

COVID-19 Recovery Committee

4th Meeting, 2022 (Session 6), Thursday 23 February 2023

Long COVID inquiry

Introduction

1. This inquiry will focus on which will focus on diagnosis, treatment and current support available to those with long COVID. The aim of the inquiry is to scrutinise what action the Scottish Government is taking to address long COVID and post COVID syndrome. The inquiry will focus on the following three main themes—
 - Awareness and recognition
 - Therapy and rehabilitation
 - Study and research
2. This is the second formal evidence session of the inquiry, in which the Committee will focus on therapy and rehabilitation services and will explore the development of long COVID services and pathways in Scotland. The Committee will take evidence from the following two panels of witnesses—

Panel 1

- Jane-Claire Judson, Chief Executive and Dr Amy Small, Clinical Advisor Chest Heart & Stroke Scotland (CHSS)
- Dr David Shackles, Joint Chair, Royal College of GPs Scotland (RCGP Scotland)
- Lorraine Crothers, Board member, The Royal College of Occupational Therapists (RCOT)
- Dr Claire Taylor, Tayside Complete Health Ltd

Panel 2

- Judy Thomson, Director of Training for Psychology Services, and Professor Lindsay Donaldson, Deputy Medical Director, NHS Education for Scotland
- Linda Currie, Associate AHP Director, NHS Highland
- Heather Cameron, Director of Allied Health Professions, NHS Lothian

- Janis Heaney, Associate Director – National Strategic Networks, National Specialist and Screening Services Directorate (NSD), NHS National Services Scotland
- Manira Ahmad, Chief Officer, Public Health Scotland

Background

3. In July 2021, SPICe published a [blog on long COVID](#) which set out what long COVID is, how many people were affected at that time, and how it is being treated and managed in Scotland. In February 2023, SPICe produced an updated blog, [Long COVID: where are we now?](#) for this inquiry.

Scottish Government position

4. In advance of launching the inquiry the Committee [wrote](#) to the Scottish Government seeking an update on its current position regarding long COVID. The Committee requested information on the following—
 - Further information on the £2.5 million supported nine research projects commissioned by the Scottish Government into long COVID;
 - Details of funding allocations of the £10 million long COVID support fund to date and future investment plans for addressing long COVID;
 - Further details on the £370,000 supported national programme of improvement work led by National Strategic Network
 - An update on the implementation of the recommendations of the National Strategic Network on the initial priority areas for improvement in relation to long COVID
 - Details of those people who have accessed Chest, Heart and Stroke Scotland’s ‘long COVID support services’
 - Clarification on its position on long COVID clinics and information on which, if any, health boards have established them;
 - Further details on the expert group set up to identify the capacity needs of NHS Boards and staff in supporting people who have long COVID;
 - Whether the Scottish Government believes long COVID should be treated as a disability under the Equality Act 2010;
 - How the Scottish Government is meeting the recommendations of NICE around long COVID service provision
5. The Scottish Government’s [response](#) has been published on the website.
6. Following this response, the Committee then [wrote](#) to all the health boards, the Thistle Foundation and NHS National Services Scotland seeking further information in relation to long COVID services within their organisation including—
 - details on the current services available including information on how the Scottish Government funding has been used;
 - any barriers to service development and provision;
 - any examples of good practice; and

- details of future plans for long COVID service provision in the short and medium term.
7. Responses have been received from the following, which are published on the [website](#) and attached at **Annexe A** to this note—
- NHS Ayrshire and Arran
 - NHS Borders
 - NHS Dumfries and Galloway
 - NHS Fife
 - NHS Forth Valley
 - NHS Grampian
 - NHS Greater Glasgow and Clyde
 - NHS Highland
 - NHS Lanarkshire
 - NHS Lothian
 - NHS National Services Scotland
 - NHS Orkney
 - NHS Shetland
 - NHS Tayside
 - Thistle Foundation
8. NHS Ayrshire and Arran have provided a response to the call for views and a response to the letter is expected in due course. A response is yet to be received from NHS Western Isles.
9. A summary of these responses is included in the Annexe to the SPICe paper (paper 2) for this meeting.

Engagement

10. The Committee was keen to speak to people with lived experience of long COVID at the outset of the inquiry. On 12 January 2023, the Committee spoke with participants, who were contacted through Long Covid Scotland as part of the launch of its inquiry into long COVID. A note of the discussion and a briefing paper from Long Covid Scotland can be found on the [website](#). On 2 February, the Committee held an informal online discussion with participants from Long Covid Kids, a note of the discussion can be found on the [website](#).

Evidence

Oral evidence

11. At its meeting on 9 February, the Committee took evidence on its first theme of the inquiry on awareness and recognition and focused on lived experience. The papers and transcript from that meeting can be found on the [website](#).

Written evidence

12. The Committee issued a call for views on 12 January 2023, which ran until 10 February 2023 and was then extended until 19 February 2023. The Committee received more than 500 responses which can be read on the [website](#). The Committee's call for views asked the following questions —

Awareness and recognition

- Do you think there is enough awareness and recognition of long COVID by the general public, medical professionals, employers and / or policy makers in Scotland?
- What more could / should be done to raise awareness and recognition of long COVID?
- What are your thoughts on the use of long COVID assessment clinics?

Therapy and rehabilitation

- Do you consider that the correct mix of services are in place to help people who have long COVID?
- What support could or should be available for people who are supporting or caring for people with long COVID?

Study and research

- What should be the main priorities for study and research into long COVID?
- Is sufficient data publicly available on the prevalence of long COVID in Scotland?
- Do you have any other comments?

13. **Annexe B** includes written evidence provided by the following witnesses—

- Chest Heart & Stroke Scotland
- NHS Education for Scotland
- Royal College of GPs Scotland
- Royal College of Occupational Therapists

Next steps

14. The Committee will continue to take evidence on the inquiry at its meetings on 2 March, 9 March and 16 March.

Committee Clerks
February 2023

ANNEXE A – Responses from health boards, the Thistle Foundation and NHS National Services Scotland regarding Long COVID services

NHS Ayrshire and Arran 10 February 2023

Awareness and recognition

Do you think there is enough awareness and recognition of long COVID by the general public, medical professionals, employers and / or policy makers in Scotland?

No – It is our belief that public awareness of Long Covid is wide spread in the community; however, we believe they are less aware of support that could/should be available to them. We recognise that all Health professionals have not had training in the management of Long Covid, and the NSS Long Covid Steering Group are developing resources for Primary Care Team training.

It is our opinion the impact both financially and in terms of productivity nationally from the outcomes of Long Covid being present in significant numbers of the population, has not yet been fully recognised.

What more could / should be done to raise awareness and recognition of long COVID?

Through a mix of lived experience and derived data from national audit and clinical research, we need to recognise the impact of Long Covid nationally, both on a personal and health economics level.

What are your thoughts on the use of long COVID assessment clinics?

These are vital to assess clinical risk and help people to self-manage their symptoms. Long Covid for many is likely to be a ‘Long-term Condition’, and people should be afforded equal opportunities to manage their long term conditions.

Therapy and rehabilitation

Do you consider that the correct mix of services are in place to help people who have long COVID?

Multi-disciplinary Teams (MDTs) are being formed around the country. It is as yet unclear if planned resources are adequate to meet requirements once fully available to the public. There is however, a lack of available medical expertise other than secondary care routine pathways to support specialist medical review and investigations.

What support could or should be available for people who are supporting or caring for people with long COVID?

For those who are experiencing significant ongoing symptoms, a comprehensive medical and MDT review with clear investigative pathways should be available to treat and provide ongoing support to self-manage symptoms where possible.

Study and research

What should be the main priorities for study and research into long COVID?

Data that shows impact to both People, their families and the economy, so that appropriate resources can be identified to support people and mitigate financial risk.

Research should now also focus on effective treatment to treat the sequelae of Long Covid, and not just acute treatment of severe disease onset.

Is sufficient data publicly available on the prevalence of long COVID in Scotland?

No – it is our opinion that the data currently available is poor, particularly in relation to numbers and impact on children and young people. Data on above areas of ongoing > 6 months and > 1 year sequelae and the longer term impact to peoples' lives is still very limited.

Do you have any other comments?

Sadly investment and the development of post COVID pandemic services is needed to make good and better our response to the COVID legacy.

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NHS Borders 23 January 2023

Dear Ms Brown

Further to your letter dated 17 January 2023, requesting information regarding NHS Borders long COVID services please note below responses:

Details on the current services available including information on how the Scottish Government funding has been used?

NHS Borders has no dedicated long COVID service. At present those presenting with long COVID symptoms are referred to the most appropriate Primary or Secondary care service, ranging from cardiology to physiotherapy to psychology. Support for staff experiencing long COVID symptoms is also delivered through Occupational Health and Wellbeing services. Following a gap analysis and stakeholder engagement NHS Borders committed to utilise Scottish Government funding to support the appointment of an Advanced Practice Occupational Therapist who will develop and co-ordinate long COVID pathways across Primary and Secondary Care. This development has been built into NHS Borders Annual Delivery Plan for 2023.

Any barriers to service development and provision?

The relatively small numbers of patients presenting with the vast array of symptoms of long COVID mean it is unviable for NHS Borders to deliver a dedicated long COVID service, thus utilising existing services and referral pathways has been the preferred direction of travel. Whole system pressures have also prevented clinicians and service leads from dedicating time to this particular service development over the winter of 2022/23.

Any examples of good practice?

Individual clinicians are delivering high quality care in this regard with a specific example linking together clinical psychology services, wellbeing service and respiratory physiotherapy services to provide an MDT approach to the management of long COVID symptoms

Details of future plans for long COVID service provision in the short and medium term?

The Advanced Practice Occupational Therapist referenced above will come into post in February 2023. This role over the course of 12 months will seek to establish clear pathways for patients and clinicians regarding the management of symptoms. The development of a once for Scotland self-management digital solution will also be critical in supporting local developments in NHS Borders.

In conclusion, NHS Borders continue to be committed to meeting the needs of those living with long COVID and will continue to be engaged in both local and national planning regarding the on-going provision of services.

NHS Dumfries and Galloway 13 February 2023

Dear Ms Brown

Inquiry into Long COVID

Thank you for your letter of 17th January 2023, please accept my apologies for the delay in responding.

NHS Dumfries and Galloway has been allocated resource associated with recovery from long COVID from both the COVID Recovery fund and the national Mental Health After COVID Hospitalisation (MACH) project.

The MACH resource was used to provide an assertive outreach programme for people hospitalised due to COVID. It was used to part-fund a 36-month 8a Clinical / Counselling Psychology post (0.6 of a 1.0 post). This post is managed and supervised within the Clinical Health Psychology team. This post was successfully recruited to, allowing for operation of the service to commence April 2022.

The operation of the service aligns with the national MACH guidance on service delivery. Patients receive self-assessment measures relating to changes in mood and cognition associated with COVID infection. On completion, these measures are used to identify potential areas of need, with those meeting clinical criteria invited to attend an assessment. Following this, the patient is signposted to existing services and pathways within the region relevant to their needs. This includes statutory and third sector services.

The focus of MACH is patients who were (a) admitted to the Dumfries and Galloway Royal Infirmary due to COVID, and (b) resident within the region.

The MACH service is single-handed and uni-disciplinary. As such the operation of the service is reliant upon the retention of the post-holder.

In addition, the COVID Recovery allocation has funded a Lead AHP for Long Covid (Advertised but not yet recruited) and a Lead GP for Long Covid (1 session a week, started 8th February).

These two new Specialty leads will work alongside the already established Psychology lead to work with the Third Sector and other agencies to establish a more cohesive and robust service. They will also develop a communications strategy, both to Healthcare Professionals and the Public, describing how to access this service. "

Yours Sincerely
Jeff Ace, Chief Executive

NHS Fife 8 February 2023

Covid-19 Recovery Committee Consultation – Long Covid Feb 2023

1. Details on the current Long Covid services available, including information on how the Scottish Government funding has been used

Currently within NHS Fife, for patients we do not have a specific co-ordinated Long Covid service. However, as patients are referred with this diagnosis, they are receiving assessment and interventions from our existing range of services e.g. Post Viral Fatigue, Pulmonary Rehabilitation, Physiotherapy, Occupational Therapy, Psychology etc. They are also accessing GP services for consultation and onward referral for diagnostic testing, and further specialist review.

Unfortunately, we have had no spend in this year against the Scottish Government funding that is available (Fife - £178,051). The primary reason for this is that we have had recruitment challenges into our specified posts (Rehabilitation Co-ordinator, Occupational Therapist and Physiotherapist).

For staff affected by Long Covid, our Occupational Health Service has had a dedicated post supporting staff with Long Covid / Fatigue since July 2022. The aim is to assist staff who have experienced Covid and as a consequence are experiencing fatigue impacting on their return to, or functioning at, work. The majority of individuals referred require between 6-8 sessions of intervention and this is delivered via telephone, Near Me virtual appointments or Face to Face, as required

All referrals are made by an Occupational Health Nurse, or Occupational Health Physician, following initial management referral. Individuals can be either off work at the time of referral, or struggling with the impact of fatigue and demands of workload whilst at work. Support is often required from the service when an individual is planning a phased return, to help staff to consider what this might look like, and to balance their recovery with an appropriate level of work-related activity. Support is regularly provided to both the individual and their manager at this point. The average waiting time is currently 4 to 5 weeks from referral to initial assessment.

A total of 49 staff members have been referred to the service to date; 23 staff members are currently open to the service and receiving regular input, of which 11 are in work and 12 are currently off work.

Input is individualised depending on the client's specific identified needs and priorities, based around the development of self-management strategies to support the individual in gaining control of their fatigue and related symptoms, to promote functioning in activities of daily living, in particular work.

Emerging trends include:

- Need for education around fatigue management strategies
- Sleep Hygiene
- Guided Relaxation

- Job Site Evaluation, i.e. recommendations regarding adjustments to work role or environment

2. Any barriers to service development and provision

There are several significant barriers to developing and providing a co-ordinated patient-facing service. Nationally and locally, we are experiencing significant challenges around the recruitment of a wider range of staffing groups, but particularly within nursing, occupational therapy and physiotherapy; and these groups of staff are the one we were targeting for our posts.

The other significant challenge has been around the non-recurring nature of the funding. Therefore, when advertised, these posts are temporary in nature with the offer of a 21-month fixed term contract. Given the significant challenge we have in recruitment across these professions for permanent posts, the temporary nature of these makes them less attractive to prospective applicants.

However, as stated in response to Q1, we do provide services to individuals with the diagnosis of Long Covid; however, these services are not as co-ordinated and responsive as we would like given the challenges in recruiting to key posts.

3. Any examples of good practice

In Fife we developed information packs for Long Covid that provided a range of information and signposting for patients and carers. This has been shared with other health boards, who have adapted for their local use.

We also utilise the Chest Heart & Stroke Scotland (CHSS) Service and refer patients to it directly. We also direct them to the CHSS website, where they can access further information about symptoms and support groups.

4. Details of future plans for Long COVID service provision in the short and medium term

We are currently exploring a different model to allow us to map pathways, service, and referral routes, as well as work around patient identification and data collection. We are hopeful that if agreed we can then re-advertise for the co-ordinator post based around a programme/project manager approach. This would be underpinned with the development of a clinical reference group and would also need to develop links with lived experience groups to ensure that voice is included.

The clinical Occupational Therapy and Physiotherapy posts are also being reviewed, to see if we might be able to look at different models of care and skill mix to build capacity in our existing teams and services.

NHS Forth Valley 9 February 2023

Dear Siobhian

Enquiry into Long COVID

Thank you for your recent letter requesting information for submission to the Covid Recovery Committee.

NHS Forth Valley and Partners are committed to delivery of safe effective efficient and person-centred care for the people in Forth Valley living with the long-term impact of Covid 19.

Forth Valley was awarded £154k for the year 22/23 being the proportionate monies allocated based on agreed calculation. As you will be aware, this money is recurring over the next 3 years and most Health Boards in Scotland have proceeded to service provision on a time limited basis.

NHS Forth Valley took the decision to delay recruitment in order to secure agreement across our HSCPs to proceed to recruitment on a permanent basis and our recruitment campaign is in hand. Our service delivery offer includes a full time permanent Long Covid Coordinator, a full time permanent Respiratory Physiotherapist and permanent Clinical Psychology staffing.

We have a Long Covid oversight group which is multi-professional and strategic and tasked with taking forward the pathway developed for people living with Long Covid to access support. We are linking with the National Groups and ensuring our workforce are fully briefed on the expectations in respect to referral and support for people presenting with the impacts of long Covid symptoms.

The lived experience of people with Long Covid is central to our service delivery and design and our Long Covid Lead is meeting with the local lived experience group to understand their frustrations and needs. Two people from our local long covid lived experience group who are permanent members of our strategic oversight group, will be pivotal members of our implementation group which will be established to support our Long Covid staff group in developing and evaluating our service offer. In respect to barriers to development and provision, one of the most significant barriers is the recruitment of skilled staff to develop and provide services.

There are significant current pressures in Allied Health Professions in respect to recruitment and we are experiencing difficulties in recruiting skilled staff to all roles across the system. We are hopeful we will recruit to the staffing to develop our offer however we must be realistic about how we will develop supports in the absence of recruitment to the roles supported by the funding from Scottish Government.

We are working with our Simulation Centre to develop learning supports for our workforce. This is one of the key barriers described by people with lived experience: the lack of understanding in the wider workforce regarding the needs of people living with Long Covid and the confusion in the system re how to access help and support

We are currently offering referral into specialist services based on the individual needs of individuals. We are implementing the Long Covid pathway based on the SIGN guidance. Forth Valley is committed to inclusion and engagement with people with lived experience at a practical level and plan to continue to develop this as key to our understanding of how best to meet the needs of our people.

The National Service Leads group is an excellent group focussed on meeting people's needs and developing innovative services. It may be useful for the Covid 19 Recovery group to meet with the NSS Service Leads group to discuss the national picture in respect to service development and delivery and the challenges being experienced in development of services which are being experienced across Scotland.

I hope this information is helpful.

Yours sincerely

Cathie Cowan
CHIEF EXECUTIVE

NHS Grampian

- Details on the current services available including information on how the Scottish Government funding has been used;

NHS Grampian undertook discovery work during late 2021-spring 2022 and a prioritisation exercise which informed our initial bid via Service Planning Group for our response to Long Covid. The discovery work included interrogating available data, understanding staff and service experiences and engagement with people with lived experience of Long Covid to identify key workstreams we hoped to pursue. A second revised bid was put forward at request of the Service Planning Group to bring it in line with NRAC funding formula which meant we would be unable to deliver a dedicated multi-disciplinary Long Covid Service.

Instead the funding is being used to recruit into posts to provide provision via creating clear pathways through existing services, develop supported and unsupported self-management resources and develop/deliver cross system education and training for clinical staff across our health and care system.

The model aims to include a Clinical Lead post each for Adults and Paediatrics as well as Long Covid Practitioners to sit under them for both. The practitioners may not be hands on clinical however will be of a clinical background so as to best inform discussions and decision making around the development of pathways and resources, and may offer an advice-only referral service/single point of contact.

The adult workstreams will focus on primary and secondary care however the paediatric workstreams will also include working along with the education system.

- Any barriers to service development and provision;

Although initial proposals suggested something closer to a clinical MDT service, funding was not allocated in a way that would allow for that. With what we received the short life working group continued to work together to propose the current plan (see above) which we feel goes some way in meeting the needs of those with the condition. Recruiting to part time positions with fixed term funding has been difficult in the current climate, not least because there are no 'extra' staff that can be pulled from for these roles. It requires areas to release valuable staff for the duration of the secondments which, although an initial year long period, may be extended to up to 3 if funding continues to be release from SG. We are now on our 2nd round of recruitment that has just closed with some interest and interviews to take place in the coming weeks however one post will need to go out for a 3rd round. However recruitment remains a key risk.

Services will be developed to offer sustainable pathways in existing services (predominantly rehabilitation and psychological support), however these services will have no additional resource to manage the anticipated increase in demand.

- Any examples of good practice; and

NHS Grampian have led the way in our engagement with people with lived experience (both adults and children and families/carers) and we are embedding this into our approach going forward.

We have an established project delivery board, with membership from key professional groups, people with lived experience and project support.

We have also established a Professional Network to provide a platform for our workforce to share experience and information, seek advice and discuss research, emerging evidence etc. This is in its infancy but we hope to expand it in the coming months.

- Details of future plans for long COVID service provision in the short and medium term

We do not envisage a dedicated Long COVID specific service provision in the short or medium term however pathways will be developed to ensure patients are referred to the most appropriate services to support them in managing their symptoms ensuring a holistic, coordinated approach.

We are hoping to offer digitally supported pathways, utilising the digital tool being procured by NHS Scotland. We would hope this could be offered in the short term, although timeframe is dependent on procurement process and information governance assessments.

NHS Greater Glasgow and Clyde Response

Inquiry into Long COVID - Scottish Parliament's COVID-19 Recovery Committee

Details on the current services available including information on how the Scottish Government funding has been used

Mainstream services have supported the NHSGGC response for Long COVID patient groups. However, there is recognition that patients may require either individual, peer and/or group support to manage their Long COVID symptoms. General Practice responses and lived experience feedback has determined the need for informed staff, individuals to support care coordination with community links, and a direct point of contact to access services.

Therefore, in planning Long COVID pathways within GGC utilising the SG funding, we used the body evidence from health professionals and service users, in addition to emerging clinical research. Mirroring the national strategic direction for current Long COVID Services across Scotland, NHSGGC has adopted a person-centred approach in order to provide a comprehensive Interdisciplinary approach to Long COVID services. These services will provide integrated care including assessment and interventions that include various rehabilitation strategies for individuals presenting with Long COVID symptoms. This approach primarily focuses on self-management and supported self-management pathways. This NHSGGC Long COVID Adult service model utilises Band 7 OTs with advanced dual assessment skills in mental and physical health, in particular fatigue, cognition, vocational rehabilitation, anxiety and low mood. The OT team will be centrally managed and work across the 6 HSCPs as demand dictates. Referrals will be initiated by General Practitioners to ensure exclusion of other pathology as per SIGN guidance and the decision-making algorithm for Long COVID. Post holders will deliver assessment and intervention, supporting individuals to navigate and access other services as required. This will enable people to have confidence in managing their own condition with appropriate intervention and resources. The Respiratory Physiotherapy Service will increase its outpatient/community service capacity with the addition of specialist physiotherapy sessions to augment the current outpatient /community clinics and enable coordinated pathways for patients who experience breathlessness.

Any barriers to service development and provision

The potential of creating a gold standard service for this diagnostic group, and the potential inequity for other long-term conditions.

Non-recurring funding creates risk in recruitment or unintended destabilisation of other areas of workforce. Service planning and implementation also requires consideration of Exit routes for the service if funding is not established as recurring. In GGC this is planned with a legacy of self-management referral resources and apps, peer support groups established, and education bundles to support substantive HSCP staff teams.

Lead in recruitment time frames and notice periods for successful candidates coming into post.

Any examples of good practice

Building on current NHSGGC initiatives for Wellbeing conditioning management programmes that can be extended to support individuals with Long COVID. These programmes aim to enhance the individuals' resilience with graded activity and improve physical tolerance as part of a live active programme based on meaningful activity and wellbeing.

There is an emerging population of children and young people with Long COVID. A Paediatric OT post will extend the proposed model early intervention and prevention for Long COVID (physical and mental health) within Tier 2 Children's Services around targeted and universal work. This will support access to advice line for parents, provide clinical advice and strategies around this long term condition and essentially linking with education colleagues to address the increase in anxiety in young children with Long COVID or reduced socialisation.

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

GGC are completing our recruitment processes to all professional and support worker positions. Governance is provided via an identified implementation lead and implementation design group, which is multi-disciplinary with additional members from digital health, planning team and PEPI team. Service launch is proposed by the end of March 2023. GGC are represented in all Long COVID national service planning and expert clinical groups. GGC will utilise the agreed national app assessment C19 YRS and therefore contribute to the emerging national evidence base.

NHS Highland 10 February 2023

Dear Ms Brown

Inquiry into Long COVID

Thank you for your letter dated 17 January 2023.

Please now find attached as requested our submission which provides further information in relation to Long COVID services within NHS Highland.

Yours sincerely

Pam Dudek
Chief Executive

LONG COVID INQUIRY: INFORMATION FROM NHS HIGHLAND

Details on the current services available including information on how the Scottish Government funding has been used:

- The Scottish Government funding has provided fixed term posts of 1 WTE OT, 0.5WTE Physio and 0.6 WTE administrator and 1 session per week Respiratory Consultant.
- The Long COVID referral route through SCI Gateway went live on 22 September 2022. Currently approximately 100 referrals - triaging, screening, aligning to groups, 1;1s or supported self-management.

In December 2020 our Clinical Resource Group requested that a clinical sub-group meet to consider Long COVID requirements. The recommendation for a tiered approach of screening, self-management and multi-disciplinary support was established.

The Long COVID national group had its first meeting in March 2021. Scottish Government announced in September 2021 that £10 million of funding would be made available and will be based on a board gap analysis.

NHS Highland bid was submitted on 31 March 2022.

Worked with the NSS team to prioritise:

- Phase 1 - OT, (1WTE) Physiotherapy (0.5WTE) and admin (0.6WTE).
- Phase 2 - to set up a multi-disciplinary complex patient meeting with the rehab team and appropriate secondary care representation.
- There is funding available for this from unallocated funds - currently have one session per week with a Respiratory Consultant. Exploring a primary care representative for this weekly meeting

- Our board has access to the C19-YRS App and we use this for education resources directly available to the patient and for screening and outcome measurement.
- We access a local third sector self-management provider and have funded licenses for e-learning. We are establishing groups collaboratively with “Lets’ Get on With It Together” (LGOWIT) and our clinicians co-hosting to allow for peer support and education in condition management and coping strategies.
- Our service is combined with Occupational Health referrals of our own staff reporting Long COVID, and the Mental health after covid admission to hospital (MACH) Service

It is considered that medical input is essential to support a triage and screen process for more complex patients, ensuring that the appropriate medical investigation and diagnostics have been carried out and there are no red flags.

The Long COVID service is recommended to be a GP referral route only to ensure that the ongoing management of a patient remains in primary care and appropriate diagnostics and screening are facilitated (as per SIGN guidelines).

A board wide COVID Recovery Board has been established and meets regularly and reports into the Condition Management Programme Board, part of the Together We Care strategic oversight. The board requires pathways between primary and secondary care and from the small follow-up team into wider local MDT’s including mental health services. This work is ongoing alongside the provision of training for colleagues.

Barriers to service development and provision:

No established funding yet aligned for medical assessment – requires multi-disciplinary, multispecialty approach that would support the complexity of Long COVID.

Short-term nature of current funding and requirement for security of ongoing funding to ensure those individuals developing expertise in this condition are retained. Confirmed funding agreed by Finance Teams in December 2022 for next financial year recruitment. Letters from Scottish Government did not provide early financial security.

Implementation by Scottish Government of two separate pathways and funding streams for MACH and LC services – same people to a considerable extent.

National funding provision made available in May 2022 left a delay of over a year for some people with Long COVID.

Length of time to recruit, identify and grade job descriptions, plan and set-up services means some long-term patients have established chronic conditions with secondary deconditioning and mental health issues, together with high expectations of what the service can achieve and that rapid access to the service will be facilitated.

Additional funding, in line with submission for medical and primary care support alongside allied health professionals, would enhance the service.

Funding was directed to prioritise mild to moderate presentations and supported selfmanagement. Some of our patients are complex, a handful we are aware of are severely impacted and are bed-bound. Many are moderately impacted and unable to return to work.

Expectations of patients – there is an expectation that patients will be referred to the service, be seen quickly and be provided with an answer. The lack of multi-specialty medical screening makes this more challenging.

Rehabilitation requires behavior change, motivation, compliance with management techniques to make a difference. Some are not well enough to engage with that, some are not at the right point of acceptance.

High expectations of the wider clinical teams of the team to be formed and specialist in Long COVID. Our therapists joined in November 2022 from other clinical areas with a wealth of professional skills but have not worked with Long COVID.

Time is needed to establish skills having seen patients with Long COVID, be supported in their own learning and feel supported by the appropriate medical and primary care expertise. There is still a requirement to understand the impact and pathways for children nationally and within our board.

Leadership time is non-funded and additional to an existing leadership role. The amount of time in developing, leading, education, supporting, advising, responding, meeting and planning is considerable. Currently 1-2 days per week.

Requirement to be a virtual service, funding cannot support local services – too many teams across the board. Not being able to offer face to face is difficult in some cases.

National, and in-board, siloed approach to secondary, primary and community services makes it difficult to provide a holistic approach. Need for service redesign to support.

Health inequalities and issues accessing technology and online support. There is feedback from Long COVID patient groups that people will need access to services via different mechanisms based on their functional ability, ability to work in groups, understand and utilise the education, reading ability.

Lack of alignment with model or provision in England.

Examples of good practice:

Use of C19-YRS App – validated tool, we are the first Scottish Board to use, recommended in NICE guidelines for screening and education.

Involvement of OT to work holistically in physical and psychological presentation and vocational rehab.

Physiotherapy expertise and input from Psychology due to combination with MACH service. Input from Respiratory Consultant to weekly triage.

Work with local third sector provider Lets' Get on with it Together (LGOWIT) with e-learning resource, peer support and progressing to joint delivery of groups Virtual working and use of technology.

The national Planning group is an excellent form of support and joint learning. More capacity in a Once for Scotland approach would mean each board is not doing its own learning and development with lag of service delivery

Committed clinical and operational leadership. Clinical teams keen to support.

Within our board we requested flexibility with unallocated funds, and this was approved. This is positive as the services need flexibility with the funding to provide additional sessions to cover referrals at the point of service launch, extra leadership for service development, secondary or primary care input and other items like IT equipment and phones.

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

We are currently planning the staffing based on confirmation of year 2 funding. There has been a delay in the clarity on the funding for 2023/24 that means that some secondees are returning to the substantive roles. We hope that the service continues for the third year and is linked to the board's Condition Management Programme where we hope a long-term conditions management service will be provided.

The objective of the board-wide Condition Management programme is to create and implement a holistic framework for the management of long-term conditions, which will focus on symptom management rather than conditions themselves as we know that there are symptoms which cross over multiple LTC's such as chronic pain, breathlessness and fatigue. The aim is to prevent admissions to hospital and improve the outcome of LTCs for our population by taking this symptom management approach-which will promote and provide information/education around self-management and will be partnering with 3rd sector on the design of this service.

Areas of focus for the Inquiry

Therapy and rehabilitation

There is access to 1.5 WTE dedicated OT & Physio in the board for Long COVID patients (and 0.6 WTE admin). This resource is required to screen, triage and treat patients as well as coordinate care. There are currently 100 people referred to the service. Groups and treatment pathways are being developed. Clinicians are developing skills in managing Long COVID and are required to provide education across the health and care teams within the roles.

In NHS Highland we have up to 65 Allied Health Professional teams. Staff are based across the whole board area working in multiple roles like ward, community & out-patients. Our clinicians within community teams will work with many different conditions and presentations. There are no designated community rehabilitation services in the NHS Highland community, teams will carry out many different forms of interventions like provision of rehabilitation, equipment and adaptations. The community teams will also have waiting lists. Patients who have severe and complex Long COVID should be known to the local teams due to the severity of their condition, but the clinicians will be developing skills around management of the condition as they work with the patient and by using the resource in our Long COVID service. A robust education and development programme is required. Patients with mild to moderate presentation may not be referred to rehab and may have to wait on a waiting list alongside others. We have recognised the difficulty in recruitment and capacity across our rehabilitation teams.

There is no long-term Condition Management Service in NHS Highland currently.

Awareness and recognition

There is a huge amount of recognition for Long COVID within the patient group. There is limited awareness and knowledge across the health & care professions currently. People with Long COVID report a lack of recognition by GPs and a lack of clear pathways to access services.

Study & research

We are the Scottish NHS board involved in the UK-wide LOCOMOTION study (LONg COvid Multidisciplinary consortium Optimising Treatments and services). This will provide links to the ongoing research programme from established UK clinics.

Research is required to support clinical teams in effective management. There is much research going on and available, time to study and evaluate alongside developing services and seeing patients is difficult. Feedback from other members of the health teams is that time to review current research and learn about Long COVID is extremely difficult with capacity issues and service pressures.

NHS Lanarkshire 17 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.nhs.uk/lanarkshire/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:

Funded Posts (WTE)	Expected spend to March 2023	Expected spend 2023/24
1 B8b Clinical Service Lead	£80,739	£80,739
4.8 (2x B7 3x B6) 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
Total	£671,548	£671,548

Current pathway activity:

Lanarkshire's pathway became operational on 26th 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

NHS Lothian 15 February 2023

Dear Ms Brown

INQUIRY INTO LONG COVID

Thank you for your letter of 17 January 2023 and follow up letter of 9 February 2023 confirming the extended deadline for replies. Please see the NHS Lothian response below to the questions raised.

Details on the current services available including information on how the Scottish Government funding has been used:

- People presenting with Long Covid in Lothian are currently assessed on an individual basis with appropriate treatment / intervention / rehabilitation offered, determined by the presenting needs of the individual to best support optimal physical and or mental health outcomes.
- Individuals with long COVID have access to a wide range of services including but not limited to Respiratory, Neurology, Rheumatology, Musculoskeletal and Fatigue Management teams. A number also progress onto Vocational Rehabilitation services to support them to return to work.
- Funding allocation for current financial year (2022/23) is being utilised in two key areas:
 - i. **Roll out of supported self-management pathway:-** An initial pilot group of GP referring to our Long-Covid supported Self-Management Pathway utilising a digital self-management tool and CHSS advice line was evaluated and found to be well received by those who engaged. Funding is now being used for a staged scale-up of this pathway commencing in Midlothian in January, with learning from each phase of the rollout informing the next stage to implement the pathway across NHS Lothian and its other partnership areas of East Lothian, West Lothian and the City of Edinburgh throughout 2023.
 - ii. **Application of data to develop clear clinical pathways / Lothian model for Long Covid:-** In the absence of robust data to inform services / pathway development we are undergoing a process of applying existing data to inform the development of the Lothian model for Long Covid services. This dataset includes number of referrals for people reporting symptoms of Long Covid, plus number who have received a clinical intervention, type of intervention and the routes taken to access these services and service user feedback.

Delivery of this work is under the clinical leadership of our AHP Consultant informed by a multidisciplinary Clinical Expert Reference Group. This group are considering the 4 key elements outlined in Scottish Government's paper "Scotland's Long Covid Service" i.e.

1. Supported self-management
2. Primary care and community-based support
3. Rehabilitation support
4. Secondary care investigation and support

We expect our revised Long Covid delivery model and pathways to be determined by end March 2023 with 23/24 funding being utilised to enhance appropriate clinical services. Whilst this is currently being finalised early indications suggest some services will require funding to enhance capacity and this will be allocated accordingly when 2023/24 funding is confirmed.

A multidisciplinary and multi-agency oversight board that includes patient representatives oversees our all our Long Covid service development work.

Any barriers to service development and provision;

- Paucity of robust data in terms of demand and symptom profile of Long Covid, uncertainty of diagnostic criteria and emerging and changing evidence of efficacy of therapeutic interventions made early identification of service need challenging.
- Initial lack of certainty of funding beyond 2022/23 also made recruitment to new posts challenging

Any examples of good practice:

- Collaboration between NHS Lothian, Chest Heart and Stroke Association Scotland and POGO Studios has led to successful development of an innovative Supported Self-Management approach, supported by a Digital Platform and utilising expertise across NHS, third sector and industry colleagues.

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

- See also answer to bullet point 1 above

Long Covid is a diagnosis that encompasses a broad range of signs and symptoms that are variable across individuals therefore individual's support needs are also varied.

As such, rather than develop a single service for Long Covid, NHS Lothian have taken a considered approach, applying available data and evidence where it is available, enhanced by our knowledge and learning from management of other Long-Term Conditions to develop a sustainable model for the future.

This model will deliver for people across Lothian a Long-Covid supported Self-Management Pathway in partnership with CHSS and utilising a digital platform. We expect this model to be fully available across all Lothian residents by end 2023.

In parallel with the supported self-management approach, clinical pathways, determined by individual patient presentations will be articulated and implemented to

enhance clarity and enable seamless navigation for patients, carers and clinicians alike.

Where requirement for enhanced capacity in specific clinical services is identified, this will be delivered through Scottish Government Long Covid Funding.

Our combined approach will deliver a flexible model that supports patients with long Covid to access services that result in interventions that are delivered based not on a specific service model but on an individual person's needs.

Yours sincerely

CALUM CAMPBELL

Chief Executive

NHS NATIONAL SERVICES SCOTLAND Scottish Long Covid Network 10 February 2023

Submission to the Committee Inquiry into Long Covid

1. Purpose

To provide the COVID-19 Recovery Committee Inquiry into Long Covid with a summary update of the achievements to date of the Scottish Long Covid National Strategic Network.

2. Background

The Long Covid Support Fund of £10million was established to resource the development of services over a three-year period for people with long term effects of COVID-19.

In March 2022 NHS National Services Scotland (NSS) were commissioned to develop a National Strategic Network (NSN) 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.

To deliver this, the NSN has established a strategic framework (Appendix 1) to engage health board representatives, clinical representatives from across the pathway and people with lived experience.

The NSN is overseen by a Strategic Oversight Board which links into the key NHS national groups and reports to the Scottish Government.

The delivery of services remains the responsibility of the NHS Boards and Health and Social Care Partnerships. Recommendations will be developed on the supporting actions required at a national level to support service delivery in an evolving area.

The NSN provides support for all people with long term effects from infection with COVID-19 in line with the definitions outlined in the SIGN/ NICE/ RCGP Guideline for Ongoing symptomatic COVID-19 (4-12 weeks) and Post COVID-19 syndrome (12+ weeks).

The Strategic Oversight Board agreed that:

- the scope of the NSN should encompass all ongoing symptoms arising from an infection with COVID-19 that are not related to a pre-existing condition.
- the NSN should have a role in Education/ Social Care and employment which have all been raised by people with lived experience as priorities.

NSS were allocated funding of £370,000 in 2022/23 for this purpose. £200,000 was set aside for the procurement of a national digital tool to support the assessment, intervention, and evaluation of care for people with Long Covid. The remainder was required for programme support staff, clinical sessions and to commission The Health and Social Care Alliance Scotland (the ALLIANCE) to establish the Lived

Experience Network.

The spend for the digital tool will now move to 2023/24 to allow time for the procurement exercise to complete. Recruitment of lead clinician support was not concluded until February 2023 so a reduction in funding was agreed with Scottish Government. The planned expenditure in 2022/23 NSS is shown below.

Resource	WTE	Year 1 2022/23
Clinical sessions	Flexible	£11,000
Band 8a Senior Programme Manager	0.33	£22,800
Band 6 Assistant Programme Manager	1	£46,500
Operational budget		£1,000
Lived Experience Network (Alliance)		£20,200
Total		£101,500

It is expected that funding will continue in 2023/24.

3. Vision and Objectives

The NSN's vision is that ***“All people with long term effects of COVID-19 have the support they need to live as active and healthy a lifestyle as possible”*** To do this the NSN will:

- Listen to the priorities of people with lived experience of long-term effects of COVID-19 to understand what support would make a difference for them
- Enable services to build their capacity to support people with long term effects of COVID-19 through additional resources and development of knowledge and skills
- Evaluate the effectiveness of increased capacity and adapt approach based on learning
- Support people to access the services they need through raising awareness of the services and support available
- Connect services with evolving evidence base and clinical opinion to ensure service delivery

4. Key Achievements

The following has been achieved since the NSN was commissioned in March 2022:

- The development of NSN governance structure, appointment of Chair of the Oversight Board, involvement of service planners, clinical Subject Matter Experts and People with Lived Experience (PLE), alongside other working groups.
- The network Action Plan was developed, with key aims and objectives for different aspects of the network set out in the plan.
- An early piece of work undertaken by the network was to look at gap analysis with service health board representatives and clinical colleagues. Key areas were identified through the gap analysis, some of which will sit within the remit of the network, and some will sit with territorial boards to deliver.
- In August 2022, ALLIANCE were commissioned by the NSN to launch their network for people affected by Long Covid. Following the launch, ALLIANCE released an online survey to capture the priorities needed to support Long Covid - 114 responses were received. A full report is available, however most respondents stated that all options provided should be prioritised, requesting that a holistic approach is taken to care provision, as well as further legislative recognition of Long Covid as a disability.
- The Lived Experience Group was established as part of the network, to allow PLE to feed into the development of strategy. The first Q&A session with service planners from NHS Scotland Boards and PLE was held in January 2023 to ensure that PLE felt more engaged with developments.
- The network has co-ordinated work with NHS Scotland Boards and National Procurement to procure a digital tool through Softcat, which will support the assessment, intervention, and evaluation of care for people with Long Covid. The procurement process is nearing completion and the successful supplier will be announced as soon as possible. A training plan is being developed to allow implementation over the next few months.
- NHS Scotland boards have been progressing with recruitment to roles to support Long Covid services in their areas.
- In November 2022 Peer Network sessions were established. These provide education on topics suggested by members and the opportunity to seek support from peers and share good practise. A second session was held in February 2023, and a follow up is being planned.
- In December 2022 the first Public Health Scotland Long Covid Bulletin was shared with the clinical and subject matter expert group.

5. Challenges

In a new and evolving area, the following challenges have been identified:

- **Data** – with little Scottish data available, there are challenges in knowing how large the population requiring access to the Long Covid Pathway will be. This

will continue to be reviewed as results from the EAVE II survey become available.

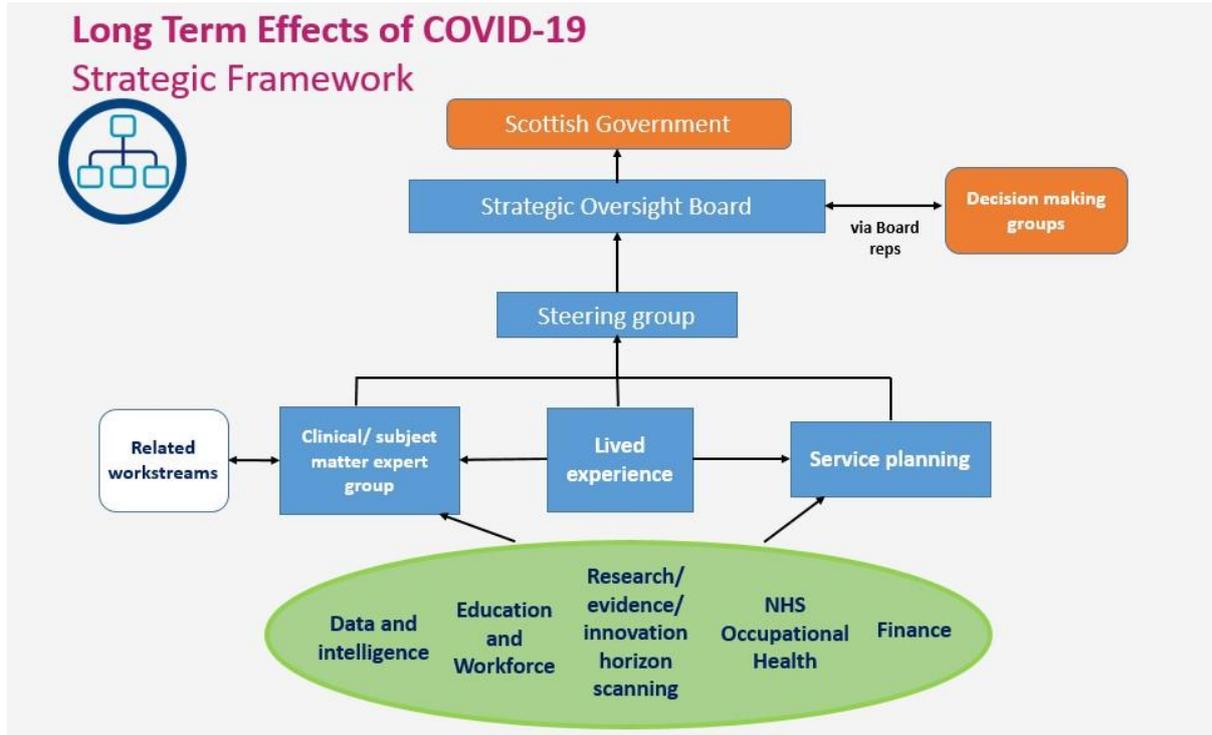
- **Education** – there are limited studies available to evidence education, therefore this has remained at a relatively informal level to date, with Peer Network sessions offered on a regular basis, as described under 4. Key Achievements.

6. Future Plans

Key actions going forward include the following:

- Rollout and implementation of national digital tool
- Continue regular sessions to update clinical and service planning teams around developing evidence.
- Establish MDT sessions whereby clinicians can bring the more complex cases to discuss with a team of experts.
- Scoping and development of clinical pathways
- Publication of Self-Management Workbook developed by NHS Lanarkshire to provide workbook that can be shared with patients to support clinical pathways.

APPENDIX 1: STRATEGIC FRAMEWORK



Janis Heaney
Associate Director
National Strategic Networks National Specialist and Screening Services Directorate

10th February 2023

NHS Orkney 18 January 2023

Dear Ms. Brown,

Thank you for your letter, dated 17 January 2023, concerning the COVID-19 Recovery Committee inquiry into long COVID and post COVID syndrome. Following your request for further information from NHS Orkney, please see below feedback from Dr Kevin Fox, NHS Orkney Long Covid Lead:

- *Details on the current services available including information on how the Scottish Government funding has been used:*

NHS Orkney have one fixed-term Physiotherapist (0.5WTE) providing assessment, support and exercise-based rehabilitation. This individual has access to speciality Physicians as needed e.g. for cardiac or respiratory specific complications. NHS Orkney broadly follow SIGN guidance, adjusted to our rural location and limited resources.

- *Any barriers to service development and provision:*

NHS Orkney is a small Board with limited facilities e.g. no on-site respiratory physician and limited lung function testing. Like all other Boards in Scotland, our therapy services are in high demand with limited capacity, despite this, we believe we are able to offer a guideline based service.

- *Any examples of good practice:*

Our physiologist provides excellent personalised, evidence based, support. The individual has readily available access to cardiology advice and cardiac investigations where necessary. While, as a single provider he is stretched, the personal relationships he develops are therapeutically important.

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

NHS Orkney have received partial support for ongoing funding of the physiology post for 2023/24. NHS Orkney will be seeking support from the Scottish Government for the service, through the Long COVID Funds, failing this we will seek direction from the IJB who are accountable for commissioning local services.

If you have any further queries, please do not hesitate to get in touch.

Yours sincerely

Michael Dickson
Interim Chief Executive

NHS Shetland 16 February 2023

Dear Ms Brown

INQUIRY INTO LONG COVID

Thank you for your letter dated 17 January 2023.

NHS Shetland set out to recruit a specific AHP to lead and co-ordinate this work however the specific challenges of NRAC funding equating to less than a full time role has prevented us achieving this.

We have factored Long Covid into our wider operational delivery plans and are seeking access to digital tools and expertise developed across Scotland.

Our Teams remain committed to providing the requisite care to patients in Shetland and this will be tailored to the individual needs of presenting patients.

Yours sincerely

Michael Dickson

NHS Tayside

Long Covid Services

1. Details on current services available including information on how the Scottish Government funding has been used

A temporary Tayside service known as CAREs (COVID-19 Assessment Rehabilitation Enablement and Support) was initially set up in 2020 during the COVID-19 pandemic to offer support to adults with ongoing symptoms after COVID-19. This has been stood down and a single Tayside pathway has been agreed with the three Tayside Health and Social Care Partnerships (HSCPs).

The local pathway (Appendix 1) was developed in line with the SIGN guideline 161, the SIGN implementation guidance, Scotland's Long Covid Paper, guidance from the National Long Covid service planning group, the national Subject expert group and the national lived experience group. As services develop, adjustments will be made to this pathway.

The focus of services in Tayside is an early intervention, supported self management service utilising remote and face-to-face opportunities for people to gain the support they need. This updated pathway is Primary Care led, utilising NHS Inform supported self management advice and then the Chest, Heart and Stroke Scotland advice line as the first line interventions.

Tayside Developments

Primary Care - investigations and management

Primary Care are the lead and the first point of contact for patients. Secondary Care Consultants from Respiratory, Cardiology and Neurology have developed guidance documents related to post-Covid risks and symptoms to support the management.

Allied Health Professions - Rehabilitation

The updated model provides funding to each HSCP to build capacity within each community rehabilitation team to support this patient group. This funding will be recurring for three years.

The teams will each nominate a Long Covid Lead who will work collectively across Tayside as a network to share learning, offer collective input to patient group training and/or other shared activities. This will support a balance of consistency and equitable service whilst also aligning to local resources and supports.

Children and Young People

Funds have been made available to this team to provide capacity to develop resources to support their teams to provide interventions and support. This funding is for six months.

Co-ordinating Services

In line with the SIGN implementation guidance, referral to service will be via Primary Care with GP assessment of the undifferentiated symptoms and onward management. Referral is via SCI-Gateway with routes for referral by email also available.

It is essential to note that all existing services based around clinical specialities are still available for this population.

The emergence of new local and national self-management resources, group programmes and advice lines will enable people to manage their own condition, accessing specialist services as required.

Funding Model

Tayside has been awarded £194,620 per year for three years to support the development of services for Long Covid. The purpose of this funding is to support those experiencing Long Covid (symptoms related to Covid which extend beyond 12 weeks from acute illness and cannot be attributed to any other diagnosis or condition).

Proposed	2022-2023 Costs	2023-2024 and 2024-2025
Community based rehabilitation and support for early intervention and rehabilitation. Band 7 Community Physiotherapist and Band 7 Community Occupational Therapist as funds allow. 0.2 WTE Band 7 Speech and Language Therapist 0.5 WTE Band 6 Dietitian	£176,620 Total £7,000 Speech and Language Therapist (0.2 Band 7, 7 months) £14,600 Dietitian (0.5 Band 6, 7 months) Remaining £155,020 to be split as per NRAC percentage between all 3 HSCPs for Occupational Therapist and Physiotherapist	£12,000 Speech and Language Therapist 12 months(x2 years) £25,000 Dietetics 12 months (x2 years) Remaining £157,620 to be split between each HSCP annually.
GP with special interest for leadership and co-ordination 0.1 WTE (9 months) 9 months are July – March	£12,000	0
Child health resource development 0.2 WTE Band 7 (6 months)	£6000	0
	£194,620	£194,620 each year x 2 years

2. Barriers to service development and provision

Recruitment for these posts has been slower than would have been anticipated. This is due to development of job descriptions and the need to re-advertise posts where recruitment was not successful. This reflects the challenges seen nationally and the short term nature of the posts potentially making them less attractive to applicants.

The previous Tayside service had been unable to match capacity with the demands and as a result some patients have had significant waits for specialist rehabilitation input. The newly formed services are focusing on supporting this group.

Whilst waiting these patients have had access to local and national information resources, locally produced animations and the community listening service, which is delivered by the Spiritual Care team.

3. Examples of good practice

A Physiotherapist and Occupational Therapist in Tayside worked to develop educational resources for staff to support them in working with people with Long Covid. This was supported by the award of an NHS Education for Scotland Career fellowship. NES have now employed the physiotherapist to develop and spread these resources as a Once for Scotland resource.

4. Future plans for long COVID service provision in the short and medium term

A new structure in Tayside will be introduced to support the network of local meetings now in place in each HSCP and this will allow collaboration to continue through the Tayside Long Covid Oversight Group. This structure will be enhanced by the development of two further groups – a lived experience patient group and a staff professional network.

A procurement process is underway to purchase the Covid-19 YRS app. Use of this App can reduce the assessment time by 80% for each patient, support people to access resources and provide outcome data and measures for evaluation. The YRS Covid-19 app is expected to be available around March 2023 and once Information Governance approvals are in place this will be rolled out to all services. It is anticipated that this will support a shorter wait for people requiring support.

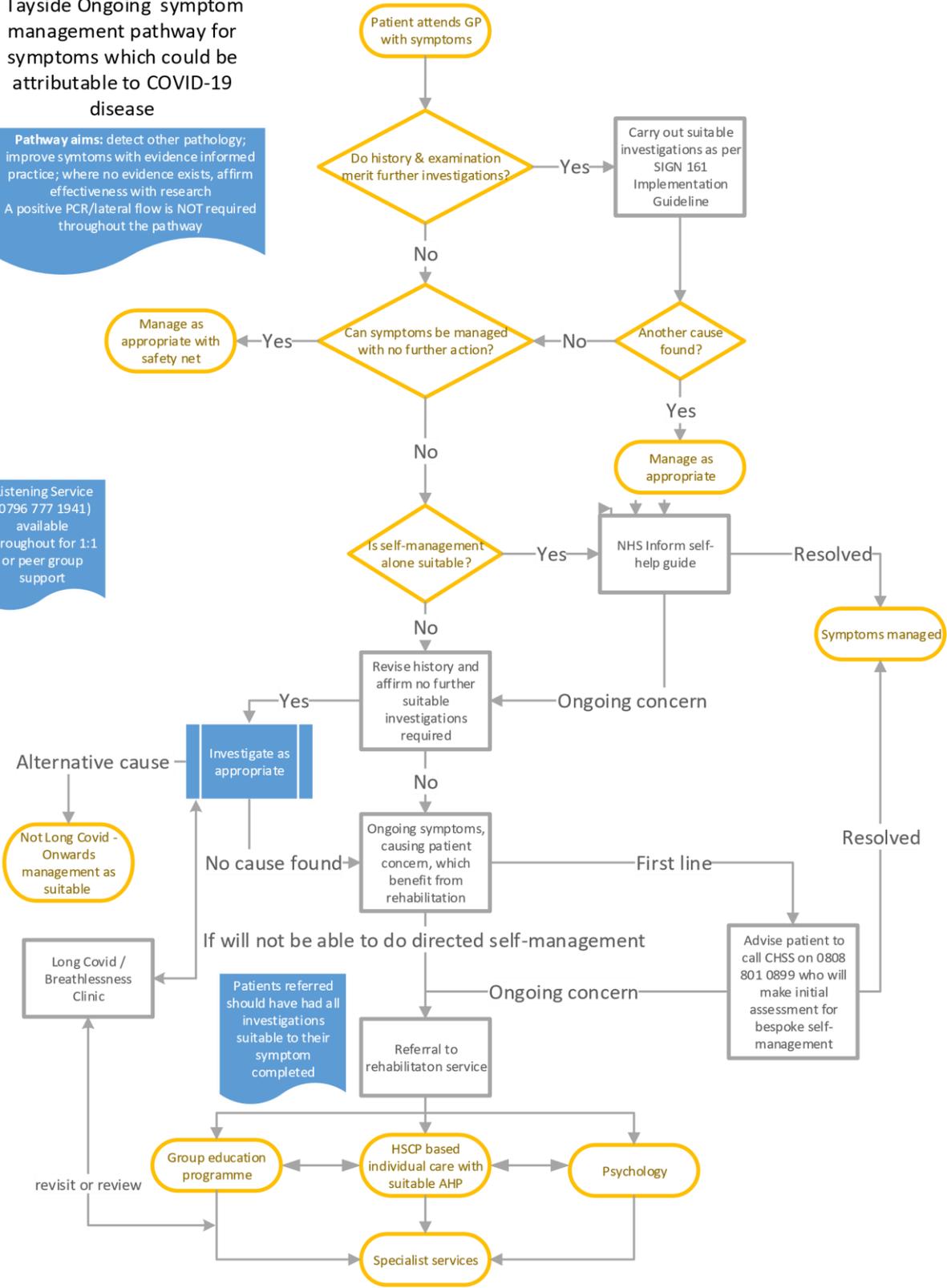
Like other Boards, NHS Tayside is seeking to strengthen their formal information sharing links with the nationally funded CHSS Covid advice line (Chest, Heart & Stroke Scotland) to enable this to be a formal step in our intervention. NHS Tayside is currently in the final approval stages for expanding the CHSS offering to include 12 weeks of 1:1 support for Tayside residents and access to local and national peer support and resources. This will enable us to offer timely access to specialist rehabilitation to those who require it.

Appendix 1

Tayside Ongoing symptom management pathway for symptoms which could be attributable to COVID-19 disease

Pathway aims: detect other pathology; improve symptoms with evidence informed practice; where no evidence exists, affirm effectiveness with research
A positive PCR/lateral flow is NOT required throughout the pathway

Listening Service (0796 777 1941) available throughout for 1:1 or peer group support



Thistle Foundation 7 February 2023

Dear Siobhian

Please find below our response to the questions outlined in your letter of the 17th January 2023 titled 'Inquiry into Long COVID'.

Details of our Programme

Thistle Foundation is a charity that supports people across Scotland who are living with long-term health conditions and disabilities, to lead good lives and achieve what matters most to them. Since 2008 we have also provided training and consultancy support across health and social care services looking to adopt an outcomes, strengths-based approach to their work.

Thistle Foundation has received £250K funding from Scottish Government to set up a national development programme which aims to reshape rehabilitation services for people living with long-term health conditions including the long-term impacts of COVID-19. The figure of £87,343 that you have referred to in your letter is part of the £250K awarded to fund this programme. The programme is aligned to the Scottish Government's Once for Scotland approach to rehabilitation.

This 'Once for Scotland' programme will not work directly with people living with long-term health conditions or the long-term impacts of Covid-19. It will work in collaboration with organisations across NHS Health Boards, Health and Social Care Partnerships and the third sector to help reshape the delivery of rehabilitation services and, specifically to:

- focus on prevention, anticipation and supported self-management;
- develop a unified, outcome focused and strengths-based approach to rehabilitation and self-management across professional groups and agencies;
- develop a person-centred approach to rehabilitation that focuses on the person, not the condition, where the individual with support from friends, family and or carers is empowered to lead and manage their situation and remain as independent as possible; and,
- make non-specialist rehabilitation more broadly accessible by introducing the principles and practices of rehabilitation to the wider health and care workforce thus enabling redesign of a wide range of current community-based services.

At our initial reporting milestone on the 23rd January 2023 £13,798.13 had been spent on initial preparatory work for launching the programme.

The programme was launched in January 2023. In line with an action plan agreed with Scottish Government, we have begun engagement activities with prospective partners and will begin the delivery of training and consultancy work in April 2023.

Barriers to service development and provision

We are experiencing and currently mitigating against a significant barrier to realising the full potential of the programme.

We learned from our Scottish Government colleagues that they are unable to

disseminate any non-essential communications across Health Boards or Health and Social Care Partnerships while winter pressures continue to negatively impact the capacity of services across the NHS and Social Care. This means colleagues in government are unable to disseminate information about the programme across the Health and Social Care system.

We are mitigating against this by using our own networks to support engagement with the programme. To ensure meaningful, nationwide engagement takes place, we hope to see the emergence of a strategy for engagement with NHS, Health and Social Care Partnership and Third Sector service providers, led by our Scottish Government funders.

Any examples of good practice

Our support is focused on the person, not the health condition and we champion a generic non specialist community based self-management approach to rehabilitation. As outlined above, this 'Once for Scotland' programme is still in the development and early engagement phase, so we have no tangible outputs to report at this stage.

The expected outputs are that services across the Health and Social Care system will model Thistle Foundation's person-centred approach to rehabilitation and supported selfmanagement. We expect to be able to demonstrate the positive impact of a generic non specialist approach to rehabilitation on the lives of people who experience this support within their local community.

Our non-specialist approach to rehabilitation includes:

- 1-2-1 support using a collaborative, outcomes focused and strengths-based tools and techniques; and,
- group based support through the delivery of Lifestyle Management courses delivered by Wellbeing Practitioners and Peer Volunteers. These courses help people understand stress, pacing, sleep management and exercise; and support transformative changes to better manage life with a long-term condition.

Through other projects and programmes, that we are separately funded to deliver, we have experienced an increasing percentage of people we support (40%), who report the impacts and long-term effects of COVID-19.

Below are three lived experience examples of people we have supported who are living with the long-term effects of COVID-19. In these stories you will see some of the outcomes we would hope can be achieved by people living with long-term health conditions, via the training provided to health or social care practitioners through our programme.

<https://www.thistle.org.uk/callums-story>

<https://www.thistle.org.uk/elpeths-story>

<https://www.thistle.org.uk/calums-story>

These are the types of stories we expect to hear reported in future by teams and services that we will work with through this 'Once for Scotland' programme.

Details of future plans for long covid service provision in the short and medium term.

With specific reference to this Scottish Government funded programme, we foresee this being a longer term 'Once for Scotland' programme that will grow over a period of time to engage with and support teams of practitioners working across the spectrum of services set out in the [rehabilitation in health framework](#) with interventions being tailored to the specific needs of each team or service.

Should you require any further information please do not hesitate to contact me.

Kind regards
Mark Hoolahan
Chief Executive, Thistle Foundation

ANNEXE B – Written evidence provided by witnesses

Chest Heart & Stroke Scotland

Information about our organisation

Chest Heart and Stroke Scotland is Scotland's largest organisation supporting people with our conditions. Every day people leave hospital feeling scared and alone - our nurses, volunteers and peer support groups are there to help people with get the most out of life. We are the voice of people with our conditions, and work with them to develop services that work for them.

We've spoken up for people with Long Covid since 2020. Since then, we've advocated for a national programme of support available to everyone with Long Covid and have invested in delivering services ourselves. We provide an Advice Line staffed by trained health professionals which offers support to anyone with Long Covid in Scotland. We also work closely with NHS Lothian to deliver integrated, collaborative care - GPs refer automatically to our teams, who provide advice and self-management support to patients with Long Covid on a case management basis. This has allowed us to provide essential support to people with Long Covid, collaborating with NHS services and freeing up capacity in primary care. We also run a peer support group for anyone living with Long Covid and a Kindness Volunteer scheme, providing regular calls for emotional support.

People living with Long Covid often feel abandoned and frustrated by the lack of coordinated care. They tell us that care is uncoordinated and difficult to access. Furthermore, many people can't access the vital self-management support they need to live with this chronic condition. In this response, we'll highlight what needs to change, including:

- Integrated referrals to third sector support services across all health boards
- Better awareness and training for clinicians, so that everyone can receive
- Coordinated access to diagnostics and treatments through multidisciplinary teams
- Support for research into treatments

Awareness and recognition

Do you think there is enough awareness and recognition of long COVID by the general public, medical professionals, employers and / or policy makers in Scotland?

Lack of awareness among medical professionals

Years after the first Long Covid cases emerged, people with Long Covid tell us their experiences of primary care continue to be poor. While most GPs have heard of Long Covid, understanding of the reality of this debilitating condition is often low, with some still doubting that symptoms are genuine.

Many GPs don't know what support they can or should offer their patients with Long

Covid, or where to refer them for treatment or support. Our own Long Covid Support Service has taken over 1500 calls from people who want advice, support or a listening ear and is currently the only nationwide source of Long Covid Support, and our partnership with NHS Lothian means that GPs can refer patients directly to our support. The partnership also allows us to provide case management support, working with the NHS to provide collaborative care. However, while our service makes a significant difference, we know it doesn't receive the volume of referrals from health professionals that it should. While anyone can ring for support, a lack of digitally integrated referral pathways from GPs, or even signposting, means that thousands of people who could benefit from this support aren't aware of it. It's essential that all health boards are able to directly refer to patients third sector services that can support them.

We also know that Long Covid is a complex and multifaceted condition, and not all aspects are equally well understood in primary care. For example, POTS (postural tachycardia syndrome) is experienced by many people living with Long Covid, but is not well recognised within primary care. The absence of any specialist provision in this area only furthers the lack of recognition.

While some people are referred for physio or further diagnostic tests, many people with Long Covid we speak to tell us they're not offered any support, leaving them feeling totally abandoned. Feedback from our Long Covid Support group suggests that for some health boards referral pathways are extremely unclear, with staff unaware of what support is available within their health board.

Most concerningly, there remain clinicians who dispute that Long Covid exists, or who believe that symptoms are at best psychosomatic. Long Covid is well documented, and has been researched in depth, at a global level. While the underlying mechanism for the condition has not yet been identified, it is demonstrably a physical illness with debilitating effects. Prevalence of anxiety and mood disorders is consistent with other respiratory conditions, and there is no evidence that physical symptoms are caused by underlying mental health. Suggestions that symptoms are purely psychological are harmful and prevent people from receiving the critical support they need.

Our Long Covid Action Plan, released in 2021, called for better awareness and resources for clinicians. RCGP have provided training modules on Long Covid, which have helped many GPs understand this condition, and have addressed harmful misconceptions around mental health. SIGN Guidelines on Long Covid have been available since 2020. However, there is a clear need for more work in this area.

The Scottish Government's Long Covid Strategy states "Providing clear information at the right time can help people to feel more in control of their condition, and live their lives better, on their terms." People have been living with Long Covid since 2020, and it's unacceptable that so many GPs are unable to offer this to their patients.

Suggestions/Recommendations:

- Integrated digital referral pathways for all health boards to ensure everyone living with Long Covid can be referred to third sector support
- An awareness-raising programme needs to ensure that all health professionals working with people with Long Covid are aware of the CHSS Long Covid
- Support Service. This could be coordinated by the Scottish Government in partnership with professional bodies
- Training needs to be made available for all clinicians to ensure they can identify patients with possible Long Covid and are aware of the recommendations made in Long Covid clinical guidance. This could be delivered in one session, minimising the time burden on busy health professionals.

Lack of awareness amongst some policy makers

As the urgency of lockdown has faded, many people with Long Covid feel forgotten by policy makers. While a surface level awareness of the condition remains, there seems to be a lack of awareness amongst policy makers about how debilitating symptoms can be and for many, this condition is chronic.

There is a common belief that symptoms are temporary, and that people affected will be able to return to normal life. However, people living with Long Covid have been very clear that this isn't the case, and research proves them right. A study at the University of Glasgow found that most people's status and severity of symptoms remained the same throughout the duration of the study. Only 13 per cent reported improvement, with 11 per cent reporting some deterioration. Many people we speak living with Long Covid to do not expect to recover. The support offered to them needs to reflect the fact that for most people this will be a chronic condition, and for some, could be lifelong.

Public Stigma

We're aware that a public stigma exists around Long Covid. We have worked with people living with Long Covid who are prepared to share their stories with us only on the condition of anonymity, due to public backlash when they have spoken out about their experiences.

The lack of workplace support and difficulty accessing benefits to support living with Long Covid also contribute to a lack of recognition. This is a problem without a simple solution but ensuring that Scottish Government and the NHS recognising Long Covid as a chronic condition and provide consistent and sufficient support for people will help to change attitudes.

What more could / should be done to raise awareness and recognition of long COVID?

Please see above

What are your thoughts on the use of long COVID assessment clinics?

Long Covid is a complex, multi system condition, but people living with it tell us that getting access to multiple specialities for treatment and diagnostics is far from straightforward. We need a much more coordinated approach. It is essential that people living with Long Covid have access to support and diagnostics from across different specialities, including integrated referrals to third sector self-management and support. Health board responses to this consultation have demonstrated the challenges in providing a multi-disciplinary service across the country – a national service is essential. Specialist assessment clinics could be part of this national service, providing diagnosis and coordination between different specialities.

Therapy and rehabilitation

Do you consider that the correct mix of services are in place to help people who have long COVID?

Three years from the start of the pandemic, people living with Long Covid tell us that they struggle to access services they need. Many feel unsupported and abandoned, and care remains inconsistent and uncoordinated. As we'll detail here, access to self-management support and rehabilitation are both essential, and should be accessible to everyone. There is also a significant need for specialist treatment.

Self-management support

Self-management is a crucial tool for living with a complex, chronic condition like Long Covid. It provides people with support, tools and techniques to live well and manage symptoms, and a growing body of evidence links it to improved clinical outcomes and mental wellbeing. Regardless of what other support or treatment individuals will need, self-management should be part of the treatment or care plan for every person living with Long Covid.

Chest Heart and Stroke Scotland has developed self-management tools and services for people living with Long Covid, including our Advice Line, which is the only national source of support available. While NHS Lothian have worked with us to automatically refer patients to us for a shared care model, they are the only health board to have done so. As previously mentioned, we have seen that this vital resource doesn't receive the volume of referrals from health professionals that it should. The lack of digitally integrated referral pathways in other health boards means that thousands of people who could benefit from this support aren't aware of it.

No one should be left to manage a chronic condition alone, and when solutions are available, they should be accessible to as many people as possible. It is absolutely vital that digital referral pathways are put in place for all health boards so that any GP in the country can refer people to our Advice Line.

Lack of Coordination between Services

In our Long Covid Action Plan in 2021, we highlighted the lack of coordination between primary, secondary and third sector services. Regrettably, people with Long Covid tell us that this continues to be a significant issue. We are repeatedly told that Long Covid care feels uncoordinated, and that patients feel passed from one professional to another without anyone actually taking a holistic perspective of their care.

Long Covid is a multi-system disorder (as are cystic fibrosis and diabetes) and requires multidisciplinary support. Patients should be offered access to rehabilitation and occupational therapy, as well as further support from specialist secondary care and third sector services. It remains essential that there is a system in place that enables easy referrals both between clinicians within the NHS, and onto services outwith the health system. A dedicated person to oversee their care could also help provide more holistic, integrated support.

Rehab

SIGN Guidelines recommend that people living with Long Covid are able to access multidisciplinary rehab. Where people have been able to access rehab, including physiotherapy and OT services, this is often an extremely helpful way to manage symptoms. Like self-management support, rehabilitation should be available to everyone with a chronic health problem. Good rehabilitation should always be tailored to the needs of the individual and include options for both physical and psychological support.

Chest Heart and Stroke Scotland is part of the Right to Rehab Coalition, which calls for rehab to be available to everyone who needs it. It is essential that pathways for Long Covid rehab exist in every NHS board and include integration into third sector rehabilitation services.

Lack of specialist treatment/diagnostics

People living with Long Covid have told us about their difficulties accessing specialist services, such as neurology and cardiology. Some patients may be referred to specialists for testing to rule out conditions other than Long Covid, while others are not. However, those who are referred are still rarely able to access specialist treatment, which is deeply frustrating for patients and leaves them feeling abandoned. Sometimes this is because few treatments within the specialism exist, though a number are in research phase. However, some support is simply not available in Scotland – for example, specialist treatment or support for dysautonomia is only available through referral to England. Where treatments are available that address different symptoms, these need to be available – for example, greater specialist resource to support people living with POTs is very much needed. Specialist treatments to tackle other symptoms of Long Covid are desperately needed, as we will address in response to Question 13.

Study and research

What should be the main priorities for study and research into long COVID?

Long Covid has emerged as a chronic condition for which there are minimal

treatment options and no cure. Since 2020, hundreds of thousands of people have been affected, with more than ninety thousand people in Scotland living with the condition for over a year. The prevalence of Long Covid is as high as type 1 Diabetes, and for many this condition is debilitating, leaving them unable to work. The lack of treatment options leaves many people living with Long Covid feeling abandoned and hopeless. While providing rehabilitation services and self-management support is vital in helping people to live with their condition, research into treatment is what gives many people hope.

We're aware of significant research efforts investigating treatment of both potential underlying mechanisms and individual symptoms, and we see this as a priority that we hope Scottish Government will support wherever needed. We're aware of several studies supported by the Chief Scientists Office, and we hope that this support will continue for as long as necessary. We're aware of opportunities for people to participate in clinical research on Long Covid, as promoted through SHARE. We are keen to see greater opportunities for people in Scotland to be involved in these studies if possible.

As the largest organisation in Scotland supporting people living with chest heart and stroke conditions, we are also aware of research into long term implications of microclots. This includes potential links to stroke, pulmonary embolisms and ischaemic heart disease. More research into what this association looks like is essential if we are to best support people living with Long Covid, and if necessary mitigate their future risk of disease.

Is sufficient data publicly available on the prevalence of long COVID in Scotland?

ONS data on prevalence has been broadly sufficient to show the scale of Long Covid in Scotland. It is also useful in giving an estimate of the number of people affected by different symptoms, for example that around 2 per cent of the general population are affected by tiredness or weakness as an ongoing symptom. We hope that this data would be able to inform initial service planning, though it may not be precise enough to be sufficient on its own.

ONS data has also been useful in demonstrating how Long Covid impacts on people's ability to work. Latest data showed that working age people who had Long Covid 30-39 weeks after a first test were 45.5 per cent more likely to be economically inactive. People living with Long Covid have frequently told us that they struggle to work as a result of their symptoms – this data validates their experiences.

However, we are aware of shortcomings in how Long Covid is coded within medical records. Coding used in general practice to indicate a Long Covid diagnosis is hard to find and therefore often not used. This means that prevalence in medical data is under representative, which can make it harder health boards to judge the number of patients who need support, and to accurately allocate funding.

We do not believe there is a paucity of data on Long Covid – but we do see a lack of action on what we already know. The data continues to back up what people living with Long Covid have been saying for three years – that for many people symptoms

do not fade, that they are wide ranging and that they affect people's ability to work. We would like to see urgent action on these issues.

Do you have any other comments?

Chest Heart and Stroke Scotland has supported people living with Long Covid since 2020. As such we have a number of additional points we wish to add.

Firstly, it is very important that this inquiry is not in any way viewed to be retrospective. Over ninety thousand people in Scotland have been living with Long Covid for longer than a year, many of those since 2020. Long Covid did not leave us when lockdown ended – it is a chronic health problem that people may be living with for the rest of their lives. We encourage the Committee not just to consider the immediate issues of how to support people with Long Covid now, but to look to the future, and consider how we plan to support people with this condition over the long term.

Secondly, we are keen to stress that despite identifying the need for self-management of Long Covid over two and a half years ago, progress to deliver this on a national level has been slow. We have continually pressed Scottish Government on the importance of this, and encouraged by Scottish Government officials and the Cabinet Secretary, we dedicated significant resources to developing services and solutions that support people living with Long Covid. This work has been slow and frustrating and we remain disappointed that two and a half years further on, this support is only available to a proportion of the people who would benefit from them.

In August 2020, we wrote to the First Minister with our concerns. CHSS's first meeting with Scottish Government officials discussing a national solution for self-management to support with Long Covid took place in October 2020. At this we outlined detailed proposals for what would become the Long Covid Advice Line and how a more intensive Long Covid Support Service would work and integrate with the NHS – as well as the need for a national approach to roll out and integration. In January 2021, we presented a detailed plan for a fully integrated service to the Cab Secretary Jeanne Freeman, which she welcomed. We were encouraged to progress this and over the following months we met with the Deputy CMO's office, the Scottish Government Covid Taskforce and the NSS Long Covid Service Planning Group.

Frustratingly, despite our best attempts to deliver solutions, only people living within NHS Lothian receive the kind of integrated support they need. We receive Scottish Government funding to support the delivery of our Advice Line, which is welcome – but until the issues we have raised around integration of third sector services are resolved, tens of thousands of people are missing out on the kind of collaborative, integrated care that they could be receiving.

Finally, we would like to address issues with the consultation process itself. Given that fatigue and brain fog are some of the most common symptoms of Long Covid, a Long Covid consultation that relies on written communication is a poor choice. We believe there is a need for far more consultation with people with Long Covid, using other mediums of communication and including more opportunities for face to face communication. While we were contacted with an opportunity to put forward

individuals to participate in face-to-face discussion, this was limited to a very small number of individuals and was in far too short a time frame for anyone to be available. Members of our Long Covid Support group expressed their frustration with the process, and iterated their willingness to speak with the committee in person. We hope the Committee will consider further consultation to ensure that their voices are heard.

People living with Long Covid have been proven to be right time and time again. It is essential that their voices are at the centre of this inquiry.

NHS Education for Scotland

Dear COVID-19 Recovery Committee

Inquiry into Long COVID – written submission from NHS Education for Scotland

NHS Education for Scotland (NES) is the national health board with statutory functions for providing, co-ordinating, developing, funding and advising on education, training and supporting health and social care staff in their learning and development. It is a national organisation with a significant regional presence.

NES is a leader in educational design, delivery and quality assurance. Utilising the very best in technology enabled learning, organisational and leadership development, workforce and learning analytics and digital development, across the entire health and social care workforce and in every community in Scotland, NES will help to facilitate staff to be supported, skilled, capable, digitally enabled and motivated to deliver improved outcomes.

NES leads national programmes such as the NHS Scotland Academy and NHS Scotland Youth Academy (with NHS Golden Jubilee), the planned National Centre for Remote and Rural Health and Social Care, and the Centre for Workforce Supply. NES also leads national level quality improvement development programmes and is leading on the development of the national digital platform and a wide range of digital technology solutions.

NES welcomes the opportunity to offer the following information to the Covid 19 Recovery Committee's Inquiry into Long Covid.

From a medical trainee perspective, there is an e-module on Post-Covid syndrome which was developed in June 2021 by the Royal College of General Practitioners and also a SIGN guideline developed in November 2021. In addition, there has been a national teaching webcast organised by the Scottish Government in 2022.

NES offers a structured work based blended education pathway to support the development of registered nurses employed in general practice nursing roles. The General Practice Nursing (GPN) Education Pathway has ensured Long Covid is identified and discussed within the learning materials. Unit 2 focuses on respiratory conditions, entitled 'Living with a Long Term Condition - Putting people at the centre of Care'. The nurses on the pathway will research and learn about Long Covid through specifically written case studies which have been encountered in clinical practice by our Clinical Facilitators (experienced General Practice Nurse/Advanced Nurse Practitioners currently working in General Practice engaged with NES to support the delivery of the GPN Education Pathway). The aim of this is to provide learning opportunities and resources for our nurses around Long Covid to use and to bring back to their own clinical areas to directly impact patient care in a positive way.

These Long Covid resources are included in Unit 2 activity map for the learners, Academic Assessors and Clinical Facilitators:

- [Royal Society of Medicine Long Covid Series](#)
- [RRHEAL webinar](#)
- [SIGN Guideline](#)

Learners will also be signposted to the Long Covid Support Scotland [website](#).

District nurses are also experienced in providing care and support to people with a range of long term conditions in their own homes. This includes supporting people with Long Covid, providing holistic care and helping them to achieve the best outcomes.

Allied health professionals (AHPs), including Occupational Therapists, Physiotherapists, Radiographers, Dietitians and Speech and Language Therapists, play an important role in the diagnosis, treatment, and rehabilitation of people with long term conditions. They offer therapy and rehabilitation to people in hospital and in their own homes, supporting people to achieve their person outcomes. NES is working with AHPs from NHS Tayside who are experienced in supporting people with long covid to consider how they can best share their learning and knowledge with other AHPs. These are at an early stage and require review before proceeding.

NES is involved in a number of strands of work to support and improve psychological care offered to the Scottish population. NES supported psychology staff working in paediatric and adult physical health services across Scotland to attend an online conference on 'Priorities for Long Covid services, care and research' in January 2023. Psychologists often work as part of wider multidisciplinary teams and it is therefore important for them to understand the medical issues around specific longterm conditions, in order to consider the psychological adjustment and coping needs for those populations and promote a shared language and understanding within their teams.

NES has a suite of resources for multidisciplinary staff working in children's and adult services in understanding how to help people adjust and adapt psychologically to living with a long-term condition, the majority of these resources are also relevant for staff working with people with Long Covid and will be included or adapted for inclusion on our learning platform section for Covid 19. This includes training on generic topics, such as building a shared understanding of symptoms and the condition, communication skills, person-centred working and shared decision making, along with more specific skills such as psychological approaches to managing pain.

Within paediatrics, NES has made links with a UK-wide Paediatric Psychology Network Special Interest Group on post-Covid-19-syndrome in children and young people and to colleagues who are developing resources for health and care professionals in England. This helps us to share good practice across Scotland and collaboration with NHS England colleagues will inform the

development of resources on the psychological impact of Long Covid in children and young people in Scotland. NES meets regularly with local clinical psychology physical health service leads and training networks to update them on the current evidence base and support the sharing of good practice.

From April, additional educational capacity will be available to develop resources for multidisciplinary staff working with children, young people and their families, focusing on psychological adjustment and support for Long Covid. This will build on existing training including the following: the psychological impact of long-term health conditions; psychological skills to promote coping and adjustment to a long-term health condition: psychological approaches to managing physical symptoms and how to communicate with families about symptoms for which the underlying pathological mechanism is not yet clear. Bespoke training around understanding Long Covid will also be considered. Key aspects of these resources will include attempting to address the stigma experienced by people with Long Covid and raising awareness of the unique aspects of adjustment to Long Covid.

We hope the Committee finds this information helpful.

Yours sincerely,

Professor Karen Reid
Chief Executive, NHS Education for Scotland

Royal College of General Practitioners Scotland

Information about our organisation

RCGP Scotland are the professional membership body for family doctors in Scotland. We are committed to improving patient care, clinical standards and GP training.

Awareness and recognition

Do you think there is enough awareness and recognition of long COVID by the general public, medical professionals, employers and / or policy makers in Scotland?

RCGP Scotland welcomes the opportunity to respond to this consultation. As the membership body for general practitioners in Scotland, we exist to promote and maintain the highest standards of patient care.

Long Covid is an emerging and not fully understood condition with a wide variety of presentations and severity of illness. It is a multisystem disease, usually presenting with clusters of symptoms, often overlapping, which can fluctuate and change over time, and affect any body system. Most people gradually recover, but a small percentage continue to have long term symptoms. In such circumstances, there can be challenges for patients, health care practitioners and policy makers alike.

Measures that reduce Covid will also necessarily reduce Long Covid, and there is some evidence that with repeated infection people are more likely to get Long Covid. Vaccines continue to play a central role in preventing both the initial infection, as well as the potential development of Long Covid. There is no evidence to suggest that vaccines themselves cause or contribute to Long Covid.

We recognise the distress experienced by those self-reporting with Long COVID, and acknowledge that it has had a significant negative effect on their physical and mental health and wellbeing. There is also a feeling amongst some sufferers, their families or carers, that it is an under-recognised and treated condition.

There are no recognised treatments for Long Covid itself, and the emphasis is on supportive and symptomatic care, rehabilitation, treating specific complications and ensuring the diagnosis is correct, which may mean excluding 'red flags' suggestive of other significant illness. Further to this is that for the vast majority of sufferers, symptoms gradually resolve over time whether with additional treatment or not. A very small number will require specialist assessment for specific issues, for example, cardiac concerns. GPs are reporting a worsening of long-term conditions more generally, including, for example, poorly controlled diabetes, deteriorating mental health and later presentations of some cancers. Increasingly Covid is part of this mix, and it can be difficult to distinguish its symptoms (fatigue, tiredness, breathlessness and so on) from other conditions, either presenting anew or pre-existing.

Long Covid can be complex, affecting both physical and mental health, with multiple

systems potentially involved: there are no standard protocols for its diagnosis and management. It often requires generalists skills to treat, but most can be fully managed in primary care, and the GP is best placed to provide this holistic approach. As referenced in an article in the British Medical Journal (BMJ) , Professor Greenhalgh and her team do recommend specialist clinics for the small numbers with severe multi-system disease, and these are not available in Scotland. However Scottish GPs are able to utilise other referral pathways, even if they are generic ones, should people need further investigation or rehabilitation in relation to their symptoms. RCGP Scotland has previously supported this, recognising the shortage of specialist care and that multidisciplinary covid clinics might divert resources needed elsewhere. We have also asked for improved support for rehabilitation services, and general practice itself, as it manages yet another new unresourced workload.

There has been reasonable cover in the medical literature of Long Covid, with some prominent GP academics also writing in the British Journal of General Practice (BJGP) about it. We believe that many Health Boards in Scotland have some specific Long Covid services, and all this serves to raise awareness. In December 2020 RCGP collaborated to develop UK wide guidelines with NICE and SIGN , and those were highlighted to GPs by the usual means. The RCGP also developed an e-learning module on the long term effects of Covid-19 and Post-Covid-19 syndrome, which shares the key recommendations from the guidance. This module sits in the RCGP's Covid Resource Hub, developed at the start of the pandemic and still updated. It has always been open to members and non-members alike and is heavily used , with over 12,000 page views since its launch.

We also know that as patients present to GPs with symptoms, GPs - as they do for any emergent condition - have had to learn about the manifestations of Long Covid and possible management approaches. We suggest therefore that there is reasonable awareness amongst most GPs. It is difficult to judge public awareness: many people seem to accept that for most the symptoms settle of their own accord, but there may be some who are not presenting to their GP and need more help.

What more could / should be done to raise awareness and recognition of long COVID?

RCGP Scotland would support further efforts to communicate the symptoms and effects of Long Covid as well as the most appropriate pathways to accessing treatment to patients and the wider public. We would want proportionate and realistic messaging, reflecting that for most, symptoms will settle without treatment, and alerting that for a minority there may be longer term or more serious complications. It's important to affirm to people that GPs don't discharge patients and will offer patients suffering from Long Covid appropriate and ongoing continuity of care. We would also want educational approaches to emphasise the messaging round the protection from Long Covid offered by vaccination.

What are your thoughts on the use of long COVID assessment clinics?

We believe that it is appropriate for the overwhelming majority of patients with Long Covid to be managed within general practice. However, there are severe pressures in general practice and those with Long Covid may require repeated evaluation. There is some variability in direct access investigations available to GPs and outpatient waiting times for specialist evaluation can be long. At this stage of the pandemic, with good vaccine coverage, and the severity of illness caused, there is an increased risk that patients presenting with Long Covid symptoms may have instead another cardiac or respiratory condition which may have similar or even identical symptoms. Patients need a GP assessment and investigation, rather than being funnelled inappropriately into a clinic that is designed for one condition, and then require further investigation and alternative management. Key to all this are generalist skills, access to timely investigations and good rehabilitation and mental health support, all of which are under pressure just now. GPs can then access specialist clinics related to the primary system involved be it cardiac, respiratory or neurological.

As we have noted in past consultations, the shortage of Multi-Disciplinary Team (MDT) professionals presents a major barrier to the possibility of operating Long Covid clinics. We are also aware that such clinics reduce the availability of staff in other areas. The needs of those suffering from Long Covid need to be balanced against the needs of those patients with non-Covid health concerns.

As Long Covid clinics have been operating in England for some months at this stage, funded in many instances by research monies, we would be keen to know of their impact and how that has contributed to our knowledge of the most cost-effective and appropriate service provision for this group. We would hope that research findings would be widely shared. We note that the English clinics have been hugely expensive for the number of patients treated, and that most treatment involves rehabilitation and symptomatic care. English GPs are offered an enhanced service to support such patients.

Therapy and rehabilitation

Do you consider that the correct mix of services are in place to help people who have long COVID?

Increased and long-term investment in access to therapies based in the community, such as physiotherapy, occupational therapy and specialist rehabilitation are important resources for patients suffering from Long-Covid.

Additionally, increased investment in community mental health services - specifically mental health clinicians based in general practice - is needed to enable patients experiencing the psychiatric and psychological impacts of Covid-19 to be able to access treatment in a timely fashion. And we need improved support for general practice itself which is absorbing the vast majority of this workload.

The management of Long Covid exemplifies the urgent need for effective interfaces across areas of health and social care delivery. We view fully funded interface

groups in each Health Board as key to ensuring that effective communication and working across primary and secondary care can be achieved. We would encourage increased data collection on both the prevalence of Long Covid and the most effective treatments for the condition in order to ensure that finite NHS resources are directed in the most appropriate way.

We note that healthcare staff are believed to have been more impacted by Long Covid than the general population, with 0.3% of healthcare staff in Scotland said to be absent from work because of the condition.

What support could or should be available for people who are supporting or caring for people with long COVID?

Within general practice, we witness on a daily basis the significant burden placed on some carers. We therefore support efforts to improve support for carers and the simplification of the system to support this and would want their rights to be on a par with other carers.

Further investigation into the specific or unique challenges faced by carers for those with Long Covid may be helpful and assist with the provision of effective holistic care for those suffering from the condition. The uncertainty over prognosis and the recovery journey brings added emotional burdens both to patients and their carers, who will not know how long they will be required to maintain this role.

Do you have any other comments?

Sources referenced within this response:

<https://www.bmj.com/content/378/bmj-2022-072117> <https://www.sign.ac.uk/our-guidelines/managing-the-long-term-effects-of-covid-19/> COVID-19 Resource Hub: Post-COVID syndrome (rcgp.org.uk)

https://www.england.nhs.uk/wp-content/uploads/2022/07/C1607_The-NHS-plan-forimproving-long-COVID-services_July-2022.pdf
<https://www.bbc.co.uk/news/health-64405899>

Royal College of Occupational Therapists

Information about our organisation

We're RCOT, the Royal College of Occupational Therapists. We've championed the profession and the people behind it for over 90 years; and today, we are thriving with over 35,000 members. Then and now, we're here to help achieve life-changing breakthroughs for our members, for the people they support and for society as a whole.

This includes giving members opportunities to learn, research, teach, practice and continuously improve their knowledge and skills. We also work with healthcare commissioners, political leaders and others to position occupational therapy as a solution at the heart of health and social care.

Awareness and recognition

Do you think there is enough awareness and recognition of long COVID by the general public, medical professionals, employers and / or policy makers in Scotland?

The Royal College of Occupational Therapists (RCOT) and its members believe that there is a lack of awareness, understanding and recognition of long COVID as a long term condition. This is particularly true within children and young people's services as our members are reporting an increase in children presenting with post covid symptoms and that there is an absence of support available for Scotland's young people. Members report referrals to children and young people's services with new symptoms post covid ranging from upper limb pain and inflammation impacting on functional tasks, post covid fatigue and chronic pain. This has potential impacts on children and young people's ability to complete activities of daily living and attend school which may have longer term impacts on development.

RCOT believe that there is a lack of awareness of how occupational therapy and rehabilitation services can support individuals experiencing long COVID symptoms.

What more could / should be done to raise awareness and recognition of long COVID?

RCOT believe that more awareness is required around the benefits of rehabilitation in relation to long COVID. Occupational therapists have the skills and expertise to support those suffering with the impact of long COVID and support them to engage in activities that are meaningful to them. We have produced guides on the role that occupational therapists can play in supporting adults, children and young people to manage and recover from the effects of long COVID.

RCOT and its members also believe more should be done to educate healthcare providers, employers and educational institutions on the scale and impact of long COVID on the population and how best to support those with long COVID symptoms. The public health agenda should make long COVID and education of the general population a priority. The public should be educated on how long COVID can impact physical, cognitive, and psychological health and how to access the correct support at the correct time. Public health should also educate the population on self-

management techniques and lifestyle advice. RCOT has produced practical advice to help people recovering from COVID to manage fatigue and conserve their energy.

What are your thoughts on the use of long COVID assessment clinics?

RCOT recognises the potential value of long COVID assessment clinics but feels strongly that these clinics would require a multidisciplinary approach and that it would be essential that clinics included rehabilitation and are not limited by medical model processes. Occupational therapists are trained at graduate level in both mental and physical health and are experts in rehabilitation (physical, psychological, and vocational). Occupational therapy will be key to Scotland's COVID recovery.

RCOT members have reported the success of Long COVID Staff Clinics in NHS Greater Glasgow and Clyde which include occupational therapists and physiotherapists who can support individuals with fatigue management techniques, graded rehabilitation to engage in meaningful activity and in returning to work. However, members have identified a lack of joined up care and lengthy waits for secondary services. Members report that often citizens are left waiting for multiple medical opinions and that 'hopeful waiting' can be a barrier to making change. An assessment clinic where the relevant specialists are present could facilitate a smoother pathway for those experiencing symptoms of long COVID.

RCOT have conducted a study of the rehabilitation workforce and have found that existing services have been forced to absorb the additional population need and pressures caused by long COVID. Increased investment in existing community rehabilitation and primary care teams may offer a longer term and sustainable approach to long COVID rehabilitation. Primary care teams such as the occupational therapy primary care service in NHS Lanarkshire have demonstrated the ability to support those with a diagnosis of long covid improve mobility, levels of fatigue, and the psychological impact of long COVID.

Therapy and rehabilitation

Do you consider that the correct mix of services are in place to help people who have long COVID?

An RCOT survey of the occupational therapy workforce has indicated that increased investment in rehabilitation services is required to meet the increased demand for rehabilitation following the pandemic due to long COVID. RCOT and its members would support an increase in occupational therapy services in community and primary care teams to ensure occupational therapists are best positioned to support early interventions and preventative support.

There is a lack of joined up support and lengthy waits for onward referrals impacting those with long COVID. There is a need for coordinated assessments by appropriate specialists as long COVID is a multi-system condition with long term effects. Support must be in place to ensure people are able to undertake their important life roles, including self-care, work and caring responsibilities.

RCOT members have identified a lack of support services for children and young people experiencing symptoms of long COVID, for example fatigue management and support returning to school. Members note that schools may not feel equipped to

support students experiencing long COVID, and may not recognise the complexity and fluctuating nature of children's symptoms. The Long Covid Kids charity has produced a guide on the ways in which children with long COVID can be supported.

What support could or should be available for people who are supporting or caring for people with long COVID?

Individuals who are supporting or caring for loved ones living with long COVID will require support to ensure that they are still able to engage in meaningful activities and maintain their role as a family member or friend. This may require emotional support or respite. Additional financial supports may also be required if long COVID is impacting an individual or their carer's ability to seek employment. Education for both the individual experiencing long COVID and their families and supporters will be key to encouraging self-management. Study and research

What should be the main priorities for study and research into long COVID?

Further research across the population to identify how long COVID impacts different groups would be beneficial to long term service planning and the future targeting of populations for interventions.

Research on how to improve quality of life and the impact of medical interventions and rehabilitation would be beneficial to ensure the workforce can provide quality evidence-based practice.

RCOT members have identified a lack of research or guidance on the impact of long COVID on children and young people. This is likely to have a long-lasting impact on future health and social care needs of the general population.

Is sufficient data publicly available on the prevalence of long COVID in Scotland?

RCOT believe that clear data should be made public on the prevalence of long COVID in Scotland as well as the demographics of those most affected. This will allow for better service design to best meet the needs of the Scottish people as well as a better understanding of the condition.

Members note that the Office of National Statistics provides useful data sets on long COVID however it is not clear if people are being appropriately categorised as long COVID in all cases, particularly within primary care settings. Members also report that it isn't always clear on where to access data regarding long COVID.

Do you have any other comments?

RCOT members have reported anecdotal evidence of individuals receiving improved levels of care and support from private health care providers when experiencing symptoms of long COVID. It is imperative that all of Scotland's citizens have access to the correct medical support and rehabilitation, regardless of their financial position. Clear guidance and standards of best practice would be beneficial to support health and social care professionals providing services for those living with long COVID. This will require the sharing of best practice across locations and sectors.