

Siobhian Brown MSP  
COVID-19 Recovery Committee  
The Scottish Parliament  
Edinburgh  
EH99 1SP

17<sup>th</sup> February 2023

Dear Ms Brown,

**Re: Enquiry into Long COVID**

The below information has been compiled in reply to your enquiry regarding Lanarkshire's response to Long Covid. Please note that an organisational submission was also made via the online form, which in part duplicates the below detail.

**Current services available including information on how the Scottish Government funding has been used:**

In Lanarkshire, the ONS data suggest there are 22,500 people reporting Long Covid symptoms. Of those, 3,800 report their symptoms limit them a lot on a daily basis. This is the cohort of people who may require rehabilitation, a slowly rising figure. Informed by SIGN 161 Managing the long term effects of COVID-19, local funding along with Scottish Government allocation supported a business case to establish a Long Covid Rehabilitation Pathway for a fixed term, 2022-2024 (Scottish Government funding applicable 2022-2025). As per SIGN 161, this pathway includes a single access point to a skilled interdisciplinary team of dietetics, occupational therapy, physiotherapy, psychology and speech & language therapy – the Covid Rehabilitation Team. The pathway functions as 'one-stop shop' for rehabilitation but is appropriately integrated within the wider health and care system to support individualised care planning. Leadership is provided through a clinical service lead with associated organisational management and professional oversight.

Once appropriate investigation of presenting symptoms has occurred and Long Covid is considered a reasonable diagnosis, the first recommendation is sign-posting to self-management resources, such as NHS Inform, Chest Heart and Stroke Scotland, local NHS Lanarkshire microsite– ([www.nhslanarkshire.scot.nhs.uk/services/covidrehab](http://www.nhslanarkshire.scot.nhs.uk/services/covidrehab)). However, for those for whom self-management is not appropriate, or has not helped, referral can be made to the Covid Rehabilitation Team.

Once referred to the Covid Rehabilitation Team, the person completes four patient reported outcome measures. Each referral is currently triaged by the team using the outcome of these measures, the information from the referral form and electronic patient records. The

triage outcome informs which intervention is appropriate (continued self-management, virtual group programme and/or one-to-one intervention) and which profession will provide first assessment. All people receiving one-to-one intervention receive a general assessment across all symptom domains and commence shared goal setting.

A person's rehabilitation episode can include multiple professions and intervention modes. For example, one person could receive intervention from physiotherapy, occupational therapy and dietetics as well as attending the group programme. Interventions can be delivered virtually, in clinics across Lanarkshire or in a person's own home.

The pathway is well integrated with primary and secondary care along with third sector provisions supporting an individual's journey. Along with national tools, support for clinicians regarding Long Covid is provided via Lanarkshire's Clinical Guidelines App, Long Covid intranet page and via informal contact with the team. Multiple standard operating procedures support the practical application of the principles of Realistic Medicine to ensure people with Long Covid have the appropriate rehabilitation episode required to have maximal effect.

Lanarkshire has representation throughout the groups of the National Services Scotland Long Covid Network. Lanarkshire has relational links with Long Covid charities and advocacy groups. Lanarkshire's pathway benefits greatly from the lived experience of its residents.

The pathway is fully funded until 31/03/2024 with an almost 50:50 split between local and national funding; £358,207 from Lanarkshire and £320,007 from Scottish Government. From 01/04/2024, the local funding will cease leaving national funding only with no additional funding currently anticipated after 31/03/2025.

Detail of funding use:

<b>Funded Posts (WTE)</b>	<b>Expected spend to March 2023</b>	<b>Expected spend 2023/24</b>
1 B8b Clinical Service Lead	£80,739	£80,739
4.8 (2xB7 3xB6) Physiotherapist	£261,620	£261,620
1.8 (1x B7, 0.8wte x B6) OT	£86,484	£86,484
2.0 (1 B8a, 1 B7 CAAP) Psychologist	£122,114	£122,114
0.2 B6 Speech & Language Therapist	£8,128	£8,128
0.2 B7 Dietician	£9,485	£9,485
2x B3 Admin & Clerical	£57,599	£57,599
Digital Screening Platform	£10,379	£10,379
IT resources	£20,000	£20,000
Equipment and supplies	£10,000	£10,000
Travel	£5,000	£5,000
<b>Total</b>	<b>£671,548</b>	<b>£671,548</b>

### Current pathway activity:

Lanarkshire's pathway became operational on 26<sup>th</sup> May 2022. The communication strategy focused on raising awareness regarding Long Covid, increasing the profile of pathway and referral process.

As of end of January 2023, the pathway has directed 586 referrals to the Covid Rehabilitation Team. This team have 285 people currently under active review. The average waiting time is 20 weeks. The majority of people require the intervention of more than one profession. The significant majority of people reviewed are triaged with moderate-severe and severe symptoms and require one-to-one intervention. The median monthly referral rate is 79 referrals per month with no observable reduction at the end of the eighth month (January'23). 57% of referrals come from GPs, with the rest spread between secondary care, rehabilitation and NHS Lanarkshire's occupational health.

So far, 26 people have completed their rehabilitation episode with the Covid Rehabilitation Team. Discharge from the Covid Rehabilitation Team does not indicate symptom resolution, but rather ability to self-manage. The person is able to contact the team to self-refer if they require support a later date.

Current evaluation of clinical outcome measures to report on the impact of the pathway has not occurred because the required number of datasets from people completing their rehabilitation has not yet been achieved.

### **Barriers to service development and provision:**

- Public Health Data – initial absence of national and local data to understand prevalence, severity, aetiology, risk factors. This is improving through the National Services Scotland Long Covid Network.
- Research – initial lack of Long Covid specific research to inform response and support service modelling.
- Biopsychosocial Model – rehabilitation is most effective within a biopsychosocial model of care as it allows for biological, psychological, interpersonal and contextual health determinants. This has been a barrier for some people seeking support from the pathway who have more experience, and thus understandable expectation, of a biomedical model. A simplified description of the biomedical model would be diagnosis, medical treatment and cure.
- Operational context – systemic operational pressures required an organisational emphasis on urgent care.
- Clinical capacity – For those referred to the Covid Rehabilitation Team, the majority of people have severe symptoms (measured using the C-19 Yorkshire Rehabilitation Scale). Most people require face-to-face intervention from multiple professions. Clinical capability has been grown, but clinical capacity to provide the necessary interventions for the required period is stretched. Uncertainty regarding recurrent national funding allocation is a limiting factor.

- There were other operational matters which required to be worked through locally such as, access to RT proBNP diagnostic blood test in the community setting, introducing a digital screening platform, establishing electronic pathways and recruitment.

### Examples of good practice:

We are confident that Lanarkshire’s model of an integrated rehabilitation pathway supported by primary care, secondary care and third sector reflects the current evidence base for management of Long Covid. We assess the impact of the pathway through a variety of measures, these are the core set:

Outcome Measures	Process Measures	Balancing Measures
Number of Referrals Received	Average waiting time	Datix / Complaints / Compliments
Clinical: Covid-19 Yorkshire Rehabilitation Scale	Average length of episode	Staff Well-being
Clinical: Patient Health Questionnaire (PHQ-9)	Number of patients on waiting list	Professional Satisfaction with CRT
Clinical: Generalised Anxiety Disorder Ass'ment (GAD-7)	Number of breaches	– all referrers, emphasis on GP & SALUS
Clinical: Quality of Life measure- EQ-5D-5L	Longest wait	
Clinical: Goal Attainment Scale (GAS)	Referral Source	
Patient Experience	Number of return referrals due to relapse	

Sandra’s experience (shared with permission) demonstrates the use of the crucial Patient Experience outcome measure. Her story is indicative of many of the people who have accessed the Lanarkshire’s Long Covid Rehabilitation pathway:

Hi I’m Sandra, I’m 39 and I’m married with 2 kids. Before covid I was a community carer, full time. I walked my dog 4 miles every morning. I had a boxing bag in my living room and was a very active person from the minute I woke up.

I caught covid in October 2020 and my breathing was terrible, I couldn’t swallow and spent most of the 14 days’ isolation in bed, I lost all sense of taste and smell which still hasn’t returned so now eating is a chore as I used to enjoy my food.

When returning to work, my Dad passed from covid so I took some time off to organise his affairs and look after my mum. When I returned to work full time I felt I couldn’t keep up, struggling to breathe and was so tired all the time and fatigued with every bit of physical activity.

Since then I have been to see a lot of doctors about how I felt. I have had lots of hospital appointments and test which range from stress test to respiratory tests to heart and blood pressure monitors and most recently a MRI which I’m still waiting results from but unfortunately they all came back normal and to no fault of their own the doctors just didn’t know how to help me. I felt very low and isolated.

I was told about the covid rehab team and felt like hopefully some help, some answers and maybe not to feel so helpless and alone in what I was going through. This whole journey has not just affected myself but my whole family especially my husband who has had to take on most of my roles of the household. I have been having regular appointments with Tara and Pamela and from the very first meeting they have helped with not just physical obstacles but mental and emotional ones too.

I went from struggling to get dressed and wash my hair to being able to learn how to pace myself. I can now manage to wash my own hair properly which is massive! I still have a long way to go and I know that, and I know I won't get back to the way I was but having the support from the rehab team is giving me the confidence to keep trying.

### **Details of future plans for long COVID service provision in the short and medium term:**

#### Short-term (2023-2024):

For 2023-2024, the pathway will continue as described. In 2024-2025, the pathway will only have 47% of current funding requiring a stepdown in bespoke delivery and consideration of how existing services can absorb activity. It is currently anticipated that the funded portion of the pathway will focus on:

- care coordination (i.e. ensuring people are screened and supported to access the interventions best suited to their needs)
- clinical capability – ensuring that capability is retained in the management of symptoms less familiar to the wider health and care system (for example, postural orthostatic tachycardia syndrome)
- clinical capacity – ensuring that capacity is retained in the areas that absorption of Long Covid activity has significant negative impact on the service undertaking the absorption.

Local, national and academic focus will support the data collection needed to better inform medium to long-term planning in relation to Long Covid.

#### Medium-term (2025 onwards):

As the data emerges, stakeholder discussion will inform the medium and long-term management plan. This will also be influenced by national discussion and any further iteration of relevant clinical guidelines.

The currently unquantifiable risk related to the unknown long-term Long Covid prevalence and the associated need for health and care intervention. Initial local and national hypothesis expected activity to follow a bell-shaped trajectory with an initial 'hump' of demand but with a subsequent reduction back down to a low level. Once that initial demand is managed, this would allow for relatively simple mainstreaming into existing service provision.

For Lanarkshire's pathway, now in its eighth month, it is too early to assess against that initial hypothesis. Aside from an initial spike, the monthly referral rate has not grossly varied. It is unclear if the monthly referral rate will reduce, and if so when.

Along with other unknowns that clinical research *may* establish, one potential development is improved Long Covid phenotyping. Better defined symptom clusters and an

understanding of the differing underlying pathophysiology allows pathways to better meet the needs of people.

Building on the learning and our experience of the pandemic, rehabilitation for Long Covid would now benefit from the condition specific pathway being transitioned into ongoing delivery through mainstream rehabilitation pathways thus enhancing value-based care provision.

Long Covid has been, and will be, an opportunity for Lanarkshire to learn. The lessons from Long Covid are already being shared across the whole health and care system with specific focus for rehabilitation and long term conditions management.

If you require any further detail in relation to the content of this response, please don't hesitate to enquire.

Yours sincerely,

Paul Cannon  
Board Secretary

On behalf of NHS Lanarkshire