-19 tier 3 service, where required.
- Referral to post COVID-19 services for post COVID-19 syndrome will be made (tier 3)

## 6.2 Workforce

Tier 2 services will offer (where available and applicable) access to community based:

- Allied Health Professionals (Physiotherapy, Dieticians, Occupational therapists)
- Mental health support services
- Peer support groups
- Rehabilitation programmes

- Nursing
- Smoking support
- Weight loss programmes
- Physical activity programmes/initiatives
- Social prescribing
- Pharmaceutical support
- Optometrists
- Dentistry

There must be local agreements with tier 3 services as to which services (other than the GP practice) that will assess and refer in to tier 3.

Tier 2 services will offer advice and guidance to tier 3 services when requested, as to what local support can be offered for a patient to aid their recovery.

### 6.3 Equipment

The provider will provide the tools and equipment to enable the necessary assessments. This also includes the necessary equipment to review results and liaise with the patients and/or their carer.

### 6.4 Accessibility and inclusion

All healthcare systems should consider health inequalities in the planning and delivery of post-acute COVID-19 care. This includes, but is not limited to:

- Being supportive to those with learning disability and/or autism or pre-existing mental health problems and being aware of diagnostic overshadowing (see here for further resources)
- Socio-economic inequalities
- Black, Asian and minority ethnic (BAME) group inequalities
- Lesbian, gay, bisexual and transgender plus (LGBT+) people
- Sex and gender
- Language and cultural barriers
- People with and existing disability such as visual or hearing impairment
- People in secure units
- Marriage and civil partnership
- Pregnancy and maternity
- Religion and belief

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

## 7. Tier 3 services

Tier 3 services are secondary care services that provide specialist assessments, diagnostics, advice and treatment.

Tier 3 services are provided throughout the COVID-19 recovery pathway: and through all phases:

- During the acute phase / post-acute phase when a patient remains in the community under the care of their GP or other primary care service
- During the post-acute phase when a patient either undergoes a clinical review or self presents, and
- During the post-acute phase to support the management of ongoing symptomatic COVID-19 (>4 weeks), or post COVID-19 syndrome (>12weeks) where secondary care intervention is not deemed necessary.

Non-admitted patients may only require tier 3 services to support the management of post COVID-19 syndrome where it is deemed appropriate.

For hospital follow ups (typically between 4 and 12 weeks) tier 3 services are often respiratory led post COVID-19 clinics, or post COVID-19 ICU clinics where a patient has had a stay in ICU. Following these follow ups, a decision is made as to whether the patient is stepped down to tier 2 services, is referred for post COVID-19 assessments (still at tier 3) or is escalated to tier 4 services; in the case of complex patients requiring highly specialised intervention/rehabilitation.

Where post COVID-19 syndrome is suspected in patients that had a stay in ICU, a decision will be made as to which tier 3 service (post-acute COVID-19 clinics that are respiratory led, or post COVID-19 ICU clinics) will assess them and plan treatment.

### 7.1 Tier 3 services for the management of post COVID syndrome (>12 wks)

Typically, respiratory led post-acute COVID-19 services, or Post COVID-19 ICU services. However, these should be multidisciplinary or multi-specialist if available.

### 7.2 Aims

The main aim of this service is to:

- Provide a holistic assessment that includes physical, cognitive, physiological components, taking into account non respiratory COVID-19 symptoms, and,
- Use the expertise available, to adopt a personalised care approach that seeks to plan and provide care based on what matters to the individual.

### 7.3 Acceptance criteria and referral routes

There are 3 main cohorts of patients to be reviewed within respiratory led post-acute COVID-19 services:

- Suspected or Positive result who have never been admitted to hospital with their acute illness but managed independently or in the community
- People hospitalised with COVID-19
- People cared for in an Intensive Care Unit (ICU) or High Dependency Unit (HDU) with COVID-19

Post COVID-19 ICU clinics will only receive patients that had a stay in ICU.

For those referred to a respiratory led post-acute COVID-19 service from primary care or from tier 2 services, these will have:

- A GP assessment of new, changing or persistent symptoms (>4 weeks as appropriate)
- Alternative diagnoses ruled out using investigations and locally agreed screening tool such as the Newcastle post-COVID syndrome Follow-Up Screening Questionnaire.

Post-acute COVID-19 clinics will collaborate with Post-ICU clinics and be supported by locally developed MDTs (virtual or otherwise) to determine who takes responsibility for the rehabilitation of post-COVID-19 patients (including those admitted to ICU) that are discharged from hospital.

Tier 3 services should provide advice and guidance to referring services to support local management and reduce referrals where possible.

Consideration should be given to having a single point of referral triage.

### 7.4 Assessment

- Full history, clinical examination and functional assessment
- Availability and access to appropriate specialist tests (e.g. full lung function testing, Echocardiogram, Computerised tomography (CT), Magnetic resonance (MR), including cardiac MR, Cardiopulmonary exercise testing etc.) as appropriate. Note: not all patients will need all these tests
- Psychiatric assessment
- Assessment of cognitive function using validated tools which can also be applied over the phone or via video consultation (please see NICE guidance at: <https://www.nice.org.uk/guidance/ng97/chapter/Recommendations#diagnosis>)
- Impact of event scale (IES-R) or Trauma screening questionnaire (PTSD) where applicable



It is the responsibility of the clinic to refer patients on to existing services as needed.

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

### **7.5 Minimum service provision criteria**

As a minimum the post-acute COVID-19 services for post COVID-19 syndrome should:

- Be available, following clinician referral, to all affected patients, whether hospitalised or not
- Have access to a multidisciplinary team of professionals to account for the multi-system nature of post-COVID syndrome including those from rehabilitation, psychology, and occupational therapy services
- Support collaboration across localities where patients needs require this
- Have age appropriate arrangements in place for managing children and young people with post-COVID syndrome including support for psychological needs
- Have access to diagnostic tests
- Ensure coverage of the population in that geography
- Have a plan for ensuring equity of access (bearing in mind many population groups have been disproportionately affected by COVID-19)
- Have a local communications plan for raising awareness within the clinical community
- Have an external communication plan for informing and raising awareness with patients
- Have plans in place for regular data collection to support audit and quality improvement processes
- Services will have the ability to direct patients to Your COVID recovery phase 2 for ongoing support
- Support vulnerable groups including the homeless, learning difficulties, mental health etc

### **7.6 Geography and population coverage**

Assessments will be carried out virtually, where possible and face to face where necessary. Face to face assessments will be carried out as close to home as possible and provided using locally agreed COVID-19 safety protocols.

Multi-disciplinary teams will review the results from the assessments and offer a personalised care approach that seeks to plan and provide care based on what matters to the individual.

Multi-disciplinary teams will be provided virtually where possible and may not be limited to the specialisms of a single provider.

The post-acute service must cover the populations locally agreed either at GM level, sector level or at Trust level.

### **7.7 Workforce**

Post-acute COVID-19 clinics will need to appoint a lead respiratory physician. The following professionals need to be considered as part of the wider respiratory led multi-disciplinary team:

- Physiotherapists
- Occupational Therapists
- Specialist Nurses (district nursing, community nursing, psychiatric nursing, Speech and Language Therapy, clinical nurse specialists and general practice nurses)
- Psychologists
- Dieticians
- GP/GPSI

### **7.8 Equipment**

The provider will provide the tools and equipment to enable a holistic assessment to be carried out in accordance with national guidance. This also includes the necessary equipment to review results and liaise with the patients and/or their carer.

### 7.9 Clinic accessibility and inclusion

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

- Being supportive to those with learning disability and/or autism or pre-existing mental health problems and being aware of diagnostic overshadowing (see here for further resources)
- Socio-economic inequalities
- Black, Asian and minority ethnic (BAME) group inequalities
- Lesbian, gay, bisexual and transgender plus (LGBT+) people
- Sex and gender
- Language and cultural barriers
- People with an existing disability such as visual or hearing impairment
- People in secure units
- Marriage and civil partnership
- Pregnancy and maternity
- Religion and belief

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

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

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

### 7.10 Outcomes

The referrer should be informed of any outcomes from the assessment.

Outcomes from the assessment are to include:

- An MDT evaluation of physical, cognitive and psychosocial need and management of impairments, including a holistic assessment
- A recommendation of service(s) most likely to meet the assessed needs including signposting/referring to community mental health services (urgent referrals should be initiated in the case of risk to individuals)
- Referral to specialist rehabilitation services as needed (i.e. pulmonary rehabilitation or cardiac rehabilitation)
- Specialist intervention through referrals as appropriate (i.e. referral to heart failure services, referral to renal services etc)
- 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).
- A plan with patient goals derived from a shared decision-making process with the patient
- Wherever appropriate, stepping the care back to tier 2 through appropriate transition of care

### 7.11 Onward referrals and interdependencies

Providers will have clear pathways to ensure referral into appropriate services which may include rehabilitation, psychological support, specialist investigation or treatment, or to social care support services or the voluntary, community and social enterprise sector.

The GP will receive communication from the clinic on the patients care, and consideration should be given to the provision of Med3/ fit to work certificates to avoid further appointments, unless the patient is discharged back to the care of primary care for ongoing management.

Clinicians will work together to ensure that physical and mental healthcare are integrated as closely as possible. Where available, patients with mental health and psychological issues with persisting physical problems may benefit from referral to integrated IAPT-LTC (Improving Access to Psychological Therapies-Long Term Condition) services or in the case of an under 18 year old, the relevant children and young people's mental health service.

Transition between children's and adult services will be supported and services should work flexibly to provide support based on the needs of the young person. Where possible an episode of treatment should be completed before consideration of transition to ensure continuity of care.

Services that might be of particular benefit include:

- Specialist lung disease services, sleep clinics, and pulmonary rehabilitation
- Cardiac services
- Pain management
- Gastroenterology
- Renal
- Rehabilitation services
- Dietetics and nutrition services
- Primary care led care including care coordinators and social prescribers
- Improving Access to Psychological therapies (IAPT) and other mental health services
- Co-morbidity management e.g. for diabetes or obesity
- Neurology
- Rheumatology
- Dermatology
- Ear, Nose and Throat
- Infectious disease services
- Occupational health

## 8. Tier 4 services

Tier 4 services are highly specialised services designed to support highly complex patients or patients requiring highly specialised intervention. This specialist intervention is typically concerned with:

- Post viral fatigue/ chronic fatigue syndrome
- Post ICU syndrome
- Multi organ damage syndrome
- Neurological / neuropsychiatric syndrome

### 8.1 Aims

The main aim of this service is to:

- Provide a specialist and holistic assessment, and,
- Use the expertise available, to adopt a personalised care approach that seeks to plan and provide care based on what matters to the individual through shared decision making.

Tier 4 clinics will be supported by network-based sector type MDTs with input from tertiary and specialist rehabilitation services to deal with patients who have complex medical or rehabilitation needs as a result of suffering from COVID-19.

Clinicians referring a patient to a complex Post-COVID-19 MDT clinic will assume clinical responsibility of the patient including the coordination of care and until the patient's care has been formally transferred to another clinician through the MDT.

Some localities will choose to have these MDT clinics to be virtual without patients physically present; instead, cases will be discussed in a virtual MDT; and decisions about referring these patients to relevant

services can be made through these MDTs. These can be used as means to coordinate care and make decisions on the best way to proceed with the care of a particular patient.

Tier 4 services should provide advice and guidance to referring services to support local management and reduce referrals where possible (both tier 2 and 3).

### 8.2 Acceptance criteria and referral routes

- Patients will normally be referred through tier 3 services. Specific reason for referral has to be clearly stated.
- Referral proforma to be agreed by MDTs
- Patients who have been clearly identified through tier 3 to require onwards referral to other specialist tertiary services do not always need to go through the MDT clinic, and can be referred directly to these services (i.e. Interstitial Lung Disease clinics, heart failure and cardiology services)

### 8.3 Workforce

As a minimum the core tier 4 service should have an MDT consisting of:

- A respiratory specialist
- A neurology specialist
- A Cardiology specialist
- A mental health specialist such as a clinical psychologist
- A chronic fatigue specialist

With links to dermatology, Ear, Nose and Throat, renal etc as required.

The MDT should be supported by an MDT co-ordinator, a system navigator, and the necessary business and technical support.

## 9. Applicable service standards

NICE COVID-19 rapid guideline: managing the long-term effects of COVID-19 (Dec 2020)

Management of the long term effects of COVID-19 v1 (October 2020)

NICE - COVID-19 guideline scope: management of the long-term effects of COVID-19

A guideline to supporting the recovery and rehabilitation of adults with confirmed or suspected COVID-19 in Greater Manchester (2020) v2.4 upward

NICE: Dementia: assessment, management and support for people living with dementia and their carers (Jun 2020)

## 10. Provider Premises (all tiers)

The provider must be able to improve on this current coverage, providing care close to home and continuity of care for patients.

All premises and equipment to be used must be subject to proper maintenance, the responsibility for the provision of suitable premises and equipment will be with the provider and must be relevant to the service, including as a minimum:

- Premises must be Disability Discrimination Act (DDA) compliant either ground floor or with lift access if not;
- Premises to enable safe and convenient patient access in relation to transport links;
- Adequate seating to enable all patients to sit while waiting, including chairs for patients who have difficulty sitting low down.
- WC facilities should be provided;
- Have access to interpretation and translation services;
- Ensure that all premises and equipment to be used is subject to proper maintenance;

- Decontamination and clinical waste disposal as appropriate;
- Toilet access (DDA compliant);
- Hand-washing facilities for provider/patients;
- Non-slip flooring;
- Patient changing facilities/curtain area;
- Storage facilities for consumables

### 11. Data collection

- Number of referrals received
- Number of patients accepted, and numbers rejected
- Number of patients reviewed
- Method of review (face to face, Tel, Video)
- Route of referral (Post COVID tier 3 service, community team, physios etc)
- Number of episodes (appointments or contacts) of COVID related care for each patient
- Date of referral for each patient
- Date of initial review for each patient
- Date of initial COVID-19 episode for each patient
- Onward referrals to other services for each patient
- Date onward referral generated for each patient
- Date of discharge for each patient (if applicable)
- Number of patients referred:
  - a) With a learning disability/autism/hearing loss/visual impairment/prior diagnosis of dementia
  - b) From the criminal justice system
  - c) Who are homeless or rough sleepers
  - d) Who are refugees and asylum seekers
  - e) Who are from gypsy, traveller, and Roma communities
 In full time education
- Number of patients attending the clinic that were able to return to work.
- Outcome of the assessment (discharged, referred onwards to other services including Tier 3) and date
- Service user satisfaction assessed using standardised satisfaction surveys.

### 12. Research and evidence generation

Services should look at the following research questions and work collaboratively to try and provide some answers to the following:

- 1- Risk factors for POST COVID-19 syndrome
- 2- Relationship between severity of acute COVID event, and the incidence of Post COVID-19 Syndrome
- 3- Possible effective therapies/ interventions for Post COVID-19 syndrome
- 4- Prevalence of Post COVID-19 syndrome
- 5- Explore the relationship between on-going systemic inflammation and the occurrence of Post COVID Syndrome

### 13. Children and Young Adults (addendum)

See attached document.

### 14. Mental Health

Recommendations to follow when agreed.



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**Appendix One – Crude estimates of post COVID-19 syndrome numbers**

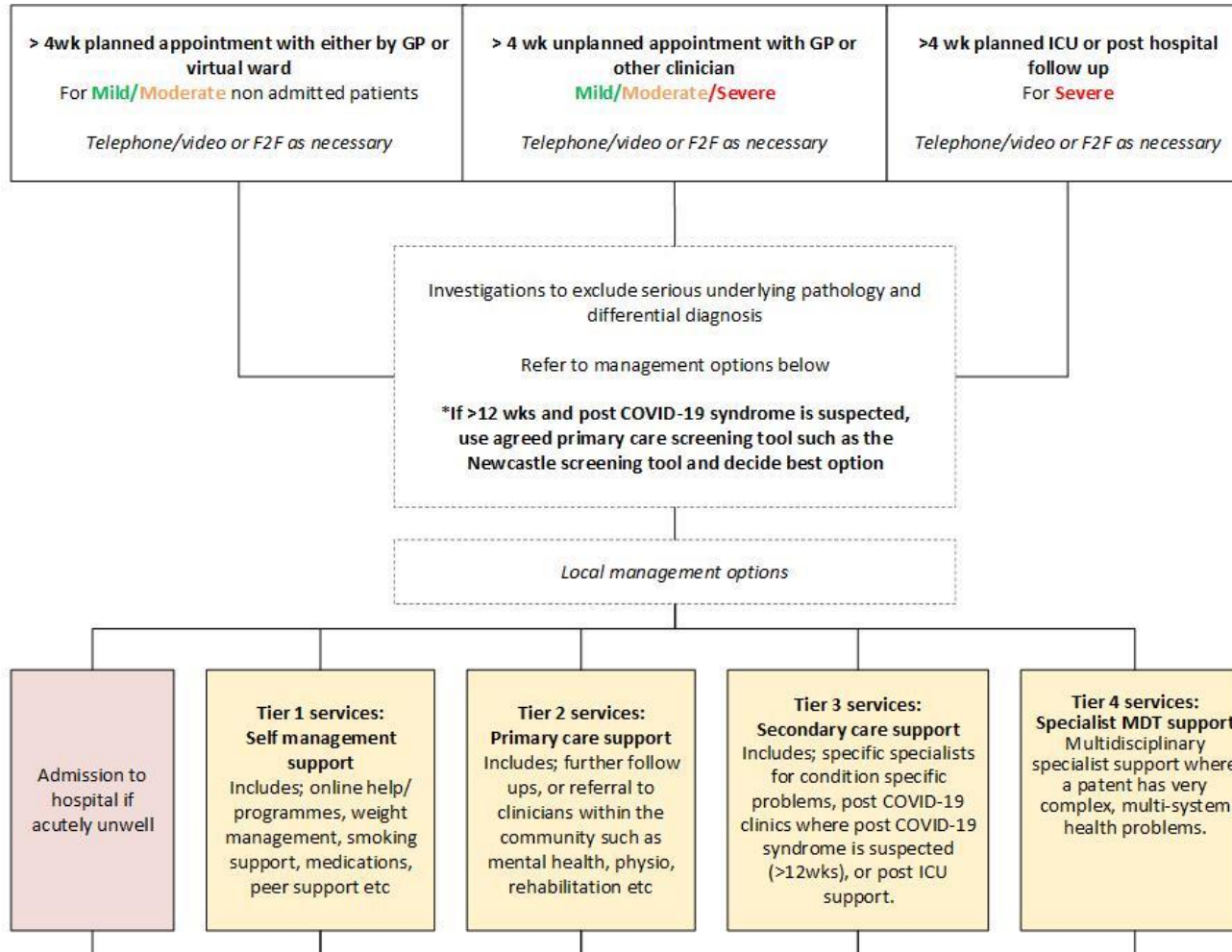
	March COVID positive Patients (resident)	April COVID positive Patients (resident)	May COVID positive Patients (resident)	June COVID positive Patients (resident)	July COVID positive Patients (resident)	August COVID positive Patients (resident)	September COVID positive Patients (resident)	October COVID positive Patients (resident)	Lower estimate of those diagnosed in Oct having symptoms >90days (1%) (Post COVID syndrome)	Middle estimate of those diagnosed in Oct having symptoms >90days (2.3%) (Post COVID syndrome)	Upper estimate of those diagnosed in Oct having symptoms >90days (4%) (Post COVID syndrome)
Bolton	102	921	511	258	218	465	2,693	5,652	57	130	226
Bury	101	611	392	157	96	254	1,321	3,802	38	87	152
Manchester	228	1,247	897	468	514	1,033	6,770	12,984	130	299	519
Oldham	150	729	541	397	359	804	1,581	5,664	57	130	227
Rochdale	126	564	426	418	363	404	1,438	4,991	50	115	200
Salford	191	697	278	132	187	369	1,772	6,063	61	139	243
Stockport	160	896	431	128	166	222	1,047	4,384	44	101	175
Tameside	116	492	605	281	148	328	1,378	4,191	42	96	168
Trafford	146	584	390	121	207	275	872	3,697	37	85	148
Wigan	124	1,167	717	109	74	152	1,544	7,598	76	175	304
<b>GM Total</b>	<b>1,444</b>	<b>7,908</b>	<b>5,188</b>	<b>2,469</b>	<b>2,332</b>	<b>4,306</b>	<b>20,416</b>	<b>59,026</b>	<b>590</b>	<b>1358</b>	<b>2361</b>



## in Greater Manchester

### Appendix 2 - A structured approach to following up patients with confirmed or suspected COVID-19 in GM >4 wks

GM COVID-19 Acute Pathway >4 wks





in Greater Manchester

### Appendix 3 - 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 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 be comprehensive. If other issues are identified (that are not obviously related to a pre-existing 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 .....





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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?

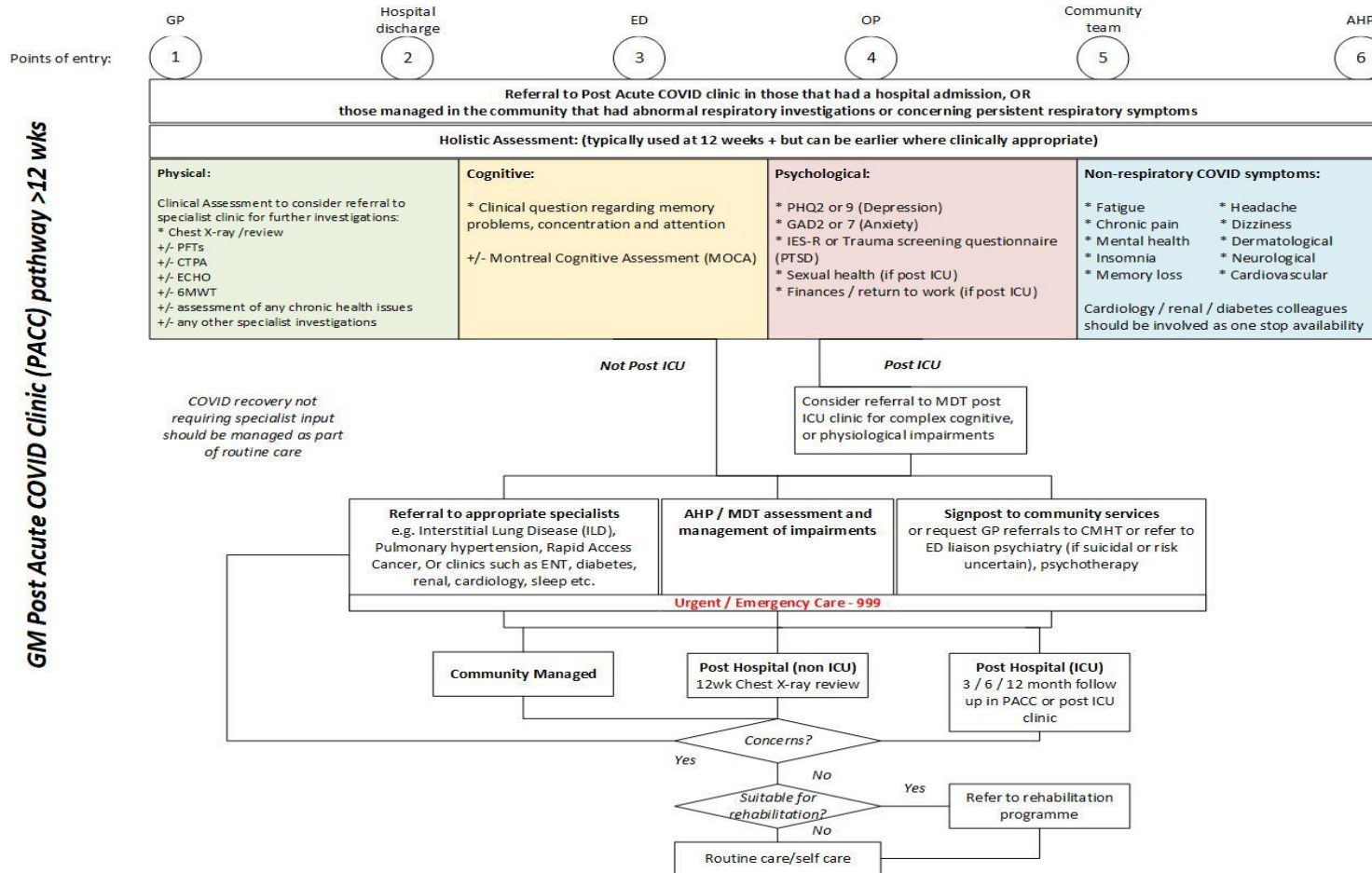
3. Do you feel fatigued (worn out/lacking energy or zest) compared with how you were before you COVID illness?



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- 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 palpitations (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 (> ½ stone, 3 Kg) since your COVID illness? Yes No
- 14. Any other symptoms (list)

## Appendix 3



<b>VERSION CONTROL</b>
<b>2021.01.12</b>
<b>V0.3</b>
<b>Author Julie Flaherty</b>

## **Addendum to Adult Service Specification for Long-COVID and COVID Complications**

### **GM Paediatrics Services**

In line with the proposed model for services to support and manage those with confirmed or suspected COVID-19, in the post-acute phase in adults, there is increasing evidence that children and young people (CYP) post COVID-19 will require follow up depending on their symptoms and severity in primary care or in paediatric services.

The clinical picture of COVID-19 in CYP is very different to that of adults except for a small cohort. The vast majority of CYP experience only mild to moderate symptoms which in the main are managed within the family unit. However, some children do become very ill between 4 and 6 weeks post infection with COVID-19 with Paediatric Inflammatory Multisystem syndrome associated with COVID-19 (PIMS-TS). Initially PIMS-TS is categorised by type of disease – Kawasaki disease like or non-specific disease with initial clinical investigations determining the severity of the disease. The phenotype of the disease should be determined by clinical assessment. PIMS-TS has similar symptoms to Kawasaki, Toxic Shock and hyperinflammatory syndromes such as Hemophagocytic Lymphocytic Histiocytosis (HLH) and Systemic Lupus Erythematosus (SLE). PIMS-TS will require MDT clinical input including, Paediatric Infectious disease & immunology, Rheumatology, Respiratory, Cardiology, Critical Care, Radiology and laboratory services.

There is no current definitive data of CYP impacted by COVID-19 with subsequent secondary complications of PIMS-TS or those CYP who have developed other significant disease. There is a pressing need to establish robust data collection.

With respect to other complications children are presenting with post COVID-19 infection pathologies, such as:

- Type 1 Diabetes Mellitus with DKA presentations (currently figures compared to 2019 in 2020 this has doubled). Current information indicates that at least 25% of these presentations require PICU level 3 and 4. A report by Imperial College London (August 2020)<sup>1</sup> indicates the plausibility of the link between COVID 19 infection and new-onset diabetes in children. Great Ormond Street Hospital (GOSH) reported an increase in referrals of children with DKA during the pandemic, compared to previous years (BMJ, 2020)<sup>2</sup>.
- Some children are presenting with ME type symptoms and will require multi-disciplinary team assessment and management.
- CAMHS services are seeing a significant increase in referrals. Further data is required to determine the nature of referrals and the impact that closure of educational establishments has had on CYP mental health, including broader issues

<sup>1</sup> <https://www.imperial.ac.uk/news/201473/covid-19-linked-increase-type-diabetes-children/>

<sup>2</sup> <https://adc.bmj.com/content/early/2020/09/16/archdischild-2020-320471.info>

around safeguarding. During the autumn of 2020 as children and young people returned to school, high rates of infection in the North of England compared to the South in the second wave meant that children were frequently sent home to isolate or because of staff shortages leading to further disruption to their education.

### **The acute and post-acute phase of COVID-19**

As described above the clinical presentation for CYP in the main is different from that of adults but that does not alter the presentation and management of COVID-19 which should be broken down in to the acute phase (0-4 weeks) and the post-acute phase (>4 weeks), defined by NICE Guideline NG188 as 'ongoing symptomatic COVID-19', and 'post COVID-19 syndrome' which is typically symptoms lasting 12 weeks or more. Management within these phases should be seamless.

The post- acute phase, or ongoing symptomatic COVID-19, 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 secondary care service (tier 3) or Specialist management of specific complications and ongoing concerns (tier4) if post COVID syndrome is suspected.

This addendum to the adult service specification is specifically for Children and Young people and outlines the approach to supporting those with confirmed or suspected COVID-19, in the post-acute phase >4wks; with particular attention to those between 4 and 12 weeks.

### **Rationale and Population Needs for CYP**

#### **National Context**

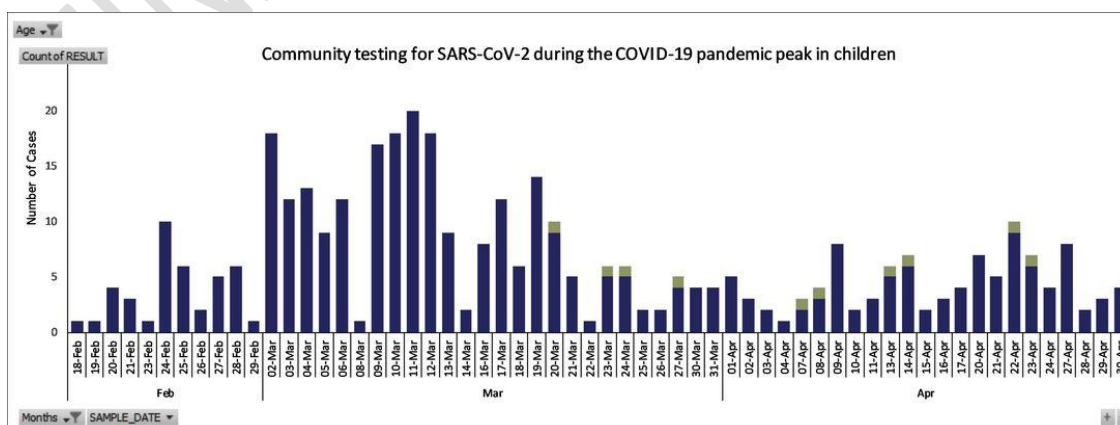
#### **At present it is recognised that:**

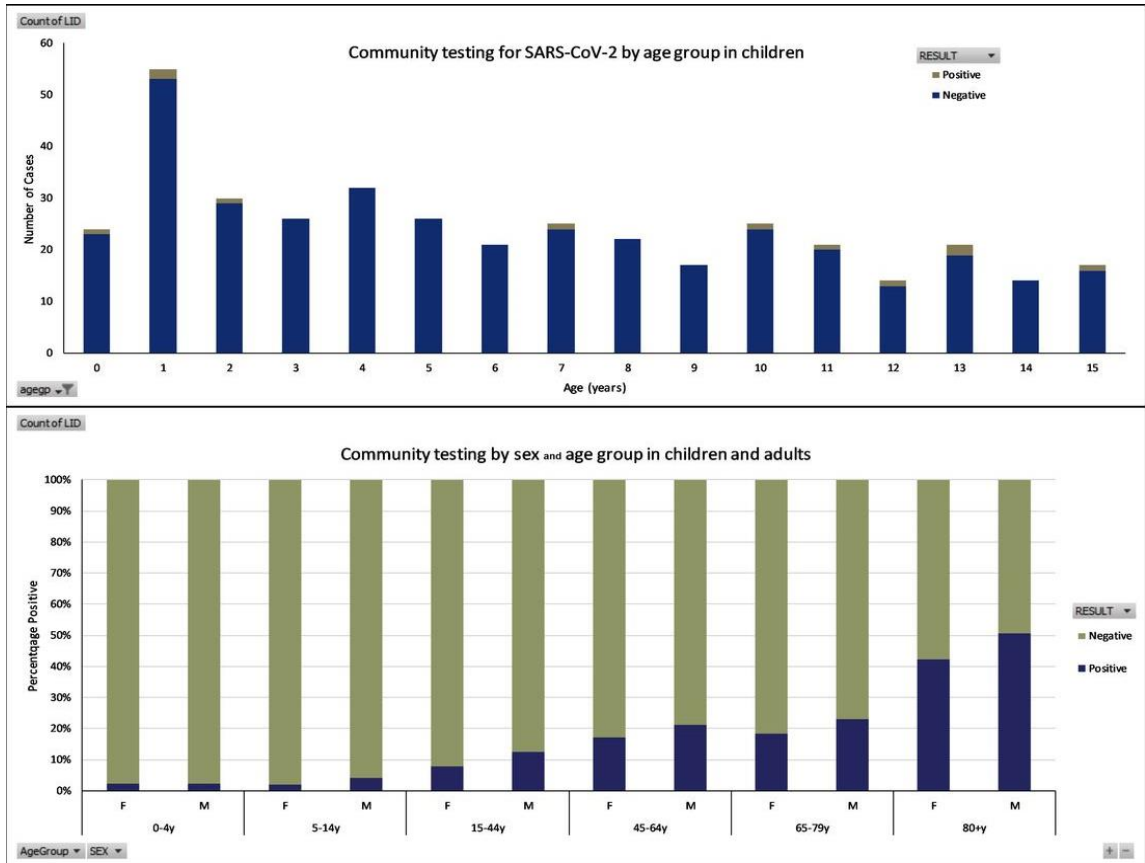
- CYP appear to be lower risk of COVID-19, with around 5% being hospitalised in USA of which less than 1% needed critical care. (BPSU RCPCH 2020<sup>3</sup>) This figure is constantly under review as more data becomes available.
- In the UK the detail of the data of incidence in CYP is currently being collated.
- Unlike adults, CYP usually have a very mild illness and it is rarely fatal.
- A number of CYP across the UK have been reported to have severe illness, often requiring paediatric intensive care unit because they are so unwell.
- It is recognised that some CYP develop symptoms around the 4 to 6 weeks post infection either confirmed positive C19 or negative C19, develop a multi-system hyper-inflammation disease currently known as PIMS-TS.
- At the current time research is underway studying the relationship between SARS-CoV-2 and multisystem hyperinflammatory disease.
- Data is currently being collated across the UK and more locally in GM of CYP who have been diagnosed and clinically managed with PIMS-TS.
- CYP can develop post Covid19 symptoms if they have had a positive test or negative test results regardless of symptoms of acute symptoms or asymptomatic.

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<sup>3</sup> <https://www.rcpch.ac.uk/work-we-do/bpsu>

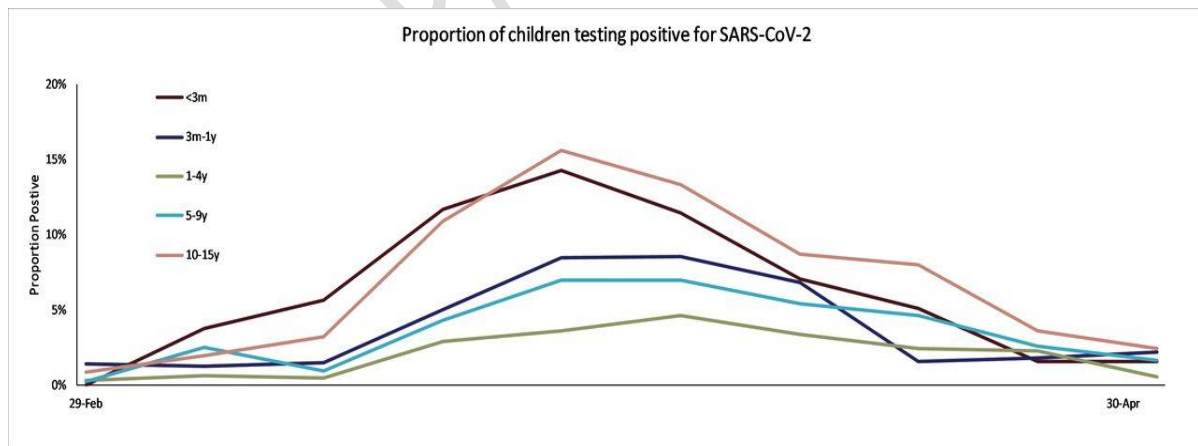
- Likelihood of developing ongoing symptomatic COVID-19 or post-COVID-19 syndrome is not thought to be linked to the severity of their acute COVID-19 (including whether they were in hospital)
- New or ongoing symptoms occur; they can change unpredictably, affecting them in different ways at different times. Be aware that some CYP may not have the most commonly reported new or ongoing symptoms after acute COVID-19
- Post Covid19 recovery time is different for everyone but for most people symptoms will resolve by 12 weeks as yet this is unknown with CYP
- Suspect previous COVID-19 illness as a possible underlying cause of new or ongoing symptoms in CYP after acute COVID-19 as follows:
  - ongoing symptomatic COVID-19 if people present with symptoms 4 to 12 weeks after the start of acute COVID-19 or
  - post-COVID-19 syndrome if the person's symptoms have not resolved 12 weeks after the start of acute COVID-19
- Many CYP experiencing ongoing health effects following COVID-19 infection managed their condition independently at home while acutely infected
- The number of CYP who need post-COVID syndrome management focusing on recovery and rehabilitation is likely to grow as COVID-19 infection rates continue to rise
- Parents and carers of CYP with post-COVID syndrome have reported that whilst some GPs have been sympathetic, some have been unsure how to refer into treatment services.
- 67% of GPs surveyed reported that they are looking after patients with COVID-19 symptoms lasting longer than 12 weeks.
- There is increasing evidence that COVID-19 has a disproportionate impact on those in deprived populations and people in black and ethnic minority groups and exacerbates existing health inequalities
- Support should be made available for access to assessment and care for CYP with new or ongoing symptoms after acute COVID-19, particularly for those in underserved or vulnerable groups who may have difficulty accessing services. This might include providing extra time or additional support (such as an interpreter or advocate) during consultations.
- To date there have been concerns around increased malnutrition, jaundice, anaemias, injuries from NAI, child suicide, magnet and battery ingestion (SK 2021). Further investigation into causality and links with COVID-19 infection and the impact of system response to the pandemic, as well as social factors, is required.



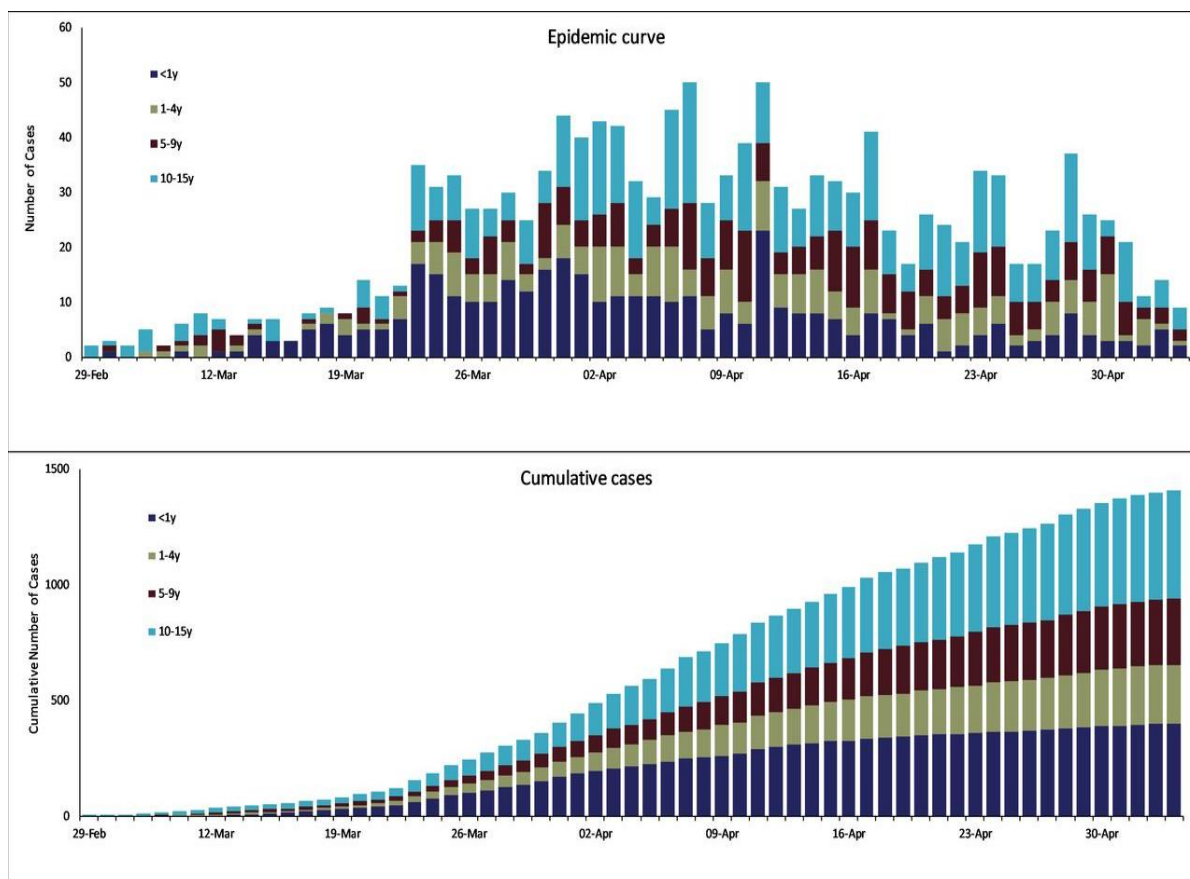


**CHART 1: Number of children with acute respiratory infection who were tested for severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) in general practices across England over the course of the pandemic (A) and by age (B).**

Shamez N Ladhani et al. *Arch Dis Child* 2020;105:1180-1185<sup>4</sup>



<sup>4</sup> Available at: <https://adc.bmj.com/content/105/12/1180>



**Chart 2: Epidemic curve (A), cumulative number of confirmed cases (B) and proportion of test positives (C) by age group for COVID-19 in children during the first pandemic peak (February to May 2020) in England.**

Shamez N Ladhani et al. *Arch Dis Child* 2020;105:1180-1185<sup>5</sup>

Interpretation of the national data before summer 2020, when mass testing became more widely available and was mostly pillar 1 (hospitals) up to June is of limited value (Above graphs).

### Local context

- GM has additional challenges that impact on population health. These include areas of deprivation and vulnerable population demographics such as multiple occupancy homes, high prevalence complex health care needs as well as diabetic conditions known to lead to more serious consequences of infection.
- GM paediatrics has been impacted more significantly than other areas of the UK. This is consistent with the over-representation of this disease in children from BAME backgrounds and the high BAME population within the region. (*The Lancet Child & Adolescent Health, 2020*).<sup>6</sup>
- The emergence of long covid in CYP is less familiar and has lesser consideration than in the adult population, however there is a qualitative feedback from parents and children of fatigue, gastrointestinal issues, sore throats, headaches, muscle pain and weakness (BMJ opinion 16/10/2020). Other symptoms include fevers, nausea, mood changes, rashes, dizziness, breathing difficulties and cognitive blunting.

<sup>5</sup> Available at: <https://adc.bmj.com/content/105/12/1180>

<sup>6</sup> Available at: [https://doi.org/10.1016/S2352-4642\(20\)30167-X](https://doi.org/10.1016/S2352-4642(20)30167-X)



- Active case finding in the local community by patient engagement and research in primary and secondary care will aid identification of affected CYP with a needs analysis and assessment of equality and impact (particularly relevant for CYP from vulnerable families and BAME communities).
- There is a need for continuing and developing research into pathophysiology of these symptoms as is being currently investigated by adult cohorts.

### **PIMS-TS impact**

- PIMS-TS, National consensus for management of this disorder is that an MDT approach is Key (Harwood, R. et al, 2020)<sup>7</sup>.
- CYP who will develop multisystem hyperinflammatory disease requiring Paediatric intensive care are transferred from DGH's to either Royal Manchester Children's Hospital (RMCH) or Alder Hey Intensive care units where level 3 or 4 can be delivered.
- These critical transfers to tertiary services are co-ordinated and managed by the NWTS team
- Data below identifies the numbers of CYP who have been admitted to RMCH with PIMS-TS. There are other CYP who have been managed locally at the District General Hospital (DGH) with remote clinical care from Manchester University Hospitals NHS Foundation Trust (MFT) which are not included in these figures (not requiring critical care or Biologic Medications)

April 20	May 20	Jun 20	Jul 20	Aug 20	Sep 20	Oct 20	Nov 20	Dec 20
3	13	8	6	2	2	5	19	14++

### **MFT data incidence of CYP admitted with PIMS-TS**

- CYP not requiring PICU and can be managed at local DGH's can do with remote support from the Specialist centre (RMCH within MFT). More detail around the data needs collating to identify the numbers of children not transferred to RMCH but that have PIM-TS but managed within the DGHs and remote specialist advice.
- Some CYP need to be transferred to the RMCH for further invasive diagnostics from the Specialist teams.
- Virtual be default is currently the easier way to care for these CYP who require specialist advice from Tertiary consultants when it is initially thought that the CYP can be clinically cared for locally and those not requiring PCC2 or PCC3.
- Support from MFT to the DGH is significantly impacting on service delivery and increasing waiting times for Cardiology, Rheumatology and Infectious Disease.
- It is noted that MDT approach, including General Paediatrics, infectious disease, cardiology, rheumatology and critical care consultants is recommended in the management of PIMS-TS as referenced above (Harwood, R. et al, 2020).

### **Type 1 Diabetes**

- Throughout GM there is variability around the data and numbers of newly diagnosed Type 1 Diabetic CYP however the numbers of CYP with severe DKA has increased.
- The Diabetic Network has undertaken an audit of CYP newly diagnosed and existing patients presenting with or without Diabetic Ketoacidosis (DKA) following COVID19 showing an increase in newly diagnosed Type1 Diabetes

<sup>7</sup>Available at: [https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642\(20\)30304-7/fulltext](https://www.thelancet.com/journals/lanchi/article/PIIS2352-4642(20)30304-7/fulltext)

Chart 3: New and Existing patient admissions for Type 1 Diabetes Mellitus (T1DM)

## Results so far

Table showing total no. of admissions and whether they presented as a new diagnosis of T1DM or known to have T1DM

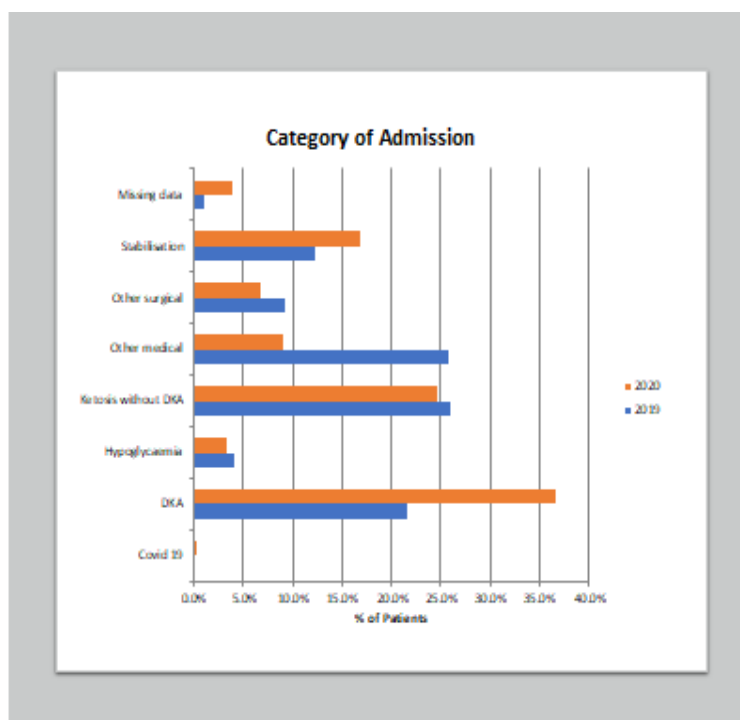
	2019	2020
Existing	241 (62%)	125 (40%)
New	151 (39%)	186 (60%)
Missing Data	0	1 (0.3%)
Total	392	312

In 2020:

- 84 new patients presented in DKA
- 29 existing patients presented in DKA

In 2019:

- 49 new patients presented in DKA
- 36 existing patients presented in DKA



- In 2020, 45% new patients presented in DKA compared to 32% in 2019

Table 1: DKA at Diagnosis

## Summary: DKA at Diagnosis

- In 2020, 45% of new patients presented in DKA
- In 2019, 32% of new patients presented with DKA
- These results are interesting, as the percentages are very high. NPDA data 2018/2019 showed that 20.9% of patients in England and Wales presented in DKA at diagnosis, and 9.3% in North West.
- Learning Points to convey to GPs:
  1. Be aware that **increased respiratory rate may be due to acidosis**, rather than LRTI. Ask about symptoms of diabetes, and consider urgent face to face review.
  2. Be aware that **polyuria is a symptom of new onset diabetes**. Ensure urine dipstick or glucose level checked same day – beware of mistakenly attributing to UTI.
  3. Patient assessment on **phone or video calls carries increased risk of missing clinical signs** – consider more thorough systems review to pick up symptoms of alternative diagnoses such as diabetes.
  4. If symptoms consistent with diabetes ensure a **urine dipstick or finger prick glucose is checked same day** – child may develop DKA while awaiting outpatient blood tests.
  5. If **urine dipstick or finger prick glucose suggest diabetes child must be referred urgently to hospital** – child can quickly develop DKA even if left for a single day.

## Summary

- Similar ages at admission
- Length of stay > 48 hours – for both 2019 and 2020
- HDU admissions higher in 2020
- **Appears to be higher percentage of delay in presentation during COVID-19**
- However cases reviewed retrospectively in 2019, so may have been harder to recognise delay from notes and more missing data in 2019
- COVID was thought to cause a delay in 34 patients with a mixture of reasons:
  - Missed diagnosis by GP ? Secondary to video or telephone call
  - Delay in GP appointment
  - Family calling 111 and not contacting GP
  - Anxiety about attending GP or AED
  - Poor compliance may have been noticed by school
- At the present time local GM data of newly diagnosed DTY1 is not complete but early evidence notes an increase in presentations in some districts.

Table 2: responses from Greater Manchester Clinical Community

Wrightington, Wigan and Leigh	Haven't seen increase in Numbers
Salford	12 newly diagnosed since Covid outbreak in March. In the same period last year (Mach-Dec 2019) they had 6 newly diagnosed
Royal Oldham Hospital	Had an increase in type 1. They are approximately up by 40% in 2020 compared to the previous year.  (haven't provided exact numbers)

- NHS England and Improvement (NHSEI) CYP Transformation plan expectations/objectives include:
  - having a short and longer term plan to manage the Type 1 diabetes and Type2 diabetes CYP populations and achieve improved outcomes, including transition to adult services using the expertise of the diabetic clinical network
  - increasing our understanding of the potential link between COVID-19 and T1DM in CYP and working with population health.

### Primary and Community Care impact

- Data from Primary & Community Care although not a complete set identify that as CYP returned to school/college the increase in positive cases increased with a decrease as schools/colleges restrict and isolated cases.

Table 3: confirmed community infection COVID-19 in Manchester

	0-4y	5-9y	10-14y	15-19y
Sep-20	156	132	199	2659
Oct-20	281	268	525	1746
Nov-20	161	211	416	464
Dec-20	111	138	269	329
	709	749	1409	5198

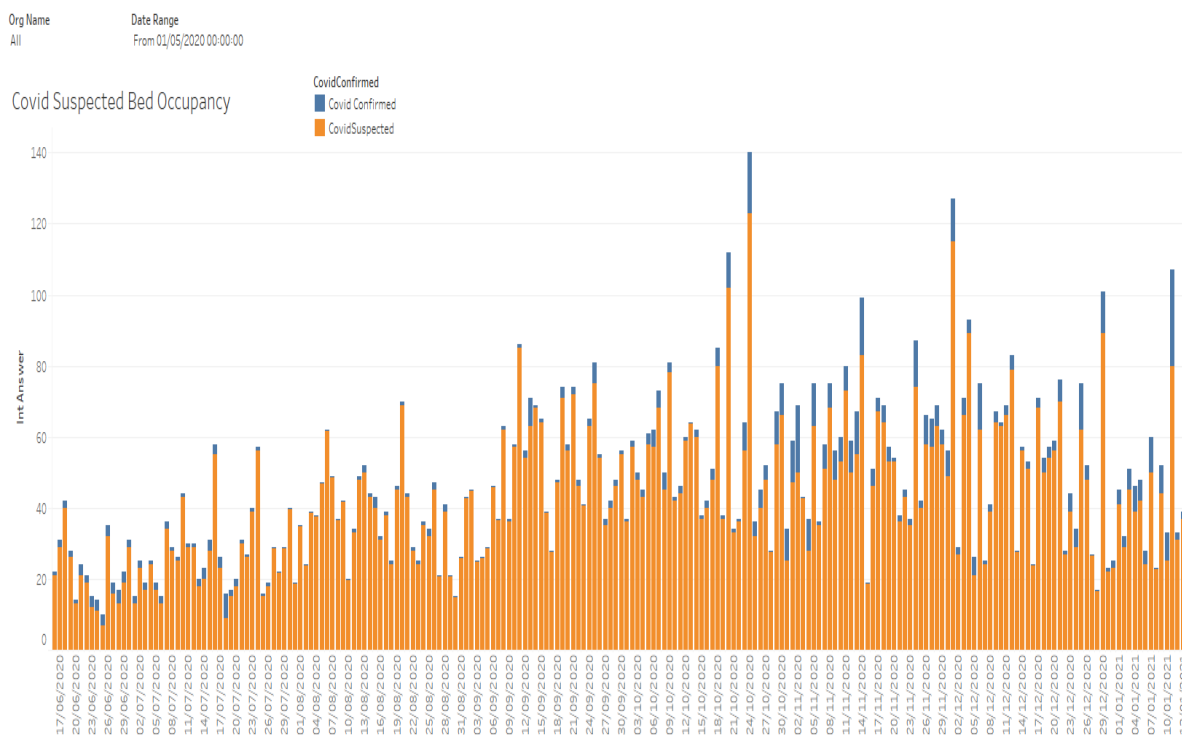
### Positive Covid-19 by specimen date, age demographics for Manchester

#### Secondary Care impact

CYP are admitted to all Children’s services across GM. The data is collated on both confirmed and suspected cases, albeit the numbers are relatively small in respect of adult admissions.

In the main, children in hospital have the common symptoms of COVID-19, fever and respiratory symptoms. The charts below are based on data captured from the Greater Manchester Tableau Bed Bureau.<sup>8</sup>

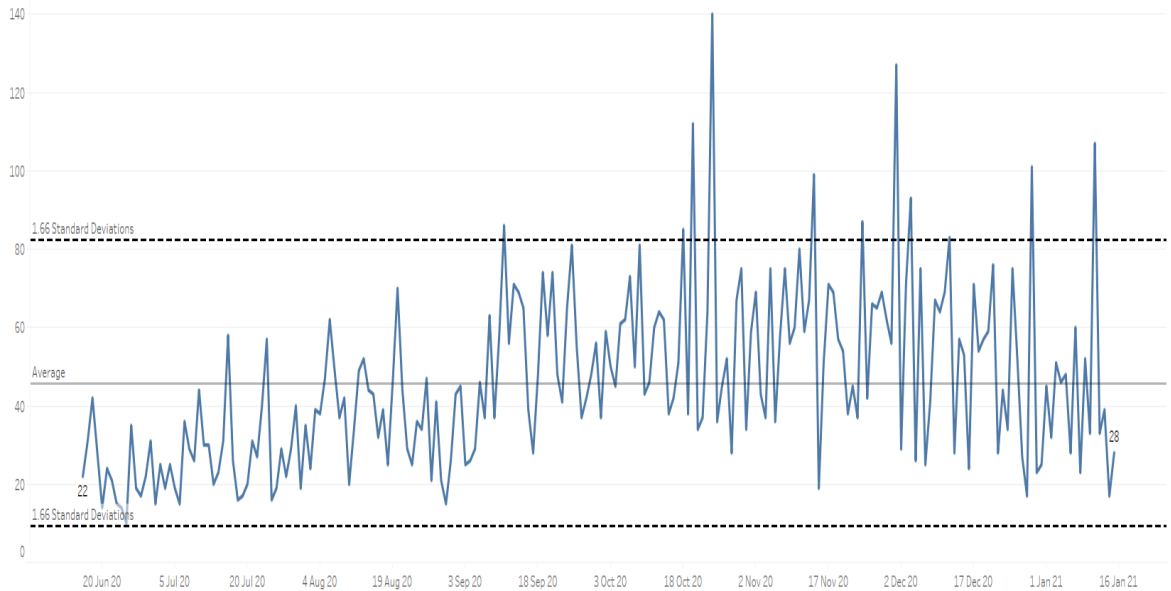
Chart 4: COVID-19 suspected and confirmed bed occupancy



<sup>8</sup> Available from:

[https://www.gmtableau.nhs.uk/t/GMHSCPPublic/views/GMPaediaticBedStatus/CovidConfirmedSuspectedTrend?&showAppBanner=false&:origin=viz\\_share\\_link&:display\\_count=n&:showVizHome=n](https://www.gmtableau.nhs.uk/t/GMHSCPPublic/views/GMPaediaticBedStatus/CovidConfirmedSuspectedTrend?&showAppBanner=false&:origin=viz_share_link&:display_count=n&:showVizHome=n)

Covid (Confirmed & Suspected) Bed Occupancy Trend



### Safeguarding impact

- There are concerns about CYP suffering Non-accidental injury (NAI) and clear safeguarding issues going unreported during the lockdown first wave.
- Known incidence of non-accidental injury decreased in GM with the first lockdown period. The relationship between COVID-19 and non-accidental injury/violence toward CYP is currently being reviewed.
- GM police have identified an increasing trend in reports of Violence toward CYP (Chart 5 below)

Chart 5: Violence with and without injury children 5 years and under

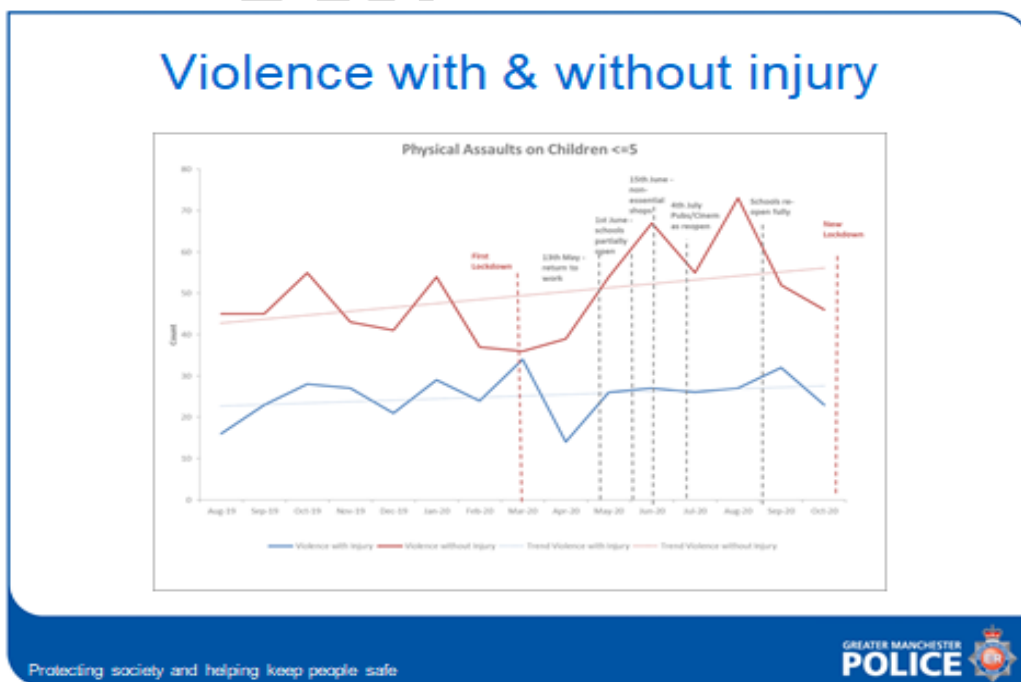


Chart 6: Violence with injury aged 1-17 years



- The incidence of Domestic Violence has increased. The relationship between COVID-19 and the increase in Domestic Violence is currently being reviewed.

Chart 7: Domestic abuse flagged crimes

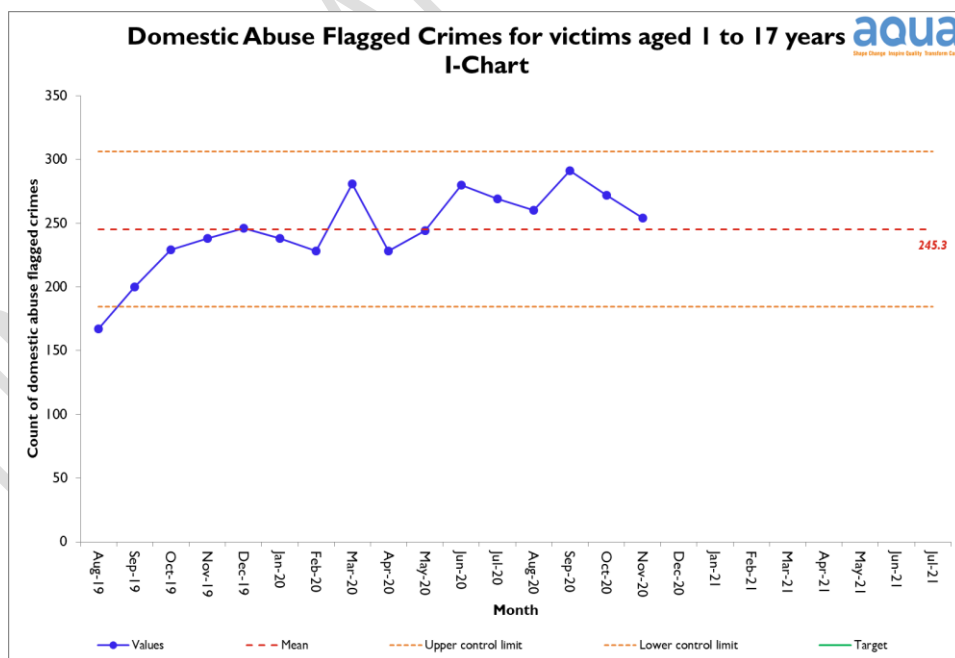


Chart 8: child death statistics

Event which caused the child's death <sup>7</sup>	All child death reviews completed in the year ending 31 March 2020 <sup>4</sup>	Modifiable factors identified <sup>5</sup>	No modifiable factors identified <sup>5</sup>	Total
		Neonatal death <sup>8</sup>	290	589
Known life limiting condition <sup>6</sup>	18	52	70	
Sudden unexpected death in infancy	151	48	199	
Vehicle collision	35	20	55	
Drowning	7	6	13	
Fire, burns or electrocution	6	*	6	
Poisoning	*	*	0	
Other non-intentional injury/ accident/ trauma	21	8	29	
Apparent violent related death <sup>2</sup>	42	23	65	
Apparent suicide <sup>3</sup> or self harm	61	47	108	
Acute epilepsy	5	28	33	
Acute asthma or anaphylaxis	11	5	16	
Acute metabolic diabetic ketoacidosis	*	*		
Cardiac congenital or acquired	33	243	276	
Other chromosomal, genetic, or congenital anomaly	90	439	529	
Infection	54	91	145	
Oncology condition	11	211	222	
Other	10	31	41	
Unknown	11	10	21	

Data in relation to cause of CYP deaths is only available until March 2020 but as identified in the table it is a cause for concern. Once data is available it will need to be determined if there is a relationship between COVID-19 and Suicide and Violent related death in CYP.

### CAMHS

- There has been an increase in CYP attending acute services with Eating Disorders, Self Harm, Suicidal Ideation, Anxiety & Hopelessness and depression, with a subsequent increase in admission to acute paediatric inpatients services.
- CYP often experience irrational thought and fears related to the cognitive stage of development.
- The relationship between COVID-19 and the increase in clinical presentation of CAMHS needs further analysis.

Chart 9: Patients in paediatric acute beds trend

Greater Manchester Paediatric Bed Status

GM Paediatric Bed Status Summary - Friday, 15 January 2021

	Total Nurses On Shift	Ward Beds Occupied	Ward Beds Available	Cubicles Occupied	Cubicles Available	HDU Beds Occupied	HDU Beds Available	CAMHS Patients	OSA Patients	Escalation Status OPEL	Open To Transfers In	Covid Confirmed (0-17)	Covid Confirmed (17-26)	Covid Suspected (0-17)	Covid Suspected (17-26)	No of children on CPAP	No of children on Ventilator	No of children on Optiflow
Bolton	6	0	11	9	8	0	3	0	4	1	1	0	0	0	0	0	0	0
NMGH	5	10	13	10	0	1	0	1	0	1	1	0	0	8	0	0	0	0
Oldham	5	6	6	8	2	0	2	1	5	1	1	0	0	0	0	0	0	0
RMCH	4	7	8	1	1	8	0	5		2	1	5	0	14	0	0	0	0
Salford	3	0	0	1	12	0	0	0	0	1	0	0	0	0	0	0	0	0
Stockport	2	1	4	0	3	0	2	1	3	1	1	0	0	1	0	0	0	0
T&G	6	0	8	7	0	0	1	1	1	1	1	1	0	0	0	0	0	0
Wigan	5	6	0	9	0	0	2	3	0	2	0	0	0	11	0	0	0	0
Wythenshawe	5	4	0	5	3	0	1	2	2	1	1	0	0	3	0	0	0	0
Grand Total	41	34	50	50	29	9	11	14	15	11	7	6	0	39	0	0	0	0

Key Operational Measures OPEL Open to Transfers

North Manchester General Hospital	1	1
Royal Albert Edward Infirmary	2	0
Royal Bolton Hospital	1	1
Royal Manchester Children's Hospital	2	1
Royal Oldham Hospital	1	1
Salford Royal	1	0
Stepping Hill Hospital	1	1
Tameside General Hospital	1	1
Wythenshawe Hospital	1	1

Time since last submission (Hours)

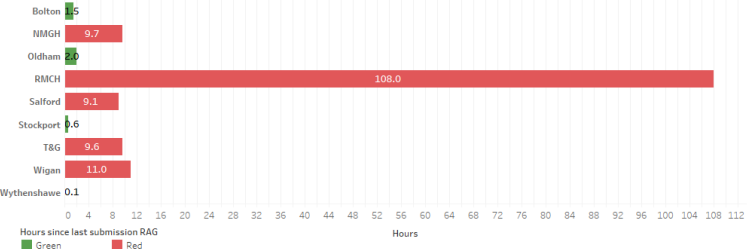
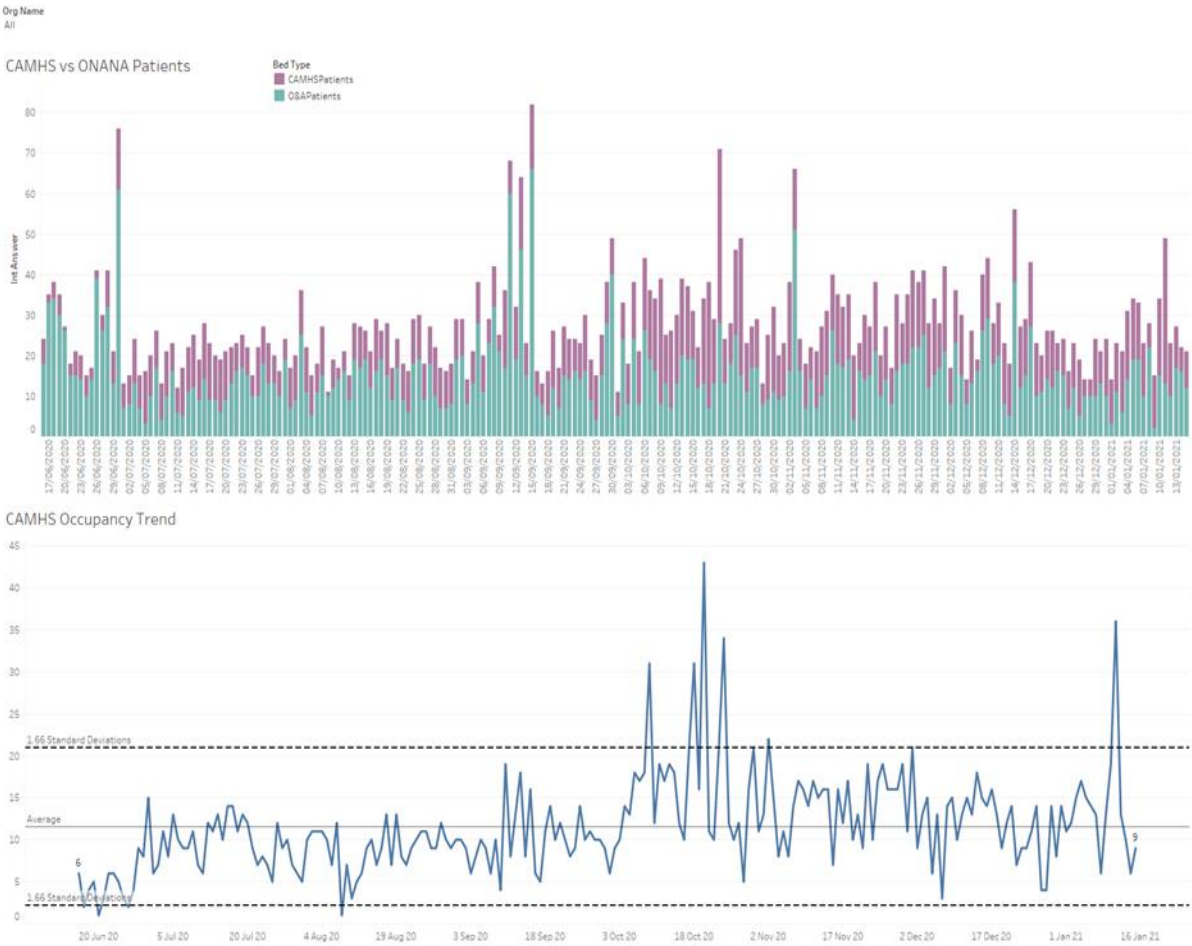


Chart 10: CAMHS patients admitted 21.06.2020- 10.01.2021 and trend data



Numbers of children admitted with CAMHS issues on a daily basis can be as high as 25% of children in beds across GM.



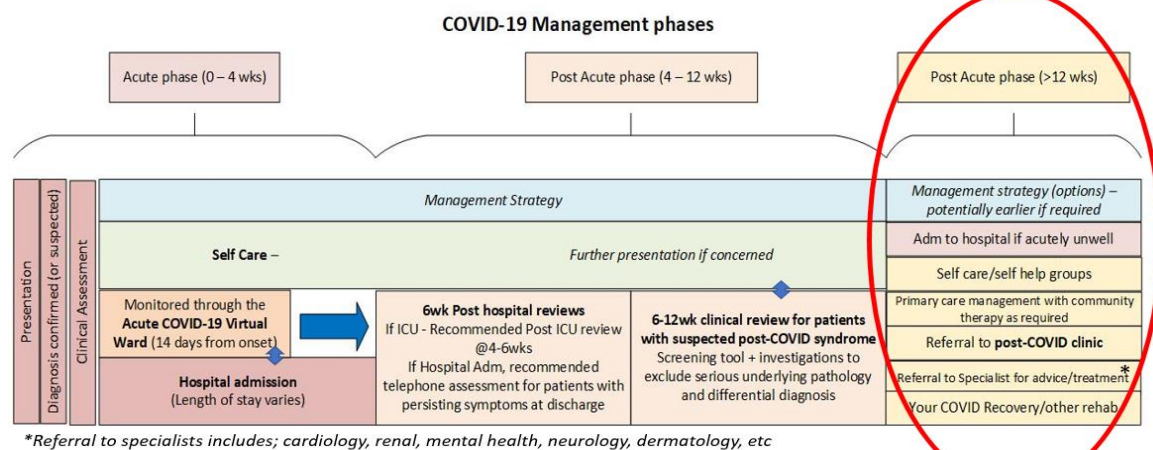
## Pathways, guidance and approach

It is known that some CYP do present and require hospitalisation with COVID-19 signs and symptoms early-on in the disease process, and that most of these children will only require DGH secondary care services. By the same rule some CYP will show no symptoms at the point of infection and require only very limited health service. At the present time it is unknown how many of these children will go on to develop PIMS-TS or Long Covid or covid complications. Data is currently being sourced to determine the likelihood of this happening in view of determining a MDT approach to the continuing health care needs.

A small number of CYP will need PICU services at the point of initial infection or later if presenting after 4 weeks being diagnosed with PIMS-TS.

In line with the adult service specification the CYP will follow the same model with the phases clearly identified as Figure 1 below.

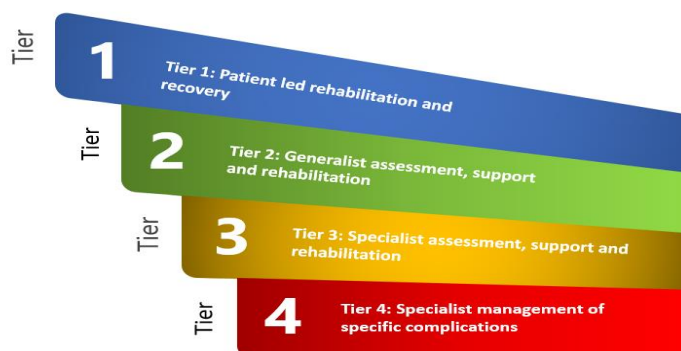
Figure 1: Guideline to supporting the recovery and rehabilitation of adults with confirmed or suspected COVID-19 in Greater Manchester (2020).



## Tiered approach to the management of Post-Acute COVID-19

Whilst the pathway in fig. 1 outlines a linear approach to managing COVID-19, the following figure outlines a management model weighted by the level of intervention necessary (see fig.2). Typically, the higher the tier, the more resource intensive. Comparatively, it is likely the higher the tier, the fewer CYP requiring it.

Figure 2: Tiers of intervention post-COVID-19



### **Tier 1 (Primary care)**

- ✓ Parent/ carer support to aid 'patient-led'
- ✓ Education/material provided about the disease and recovery e.g. <https://www.longcovidkids.org/resources>
- ✓ Referral to Your COVID recovery
- ✓ Parent, care and/or young person Self-monitoring and reporting back to GP with worsening symptoms

### **Tier 2 (primary care)**

- ✓ Therapeutic relationship with a generalist clinician (e.g. GP, ANP, Children's Community Nursing team (CCNt), physio, OT) who have responsibility for the CYP overall care and helps them navigate the system
- ✓ Full history, clinical examination including functional and psychosocial assessment
- ✓ Confirm that Post COVID Syndrome is the likely or possible diagnosis (even in the absence of a positive test), and document on medical record
- ✓ Investigations to determine on underlying illness unrelated to post COVID-19 e.g. bloods, FBC ferritin, CRP, U&Es, LFTs, Bone TFTs, coeliac screen, glucose. These children need to be reviewed in paediatric OPD within the DGHS.
- ✓ Ongoing monitoring and support (e.g. by telephone, video, or in-person check-ups) as needed
- ✓ Management of other long-term conditions (e.g. diabetes, asthma)
- ✓ Offer advice and guidance to tier 3 of what services are locally available
- ✓ Referral to Tier 3 as appropriate
- ✓ Referral to CAMHS

### **Tier 3 (Secondary care/ MDT)**

- ✓ Within RMCH Dedicated Paediatric COVID-19 rehabilitation clinic, currently these have developed within existing services and need to be realigned with an increase in available sessions without displacing the day to day service business
- ✓ CYP require assessments at 2 and 6-week intervals post-discharge and continue beyond three months.
- ✓ Personalised rehabilitation plan with (e.g.) breathing exercises, supervised pacing and psychological support
- ✓ Referral to other specialties as appropriate e.g. cardiology, rheumatology
- ✓ Testing according to specialist guidelines (e.g. CT, MRI)
- ✓ Dialogue and agreed division of responsibility between specialties, ICU and primary care.
- ✓ Offers advice and guidance to tier 2 services

### **Tier 4 (Tertiary care/ MDT)**

- ✓ GM dedicated MDT PIMS-TS service for all children that required critical care
- ✓ Management of specific conditions, cardiac, rheumatology, general paediatricians, intensivists
- ✓ Psychosocial and CAMHS input
- ✓ Chronic Fatigue Syndrome services

## **Proposals to support Long-COVID-19 and COVID-19 complications for GM CYP.**

### **Tier 3 & 4**

In line with the support for tier 3 & 4 it is clear that current provision of Specialist care is under extreme pressure. Non-urgent and new referrals are currently not able to be accommodated within the current services. Waiting list for routine activity in some of the specialist departments is now at peak level of 50 weeks plus. Clinics for PIMS-TS have developed rapidly within existing services at MFT RMCH.

To enable follow up the services would need to expand in both Rheumatology and Cardiology. Broadening both of these teams at consultant level will capture the majority of post-covid and covid complications in children.

It would be wise to consider additional support especially in relation to Rheumatology with an expansion of the team to include an Advanced Care Practitioner post.

To provide a dedicated GM MDT PIMS-TS service will require additional funding and personnel over and above what is currently in the Medical job plans.

For those CYP who straddle tier 2 and 3 and especially those that have been clinically managed locally with specialist input from RMCH given remotely, MDT clinics need to be developed. These clinics should run at the DGH localities. There should be availability for CYP who have been inpatients for follow up as described in the guidance of routine OPD as well as access if needed to the more specialist MDT outreach clinics.

Ideally the clinics should be held locally within reach from the tertiary specialist to form an MDT. This would create significant impact on the existing pressures at RMCH. If each of the respective DGH's had at least 1 MDT clinic with input from RMCH it would require 7 clinic sessions across GM. This would again increase the workload not only of RMCH but also the DGHs to clinically manage OPD for CYP with Long-Covid or Covid complications. That said it would make inroads for Primary and Community services to access clinics for CYP who present in the localities.

#### **Tier 1 & 2**

In line with support for tier 1 & 2, those CYP who require follow up should be able to access General Paediatric OPD clinically managed local with an option to access the more specialist MDT in-reach OPD clinics. Some CYP will require input from the specialist teams and both secondary and primary care teams, plus children's community health services (Local Care Organisation- LCO) such as CCNt, physiotherapy or school health.

Currently DGH services are liaising with RMCH for specialist advice. A recent diary exercise (RMCH) highlights the increase in numbers of remote consultations and time of support via telephone is as much as 2 hours a day. Any investment in development of the specialist services to maintain this substantial increase in demand on their services would need to include the 'Hot Line' specialist advice for DGHs.

Expansion of existing MDT capacity needs consideration for Virtual clinics and virtual MS Teams meetings.

Less is known about CAMHS services at the present time. And, while not a priority at the present time it is essential that acknowledgement of the considerable increase in demand for CAMHS services. It is likely to become a much bigger predicament in the very near future. There is clearly an immense issue with CYP and the anxiety/depression they are experiencing. More needs to be developed to aid the CYP cognitive ability to understand COVID19 and the impact it is having on society.

What is perfectly reasonable and understandable to adults in conversations with Children they tell us they have limited understanding of Covid19 beyond it is a virus that makes people become very ill and die. The children especially younger children with low cognitive levels have real fear and anxiety that Covid is all around.....even under their bed waiting to get them!!

It is of major importance that we can help children and alleviate their anxieties by simplifying the message and media we can develop and share.

Less is known on the demand from Primary care and the demand for follow up for CYP. It is clear that some CYP will require follow up in DGH OPD paediatric clinics while others will require more specialist input. There is limited data available to determine the demand at the present time.

## **GLOSSARY**

ANP/ACP	Advanced Nurse/Care Practitioner
BPSU RCPCH	British Paediatric Surveillance Unit Royal College of Paediatrics and Child Health
CAMHS	Child and Adolescent Mental Health Service
CCNt	Children's Community Nursing team
COVID-19	Coronavirus Disease 2019
CT (scan)	Computerised Tomography (scan)
CYP	Children and Young People
DGH	District General Hospital
DKA	Diabetic Ketoacidosis
DKA	Diabetic Ketoacidocis
GP(s)	General Practitioner(s)
HLH	Hemophagocytic Lymphocytic Histiocytosis
KAWASAKI DISEASE	A rare condition that mainly affects children under the age of five. It is also known as Mucocutaneous Lymph Node Syndrome.
MDT	Multidisciplinary Team(s)
ME (CFS)	Myalgic Encephalomyelitis (also known as Chronic Fatigue Syndrome)
MFT	Manchester University Hospitals NHS Foundation Trust
MRI (scan)	Magnetic Resonance Imaging
NAI	Non-Accidental Injury
NHS	National Health Service
NHSEI	NHS England and Improvement
NWTS	North West and North Wales Transport Service
OPD	Outpatient Department
OT	Occupational Therapy/ist
PICU	Paediatric Intensive Care Unit
PIMS-TS	Paediatric Multisystem Inflammatory Syndrome
RMCH	Royal Manchester Children's Hospital (tertiary care)
ROH	Royal Oldham Hospital
SARS-CoV-2	Severe Acute Respiratory Syndrome Coronavirus 2
SLE	Systemic Lupus Erythematosus
T1DM	Type 1 Diabetes Mellitus