CVDR/S6/23/5/2

COVID-19 Recovery Committee

5th Meeting, 2023 (Session 6), Thursday, 2 March 2023

Long COVID – Comparative approaches

At this meeting Members will have an opportunity to discuss the development of long COVID services in England and Wales.

- **Dr David Strain**, Senior Clinical Lecturer, University of Exeter Medical School, Lead on Long-Covid, British Medical Association, Member of the NHS Long-COVID Taskforce

- **Dr Melissa Heightman**, Clinical Lead, Post Covid Service UCLH and NCL Respiratory Network, National Specialty Advisor, Long COVID Program, NHS England

- **Claire Jones**, Advanced Clinical Practitioner and Long COVID Therapy Lead, Betsi Cadwaladr University Health Board

The Committee launched a call for views and the published submissions can be viewed online. The Committee also wrote to the Cabinet Secretary for Health and Social Care at the start of the inquiry and the response can be read here.

SPICe published an updated blog on long COVID on 09 February 2023.

Background

Dr Melissa Heightman leads a post covid service based at University College London Hospitals. She is also the National Speciality adviser to the long covid program in NHS England.

Dr David Strain is a Senior Clinical Lecturer at the University of Exeter Medical School. He is the Clinical Lead for COVID services at the Royal Devon and Exeter NHS Foundation Trust.

Claire Jones is an Advanced Clinical Practitioner and Long COVID Therapy Lead at Betsi Cadwaladr University Health Board.
Members may wish to discuss the following themes with witnesses.

Themes

Theme 1: Long COVID pathways across the UK

The NICE guideline on managing the long-term effects of COVID-19 applies across the UK. However, there has been some variation in how services for long COVID have been organised. In England the NHS has established 90 post COVID assessment services clinics. These are intended to provide access to specialist diagnosis, treatment and rehabilitation.

In July 2022, NHS England, published National commissioning guidance for post COVID services. This sets out post COVID service requirements, referral routes and criteria for post COVID services, pathways of care and the role of primary care, multidisciplinary rehabilitation, children and young people – including the CYP patient pathway, workforce, data management and information and key service outcomes.

This was published alongside the NHS plan for improving long COVID services.

A similar approach has been taken in Northern Ireland.

In Wales, as in Scotland, support is provided within the wider NHS services through local health boards. The Welsh Government published the All Wales Community Pathway for Long-COVID, in June 2021. The NHS Wales Respiratory Health Group has developed a long COVID Recovery App as part of the wider support available for people experiencing the longer-term effects of COVID-19.

Annexe A shows the long COVID pathways in England, Wales and Scotland. Annexe B summarises the key barriers and enablers to service development that were highlighted by Scottish NHS Boards.

Members may wish to ask:

- **How are long COVID services are organised in England and Wales?**
- **Is the approach taken consistent in each Country or are there variations in the pathways of care?**
- **What are the enablers to developing holistic and person centred services?**

Theme 2: Post COVID services

The English NHS National commissioning guidance for post COVID services sets out that post COVID services should be available if required following primary care or other clinician referral to all affected patients from four weeks after the start of acute COVID-19 illness. It notes that post COVID services "should provide a coordinated whole pathway of assessment, treatment and multifaceted rehabilitation and psychology support with direct access to required diagnostics".

In a submission to the Committee the Long Covid Rehabilitation in Scotland study team reported that in its study many of the people interviewed reported that specialist Long Covid assessment clinics would enable greater integrated holistic care from services and avoid multiple referrals to various secondary care/specialist services.

In their written submissions both the Royal College of General Practitioners and the Royal College of Physicians Edinburgh (RCPE) called for an evaluation of the clinics set up in England. The RCPE said:

> "In other parts of the UK these are up and running and appear to have had some benefit but we understand some remain overwhelmed and consider that it would be extremely helpful to see the data from England on their outcomes to make an informed evaluation about whether they may be an appropriate development here but we do believe their establishment merits serious consideration."

A submission from a team of researchers from the Universities of Stirling, Aberdeen and Oxford who have undertaken a number of linked studies including the COv-VOICES study (Long Covid: Amplifying the voices of people with lived experience to improve understanding, support, treatment and education) reported:

> "Many of the people that we interviewed said that Long Covid clinics should be available to everyone with Long Covid in all parts of the UK. They thought that people with Long Covid symptoms should be able to go to a service which involves 'joined-up' care and includes a range of healthcare professionals, such as specialists in neurology, cardiology, respiratory medicine, physiotherapy, occupational therapy, and psychology. People described the challenges and exhaustion of having to repeat their recent medical history in a range of medical settings and the difficulties of accessing appointments. Some people we spoke to lived in areas where Long Covid clinics had been set up. They told us about long waiting lists, having to chase up referrals and how ease of access varied from area to area. Participants reported mixed experiences of attending Long Covid clinics. Appointments were often remote and participants said they would have appreciated the opportunity to be seen in person. Some found their initial appointment disappointing and not useful because they were not offered any further tests, referrals, or follow-up appointments. Some were referred to other specialists by the Long Covid clinic, which meant being placed onto another long waiting list. A few participants told us about positive experiences of Long Covid clinics, which included feeling understood, believed and not dismissed by

healthcare professionals at the clinic and also feeling that practitioners had up-to-date knowledge of the relevant research."

Members may wish to ask:

- **What are the key benefits of the approach used in their area?**
- **What are the key limitations of the approach?**
- **How is the impact of the long COVID services in their area being evaluated? What are the findings to date?**
- **Have people with long COVID been involved in the planning of the long COVID services and in directing their own care?**

Theme 3: Sustainability of services

The NHS England document the NHS plan for improving long COVID services outlines key actions in relation to increasing capacity. It notes that:

> "There is likely to be an ongoing requirement for the assessment and treatment of patients with long COVID in the longer term, although the future demand for post COVID services is difficult to predict."

In relation to workforce, the national commissioning guidance for post COVID services, states:

> "Post COVID services should provide integrated, multidisciplinary rehabilitation services, based on local need and resources. Healthcare professionals should have a range of specialist skills, with expertise in treating fatigue and respiratory symptoms (including breathlessness)".

The majority of submissions from Scottish NHS Boards highlighted issues recruiting staff to specialist posts such as Rehabilitation Co-ordinator, Occupational Therapists and Physiotherapists.

The Office for National Statistics has estimated 2.0 million people living in private households in the UK (3.0% of the population) were experiencing self-reported long COVID (symptoms continuing for more than four weeks after the first confirmed or suspected coronavirus (COVID-19) infection.

Members may wish to ask:

- **Are witnesses aware of difficulties recruiting staff for long COVID posts? If so, how have these been addressed?**
- **Due to the high number of people estimated to have long COVID – is there capacity in the system to deal with this level of un-met need?**
- **Is there capacity in the long COVID clinics to meet demand? How long do people have to wait to access services and what support is available to them during this time?**
- **How are post COVID services funded? Is the funding re-occurring?**

Theme 4: Equalities

NHS England's national commissioning guidance for post COVID services, notes that post COVID services should be accessible to people from communities and sub-populations who experience health inequalities.

Stating that in planning and delivering post COVID services healthcare systems should consider how they will minimise health inequalities, including for those with a protected characteristic as well as underserved or marginalised communities:

- socio-economically deprived, especially those in the lowest 20% as measured by the Index of Multiple Deprivation (IMD)
- inclusion health groups (homeless and Traveller communities)
- rural and coastal communities
- those with language and cultural barriers, particularly those with lower literacy levels (they will need the same information as others but in accessible formats)
- people in secure units, prisons and other incarcerated people.

It also advises that post COVID services should be aware of diagnostic overshadowing and make reasonable adjustments as required for people with:

- a learning disability and/or who are autistic, or pre-existing mental health problems
- another disability such as visual or hearing impairment

Members may wish to ask:

- **What steps have been taken to ensure that post COVID services are accessible to people from marginalised groups?**
- **What lessons have been learned in the development of post COVID services to ensure that health inequalities are not exacerbated?**
- **What steps have been taken to address the possibility of diagnostic overshadowing?**

Theme 5: Research and data

The national commissioning guidance for post COVID services recommends that post COVID services support new and ongoing research. Noting that:

> "Due to the paucity of information surrounding long COVID, there is an urgent need for data to inform clinical management and health access for those disproportionally impacted by COVID-19. Data is used to support funding, operational decisions and research, and data quality is a key component of the commission for post COVID services".

The NHS plan for improving long COVID services states:

> "Since July 2021, NHS England has maintained a national registry for patients attending post COVID services. This includes data linkage across multiple NHS data sources, including demographic, inpatient and outpatient activity, diagnostic imaging, COVID testing and vaccination data. It has enabled insight into the natural history of long COVID and the journey for patients with long COVID, supporting equitable service. NHS England will further develop the long COVID registry and harness registry data, including by working with NIHR research programmes, to generate insights that add to the evidence base on long COVID and inform future service planning, treatment and care for people with long COVID."

Members may wish to ask:

- **In what ways are long COVID services able to contribute to research into the condition? Is this easier in standalone long COVID clinics?**
- **What are the potential uses for a national registry for patients attending post COVID services?**
- **How are users of post COVID services informed about opportunities to participate in long COVID research?**

Theme 6: Sharing learning

The national commission guidance for post COVID services in England recommends that services "share learning in terms of knowledge, skills and training across providers in their pathway, e.g. through webinars, video content or shared learning events".

The NHS Plan for improving long COVID services provides information on the long COVID programme national learning network. It noted this was established to provide a collaborative space for healthcare professionals to share service delivery challenges and develop creative and innovative solutions. The network is open to those setting up and running post COVID clinics and has over 1,400 members.

The Scottish Government has established a National Strategic Network. This was established in March 2022 to provide national support to building the capacity, capability and co-ordination of health and social care services for people with long-term effects of COVID-19.

At the meeting on 23 February members heard from Public Health Scotland (PHS) in relation to its long COVID newsletter/ bulletin.

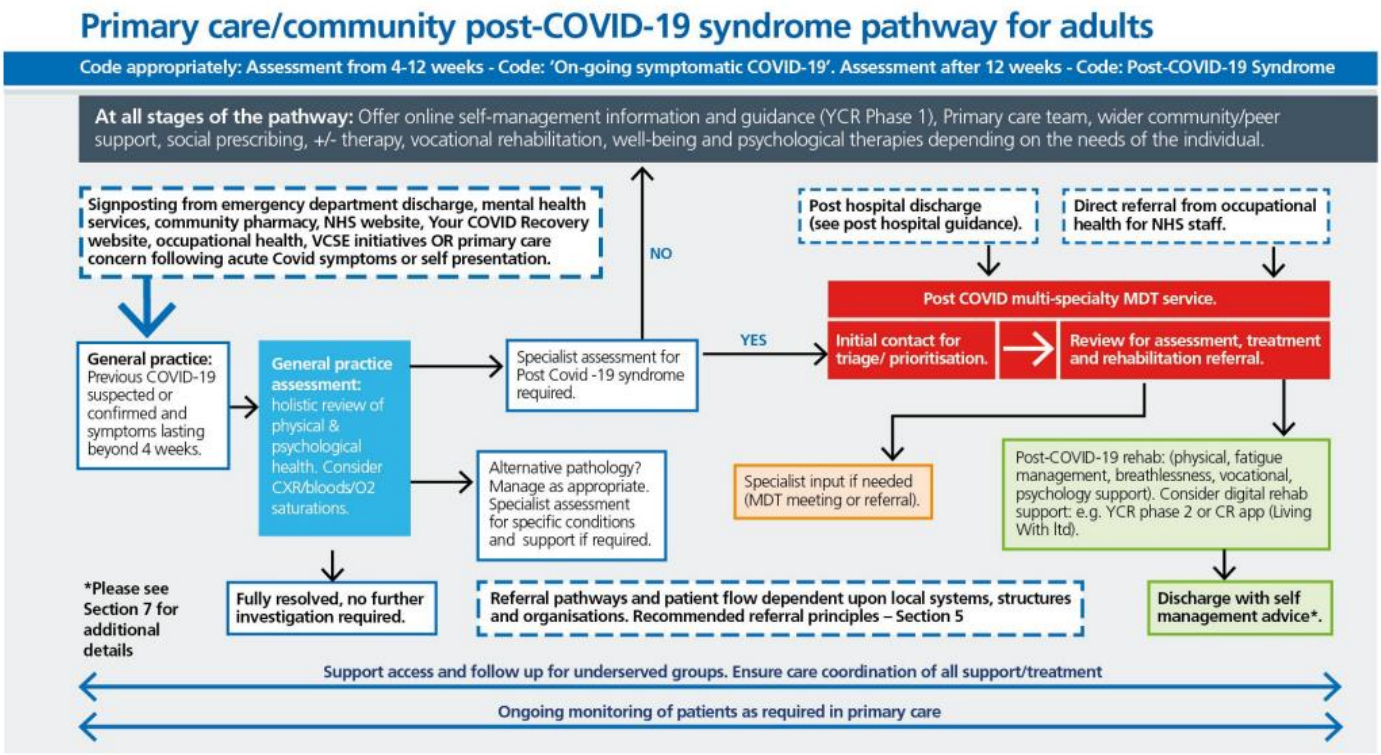
Members also heard from NHS Highland about its involvement in the LOCOMOTION long COVID study. This study is aims to set a "gold standard for care by analysing what is happening to patients now, creating new systems of care and evaluating them to establish best practice". This research will take place in three settings; long COVID clinics; at home (including self-monitoring on a mobile device); and in primary care.

Members may wish to ask:

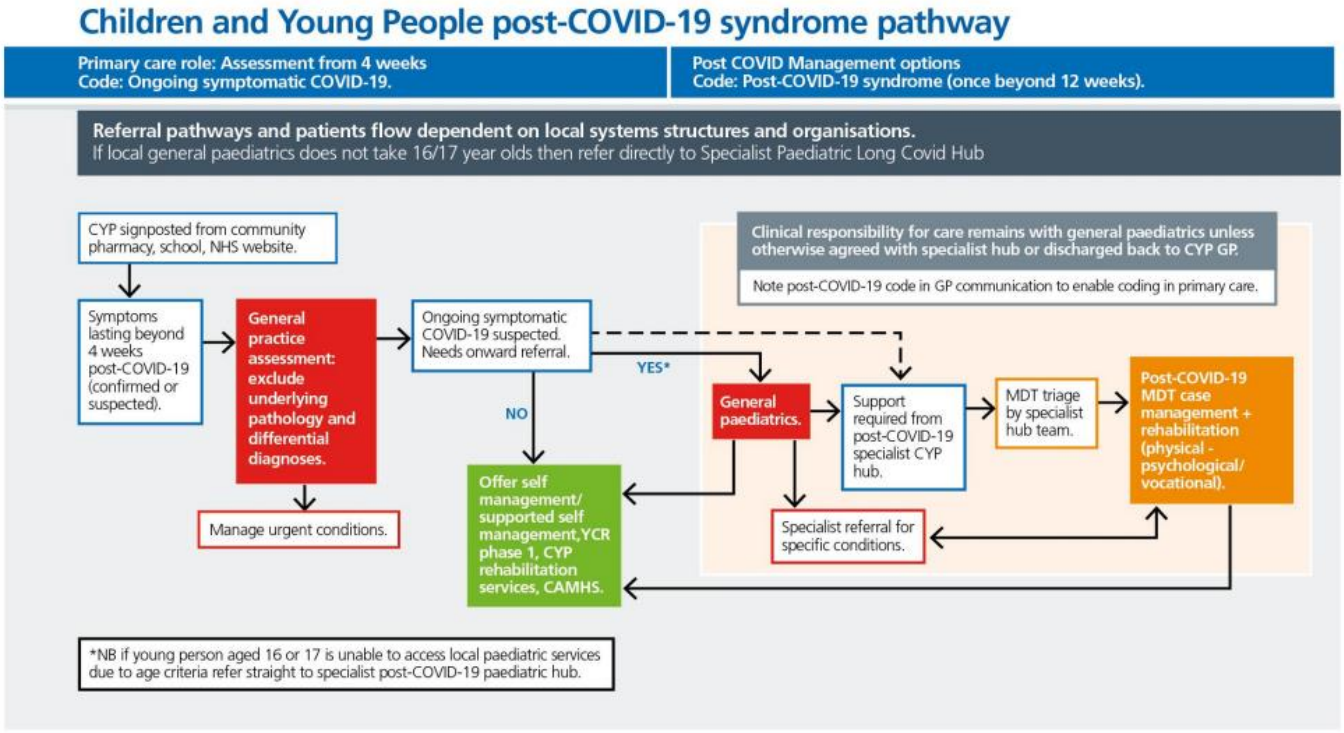
- **What impact/ role has sharing learning had in the development of long COVID services in your area?**
- **What do you consider is the best way to share information on best practice with healthcare providers across all settings?**
- **Is there a good level of knowledge among GPs in each Country about long COVID and the services available for onward referral?**
- **To what extent are examples of good practice and learning being shared across the whole of the UK? How could this be facilitated?**

Annexe A: Pathways of care

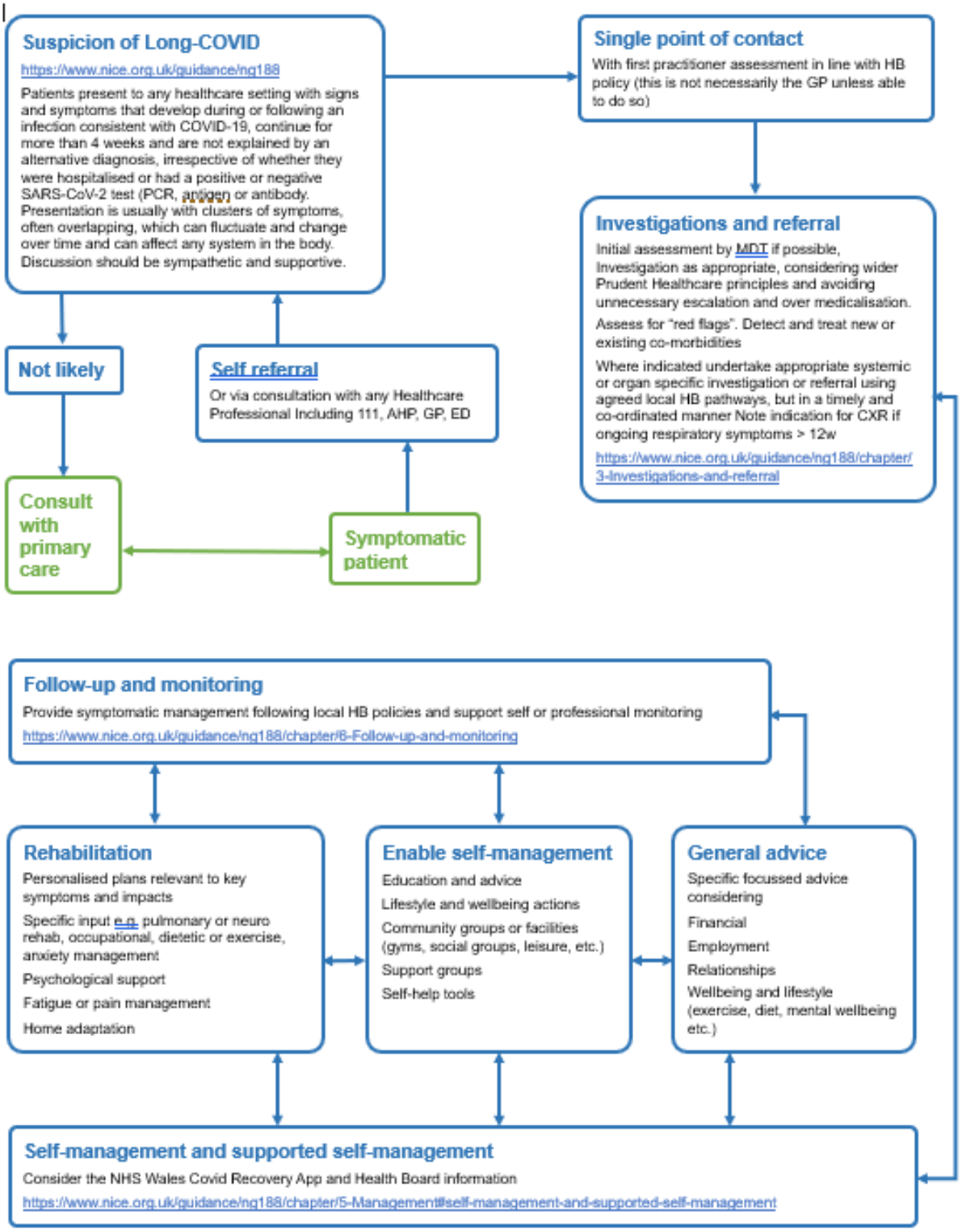
NHS England: [Post COVID-19 syndrome primary care/community pathway for adults]



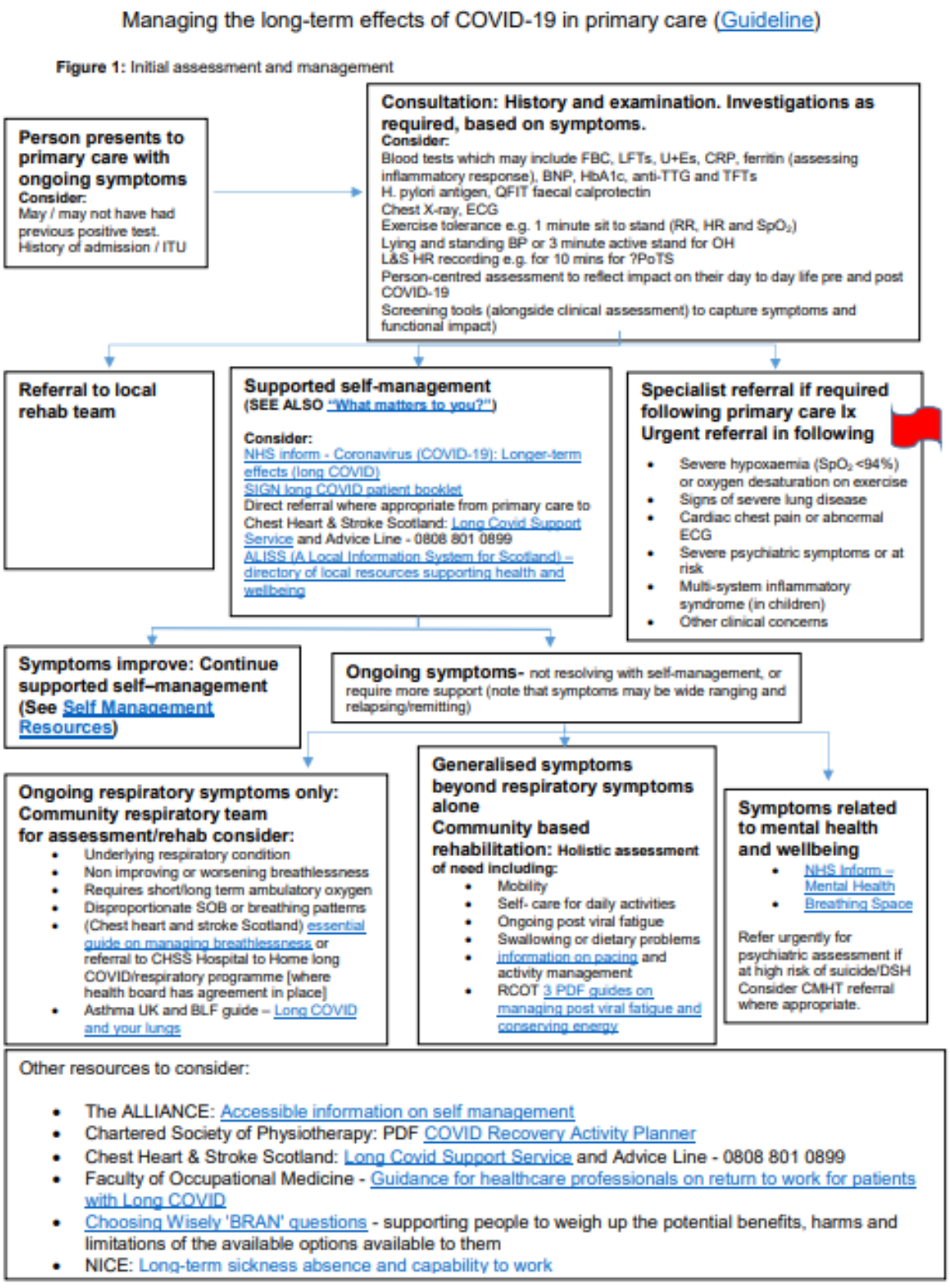
NHS England: [Children and young people post COVID-19 syndrome pathway]



All Wales Community Pathway for Long-COVID



Scottish Government: [Managing the long-term effects of COVID-19. Implementation support note.]



Annexe B Barriers and enablers highlighted by Scottish NHS Boards.

In its letter to health Boards the Committee asked for information on the barriers to service development and examples of good practice and enablers. The responses received to date have been summarised below.

Barriers

Funding

- Lack of funding available to develop a clinical MDT service
- No established funding for aligned medial assessment
- Delay in funding (May 2022)
- Non-recurring nature of the funding
- Two separate pathways for funding MACH and long COVID.
- Leadership time is not funded
- Uncertainty regarding recurrent national funding allocation is a limiting factor
- Initial lack of certainty of funding beyond 2022/23 made recruitment to new posts challenging

Recruitment

- Recruitment challenges - need to readvertise posts
- Issues recruiting within nursing, occupational therapy and physiotherapy
- Short term nature of posts makes them harder to fill – lack of financial security

Capacity

- Increased demand for existing services
- Need time to establish skills
- Lack of understanding in workforce
- Whole system pressures impact on service development
- Systemic operational pressures required an organisational emphasis on urgent care.

Expectations

- Expectations of patients
- Lack of guidance for public on accessing services outside the NHS
- Scottish Government has said it is unable to disseminate information about the Thistle Foundations programme funded by the Scottish Government
- Some people seeking support have expected a biomedical model rather than a biopsychosocial model of support
- Capacity to provide the necessary interventions for the required period is stretched

National model

- Siloed approach – difficult to provide holistic service

- Lack of alignment with model and provision in England
- More capacity for Once for Scotland approach
- Limited facilities in smaller boards
- Other operational matters such as establishing electronic pathways, digital screening platform
- Uncertainty of diagnostic criteria, emerging evidence in efficacy of therapeutic interventions

Research and evaluation

- Data – little Scottish data available
- Lack of data on demand and symptom profile
- Limited studies to evidence education – currently informal
- Initial lack of long COVID research to inform service modelling

Enablers/ good practice

Engagement

- Engagement with children and their families and adults
- Developing personal relationships with patients

Education and resources

- Information packs and signposting
- Chest Heart and Stroke Scotland's service
- Development of educational resources

National service and leadership

- National Service leads group
- Project delivery board
- Professional network
- Need for flexibility

Digital

- Use of C19-YRS App
- Virtual working and use of technology

Multi-disciplinary team

- Involvement of Occupational Therapy, Physiotherapy, Psychology, Respiratory
- Third sector and industry involvement and collaboration