

## **COVID-19 Recovery Committee**

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

## **Long COVID - Therapy and rehabilitation**

At this meeting Members will hear from two panels with a focus on therapy and rehabilitation and services for people with long COVID. In the first session Members will hear from representatives from primary care, third sector services and allied health professionals. In the second session members will hear from geographical and special health boards and will be able to explore the development of long COVID services and pathways in Scotland.

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

SPICe has [published an updated blog on long COVID](#) on 09 February 2023.

## **Panel 1: Background**

In the first panel Members will hear from representatives of:

- Royal College of GPs Scotland (RCGPs)
- Chest Heart and Stroke Scotland (CHSS)
- The Royal College of Occupational Therapists (RCOT)
- Dr Claire Taylor, Tayside Complete Health (to be confirmed)

The Scottish Government published a paper on [Scotland's Long COVID Service](#) in September 2021. This notes that its approach is based on four elements:

1. supported self-management
2. primary care and community-based support
3. rehabilitation support
4. secondary care investigation and support.

This publication highlights the role self-management for people with long COVID:

“For many people, recovery from COVID-19 can be self-managed by using the right information, advice and support. This is about making sure people have access to information and resources and are equipped with the right tools to help them participate as actively as possible and enjoy the life they choose.”

To support this the Scottish Government has provided funding to [Chest, Heart and Stroke Scotland's \(CHSS\) long COVID Support Service](#). This aims to enable people with long COVID to speak to nurses who are trained in managing some of the most common long COVID symptoms, such as breathlessness and fatigue. CHSS also works 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. It also runs a peer support group for anyone living with Long Covid and a Kindness Volunteer scheme, providing regular calls for emotional support.

As part of the Self-Management Fund, administered by the Health and Social Care Alliance Scotland (the ALLIANCE), the Thistle Foundation has also developed a remote self-management programme, with a specific focus on supporting people living with long COVID.

The [letter to the Committee from the Scottish Government](#) reported:

“As of the end of November 2022, a total of 3,444 referrals were made to Chest, Heart & Stroke Scotland's long COVID Support Service since its inception in February 2021. Data collected by the charity shows that from September 2022 to the end of November 2022, a total of 113 hours and 5 minutes were spent on calls. 92% of all calls required information on pacing, fatigue, sleep, diet and return to work issues as a combination within each call.”

[Scotland's Long COVID Service](#) also notes the central role primary care can have in the treatment and support for people with long COVID:

“For many people, their first point of contact with healthcare services will be the healthcare team based in their local GP surgery. Primary care teams have expertise in managing uncertainty and are experienced at assessing people with a variety of symptoms and conditions, as can be the case with long COVID. As part of their local communities and often with an extended knowledge of the person over a long period of time, primary care teams are ideally placed to provide holistic, person-centred care which focuses on what matters to the person.”

Occupational therapists often are part of the primary care team. The aim of [occupational therapy](#) is to enable people to take part in the activities, roles and routines that are important to them, at home, at work and in community and leisure settings. Occupational therapists can support people experiencing many of the

common symptoms of long COVID that impact on daily life, including physical, psychological and cognitive issues, as well as emotional and social needs.

In its submission the Royal College of Occupational Therapists said:

“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.”

## **Panel 1: Themes**

Members may wish to discuss the following themes with witnesses.

### **Theme 1: Knowledge and awareness of long COVID by healthcare professionals**

Members have repeatedly heard from people with long COVID that there are issues accessing healthcare services. The barriers highlighted include a lack of knowledge among some healthcare professionals, issues around not listening to the concerns of people with long COVID and problems accessing ongoing or more specialist support.

In a written submission the ALLIANCE said:

“Long Covid is outwardly invisible and can therefore lead to problems with credibility for those who live with it. As a result, people have reported facing challenges with being listened to, being believed and having their symptoms recognised [...] People living with Long Covid reported experiencing these challenges in a range of settings, including with healthcare professionals, in the workplace, with state entitlement agencies, and within wider society.”

The [RCGPs has an eLearning course on the long term effects of COVID-19 and Post-COVID-19 syndrome](#). This aims to teach people how to describe the various presentations of Post-COVID syndrome, understand the current guidance and understand the impact on patients. In its submission the RCGPs commented: “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”.

In the Committee meeting on 9 February, the Committee heard from Jane Ormerod, Long Covid Scotland about the [involvement of people with lived experience in developing and delivery training materials for health professionals](#).

“If an approach of educating healthcare professionals, predominantly, but also the wider public, is to be taken, people with long Covid need to be involved in the development of that resource. That should not be done only as an afterthought—“Come along and have a wee talk about your experience.” It should be done from the very beginning, when developing a resource, and when delivering it. That might be a pill that is hard to swallow for some healthcare professionals, but that is an important part of what should be happening, and at the moment it is not.”

The Committee has also heard from witnesses the reluctance of some healthcare professionals to diagnose long COVID and issues around coding long COVID. Stewart McIver, Long Covid Scotland told the Committee:

“Statistics from the Office for National Statistics are often quoted and derided for being self-reported. We are now three years into the pandemic, but we still do not know the scale of the long Covid issue. It is often said that Scotland has great data sets, but we are not using those. I do not know what the funding that has been allocated for long Covid services is based on, but the need will obviously grow as more people fall sick. We have heard from GPs and from people in the Long Covid Scotland group that GPs are not actually coding illnesses as being long Covid. If the illness is not being properly coded and we do not know the scale of the problem, how can we solve it? Analytical work must be undertaken to address that, and that could be done.”

The issue around coding was also discussed in the submission from NHS Greater Glasgow and Clyde which said:

“The National Strategic Network has recognised the challenge of the available data due to current systems, the inconsistent use of [SNOMED coding](#) and prevalence data within Scotland. Public Health Scotland is supporting the Long COVID service leads group in understanding prevalence, shifting demand and data trajectories, in determining need and therefore effective service planning, with Scottish Government Long COVID funding available for each Board”

CHSS said, in its written submission, “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 underrepresentative, which can make it harder health boards to judge the number of patients who need support, and to accurately allocate funding.”

The CMO has outlined the [codes that should be used to record the long term effects of COVID-19](#). He stated “As you will appreciate, accurate recording of information

within clinical systems is necessary in order to provide an accurate picture of activity in relation to this new condition.” Public Health Scotland has also published [COVID-19: ICD-10 Analytical Guidance](#).

**Members may wish to ask:**

- **What training on long COVID is available for healthcare professionals? How can healthcare professionals, including GPs, be encouraged to undertake training on long COVID?**
- **What steps are taken to ensure training resources and materials are kept up-to-date?**
- **How are people with lived experience involved in the development and delivery of training?**
- **The RCGPs, whether GPs are confident in diagnosing and coding cases of long COVID?**

## **Theme 2: Access to services – unmet need and inequalities**

The Scottish Government’s [Scotland’s Long COVID Service](#) notes: “For many people, recovery from COVID-19 can be self-managed by using the right information, advice and support.”

In the informal evidence sessions members heard about the levels of potential unmet need in Scotland and inequalities in accessing services. It is estimated that [175,000 people in Scotland have self-reported symptoms of long COVID](#).

In its written submission Long COVID Kids said:

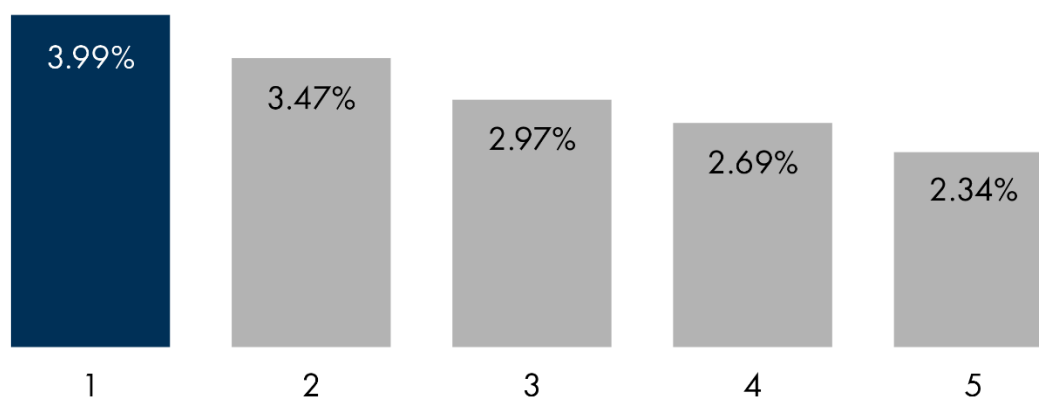
“Children, young people and their parents are unaware of potential Long Covid symptoms and therefore are not recognising and identifying Long Covid and do not know where to go to seek appropriate advice and support.”

It is considered that long Covid is likely to have significant health inequalities implications. [A study looking into Long COVID Inequalities](#), funded by the National Institute of Health Research, commented that:

“Those who are already minoritized and socially disadvantaged in society are more exposed to COVID19. Therefore, they may suffer more from job and income loss, struggle with caring responsibilities and have their illness trivialised if they develop Long Covid. It is important that those living with Long Covid receive support that is meaningful and equitable”.

Figures from the Office of National statistics suggests that there is a higher percentage of people living in the most deprived areas, of the UK, with self-reported long COVID compared to those living in less deprived areas.

### **Estimated percentage of people with self-reported long COVID by index of Multiple Deprivation quintile group.**



Source: [ONS](#)

### **Members may wish to ask:**

- **What is the current level of demand for long COVID services? Can this be met? Is there capacity in the system to deal with the level of unmet need?**
- **What inequalities exist in relation to people accessing support and treatment for long COVID? How should these inequalities be addressed?**
- **Do witnesses believe that fewer people from disadvantaged groups are presenting to healthcare services with long COVID? If so, how should this be addressed?**
- **How does CHSS ensure that its services are accessible to marginalised groups, what data is kept and reported on this?**

## **Theme 3: Multi-disciplinary teams**

A number of people with long COVID have told Members that there is a need for a multi-disciplinary team approach to long COVID.

“People living with Long Covid have had to flit between their GP and various specialists with long wait times in-between and little to no communication between departments. This has resulted in disjointed care, confusing and conflicting diagnoses and more often than not, caused additional harm to unwell people whose energy is very limited and yet they have been required to

navigate the healthcare system alone and attempt to join up their clinicians themselves.”

“I would like to see proper MDT long Covid assessment clinics across Scotland. By MDT I don’t mean just physios and staff from psychiatric/psychology services. They should have input from physicians, nurses, AHP and where appropriate mental health professionals. Access to investigations- eg scans (eg. MRI, CT, VQ), wider range of blood tests, etc. Ability to refer on to appropriate specialist teams where required.”

The Royal College of Occupational Therapists has published a [range of resources on long COVID](#). Its [Long COVID Quick Guide](#) explains the role occupational therapists can play as part of a multidisciplinary team. It notes:

“Communication between occupational therapists in tertiary Long Covid services, with community colleagues and the wider multidisciplinary team is essential to ensure coordinated and timely care for individuals. It also facilitates shared learning”.

In its written submission the Royal College of Occupational Therapists said:

“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.”

The RCGPs noted “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.”

**Members may wish to ask:**

- **Is a multi-disciplinary approach to supporting people with long COVID being taken in Scotland?**
- **Does the current approach to long COVID in Scotland facilitate a holistic person centred and joined up approach to care?**

- **What rehabilitation services are available for people, including children, with long COVID? Do witnesses consider that this level of provision is sufficient?**

## Theme 5: Specialist care

In its [letter to the Committee](#) the Scottish Government stated:

“It is for each NHS Board to develop and deliver the best models of care for assessment, diagnostic tests, and support for the treatment or management of symptoms, tailored to the needs of their local population. This may involve strengthening the co-ordination of existing services, or establishing dedicated services where appropriate. While none of the services being delivered by NHS Scotland Boards are termed ‘long COVID clinics’, initiatives being supported by the funding include key elements of care that are also offered by post COVID assessment clinics elsewhere in the UK, including pathways providing assessment and co-ordinated access to relevant support and services in line with individual patient need”.

From the submissions to the call for views it appears that people’s experiences of accessing health care support for long COVID is mixed. Concern have been raised about workforce issues, access to primary care, availability of off-licence medicines and availability of diagnostic tests.

“Long covid assessment clinics would be amazing if they actually did valid tests (checking for presence of blood clots, measuring endothelial function, assessments for POTS, knowledge of MCAS, able to offer imaging diagnostics etc). Assessment clinics that purely talk about 'managing' your condition, palm it off as anxiety, or encourage 'exercising through it', would be a total waste of resources and the time and energy of long covid sufferers.”

“There is not enough money allocated for services and not the right mix of professionals involved. There is no support for people with long covid and it feels as if we have been abandoned”

“These need to be standardised and staffed appropriately. AHP staff are fantastic however, they need to be supported but doctors who can prescribe medication as appropriate. There are off licence medications that do help people and these need to be looked at. Involve Dr Claire Taylor at a strategic level, She seems to be the only available long covid specialist. There needs to be access to doctors who specialise in neurology, cardiology and respiratory to provide specialist knowledge of how covid affects the body. There needs to be access to testing as required (MRI, CT, CXR, VQ, ECG, 24 hour tape) while not everyone needs this some do. It shouldn’t be a battle and wait for these tests, we have waited long enough. Many of these clinics seem to be physio and OT only, and that is not enough, and they are not going to work.”



“In both Edinburgh and Ayrshire I have failed to get anywhere with a doctor/NHS and have instead paid privately for treatment, supplements and looked online for community support.”

Long COVID kids suggested:

“For the current system to be effective, it would be dependent on every clinician and allied health professional in Scotland being highly knowledgeable about Long Covid, this is impractical. It is clear that a consistent and structured approach, for the development of the correct mix of services, will be needed and should encompass elements such as:

- Assessment clinics to provide a focus for diagnosis; supported by,
- Local services that provide continuity of care and the integration of health, education and social services, and,
- Specialist services integrated through multidisciplinary teams (MDTs) to effectively manage the multi-system nature of the condition.”

Ian Mullen, Covid Action Scotland, told the Committee: “I fully agree that long Covid clinics are absolutely critical. The sooner they are introduced, the better. There is an inconsistent approach at the moment.”.

In its submission the Royal College of Occupational Therapists said:

“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.”

**Members may wish to ask:**

- **What would the potential benefits be of a consistent and structured approach to long COVID across Scotland**
- **Are witnesses aware of delays for people with long COVID being able to access secondary healthcare services? Are these delays exacerbated by the wide range of symptoms of long Covid?**
- **Are appropriate secondary care services available for further referral when required?**

## **Theme 6: Workforce**

Members will be aware of [current demands in the NHS and social care](#). Like elsewhere in the UK, there are recruitment challenges facing both the NHS and social care in Scotland. [Audit Scotland](#) has noted that “workforce planning has never been more important”. The Scottish Government published its [Health and Social Care: National Workforce Strategy](#) in March 2022. The vision of this strategy is for “A

sustainable, skilled workforce with attractive career choices and fair work where all are respected and valued for the work they do”.

Workforce issues in relation to long COVID have been highlighted in some of the submissions to the Committee. Long COVID Kids said:

“In a meeting between LCK and the Royal College of General Practitioners of Scotland in November 2022, Dr David Shackles confirmed that due to current workloads, primary care clinicians are time-poor, struggling to update their learning and/or feed learning into practice cluster meetings which are often cancelled due to lack of time and resources. GPs must be supported to resolve this issue to ensure a smooth referral process to future Long Covid assessment services.”

Concerns and difficulties filling posts were echoed in most of the submissions from the NHS Boards.

NHS Fife:

“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”

It went on to outline: “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.”

NHS Borders:

“Whole system pressures have also prevented clinicians and service leads from dedicating time to this particular [long COVID] service development over the winter of 2022/23”.

NHS Tayside:

“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”.

NHS Forth Valley:

“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.”

**Members may wish to ask:**

- **What impact have workforce pressures had on establishing and delivering services for people with long COVID?**
- **What action could be taken to assist NHS Boards fill specific long COVID posts?**

## Panel 2: Background

In this session Members will have an opportunity to discuss long COVID service planning with representatives from the following NHS Boards.

- Public Health Scotland (PHS)
- NHS National Services Scotland (NSS)
- NHS Education for Scotland (NES)
- NHS Highland
- NHS Lothian

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

The National Strategic Network conducted survey and gap analysis exercises which identified the following priority areas for improvement activity.

- Additional resource to allow time to be spent on holistic assessment and support of people with long-term effects of COVID-19
- Support for professional education
- Consolidation of clinical pathways
- Ongoing engagement with people with lived experience
- Evidence and innovation
- Data and intelligence

In its [letter to the Committee](#) the Scottish Government it outlined how long COVID services are currently organised in Scotland.

“Funding has been made available to NHS Boards and partners to respond to the needs of people with long COVID in their areas. NHS Boards are using the resource to develop pathways which aim to support early intervention and

improved co-ordination of support and services for people with long COVID. For example, many Boards are introducing a single point of access for assessment and co-ordinated support from services including physiotherapy, occupational therapy and psychology, depending on what is most appropriate for a person's needs."

The Scottish Government has said that the long COVID Support Fund will [be allocated and spent over the three financial years](#) (2022-23, 2023-24, 2024- 25).

The services available for people with long COVID in Scotland varies by health board. In this session Members will hear from representatives from NHS Highland and NHS Lothian.

### **NHS Highland:**

- Development of a multi-disciplinary complex review group to help signpost and coordinate care for those patients who are severely impacted by long COVID and struggling to recover with rehab.
- The Board already has an operational long COVID pathway, including occupational therapy and physiotherapy staffing to support assessment, goal setting, rehabilitation and coordination for people with long COVID. The pathway will signpost to self management resources as a first option and can be stepped up to supported self management including one to one or group support.
- Close working with third sector colleagues, 'Let's Get on with it Together', in self management resources, groups and peer support. The team is a board wide virtual team offering remote support by telephone or NHS Near Me (video appointments). The team will be working closely with local services across the wide geographical board area to enhance local support.

### **NHS Lothian:**

- Staged scale-up of the long COVID supported Self Management Pathway including the digital self management tool and Chest, Heart & Stroke Scotland advice line. Learning from each phase of the pathway will inform the next stage to implement the pathway across NHS Lothian and its partnership areas of East Lothian, West Lothian, Midlothian, and the City of Edinburgh.
- The application of existing data including how many people have received a clinical intervention and the routes taken to access these services, to inform the development of the Lothian model for long COVID services.
- At present, existing NHS Lothian and associated Health and Social Care Partnership services are providing clinical support for people who need intervention to help them manage their symptoms. People with long COVID have access to a wide range of services including respiratory, neurology, rheumatology and musculo-skeletal teams, amongst others.

- In addition, a trial group of GP Practices across Lothian can refer through to the ‘Tailored Talks’ digital self management platform, providing access to tailored health information to help them to manage their symptoms and a 12-week programme of support from Chest, Heart & Stroke Scotland’s advice line.

The Committee also wrote to all the [geographic Health Boards, their responses can be viewed online](#).

## Panel 2: Themes

### Theme 1: Service development

As mentioned previously, the [Scottish Government](#) said that:

“Funding has been made available to NHS Boards and partners to respond to the needs of people with long COVID in their areas. NHS Boards are using the resource to develop pathways which aim to support early intervention and improved co-ordination of support and services for people with long COVID. For example, many Boards are introducing a single point of access for assessment and coordinated support from services including physiotherapy, occupational therapy and psychology, depending on what is most appropriate for a person’s needs. In addition, the Strategic Network is conducting a procurement exercise to enable a digital tool to be made available throughout Scotland to support the collection of patient reported outcome measures that can be shared with their clinicians to inform the planning of care and support.

The Committee has received a number of submissions from health boards which outline the specialist services available – these are summarised below. At the time of writing, 20 February, responses were still outstanding from:

- NHS Ayrshire and Arran
- NHS Lothian
- NHS Shetland
- NHS Western Isles

Annex A summarises the **barriers and enablers** to the development of long COVID services highlighted by the NHS Boards in the written submissions.

#### Members may wish to ask:

- **What have been the key enablers to setting up services for people with long COVID in Scotland?**
- **What have been the key barriers to setting up services for people with long COVID in Scotland?**

- **How do long COVID services in Scotland interact with research studies into the condition?**
- **How have people with long COVID been involved in the development of services?**
- **Are appropriate diagnostic tests for the conditions associated with long COVID available routinely through the NHS in Scotland?**
- **What will be the benefits of a digital tool to support the collection of patient reported outcome measures? How will this be used by clinicians? How will its impact be evaluated?**

## Theme 2: Pathways

Annex A summarises the long COVID services, and staff provision, in each health board area, collated from the written responses to the letter from the Committee. This shows some variation in provision.

In its [letter to the Committee the Scottish Government said](#):

“A clinical and subject matter expert group has been established through the Strategic Network to support the implementation of the clinical guideline within NHS Scotland and provide information and support where required to NHS Boards on the development of local referral pathways for long-term effects of COVID-19

The Strategic Network has established a clinical and subject matter expert group, bringing together professionals from different disciplines with expertise in the management of symptoms associated with long COVID. The group is currently collating information on existing pathways of care for the management of symptoms associated with long COVID, and will support the development of standardised guidance as required where variation in practice is identified”.

A clear message in the last meeting and in the written submissions is that people with long COVID are experiencing issues accessing pathways of care.

Michelle Powell Gonzalez, Long Covid Support Group:

“Pathways need to be created in the NHS for us to be able to get proper testing and treatments and so on.”

Stewart McIver, Long Covid Scotland:

“I have gone to see my GP to see what services are available in Lothian, and they told me that there is nothing. The pathways are not working”.

Rob Gowans, Health and Social Care Alliance Scotland:

“The key thing is to get holistic support in place, whatever the route. The experiences that we, like others, hear include people not being able to find care pathways or post-diagnostic care plans, nothing being joined up and things being slow, patchy and ineffective.”

NHS National Services Scotland (NSS) highlighted that its future plans included “scoping and development of clinical pathways”.

**Members may wish to ask:**

- **What has been the experience of NHS Boards in establishing pathways of care for people with long COVID?**
- **How are inequalities in care mitigated against within these pathways?**
- **NHS National Services Scotland (NSS), for an update on the work of the established a clinical and subject matter expert group.**
- **NHS National Services Scotland (NSS), whether there are plans to development standardised guidance for use across all NHS Boards? If so, when this is expected?**
- **NHS National Services Scotland (NSS), for more information regarding its future plans around the scoping and development of clinical pathways”.**

## **Theme 3: Paediatric services / transitions to adult services**

In the [informal session](#) Members heard about the experience of children with long COVID and the impact this can have on their families. The [ONS estimates that 21,000 2 to 11 year olds have long COVID in the UK and 37,000 12 to 16 year olds are estimated to have long COVID](#). NHS England has established a specialist long COVID services for children and young people through 15 paediatric hubs.

In its submission NES wrote:

“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.” [...] “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.”

Long COVID Kids wrote to the Committee:

“In a meeting with NHS Scotland Long Covid Service Clinical Leads, organised by the National Services Scotland Long Covid Strategic Network, (30th January 2023) there was admission by Health Boards that until recently they were unaware of the need for Paediatric services. This suggests a failure to put lived experience at the heart of service planning and development, and that there is clearly a barrier to care at an early stage of the health pathway which we would be keen to see investigated and addressed.”

In one submission, a parent wrote:

“My daughter has had appalling care from the NHS in particular her paediatrician who refused to acknowledge her POTs as a result of Covid infection and left her for nine months (not referring her urgently to cardiology and I had to fight to get her referred). The paediatrician told her there was nothing wrong with her heart and she did not have POTs and also relayed this to her records, CALMS referral saying I was obsessed that there was a problem. When she finally did get to see the cardiologist 9 months later - she was diagnosed with POTs and put on beta blockers which helped immensely reducing heart rate, chest pain and all the anxiety that my 15 year old daughter went through for 9 months to get the help she needed”

Members also heard examples of when children have had problems accessing both paediatric and adult services for long COVID. The Royal College of Occupational Therapists highlighted:

“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.”

Some of the submissions from the NHS Boards highlighted that some of the long COVID funding was being used for paediatric/ children’s services. For example, NHS Greater Glasgow and Clyde aims to use funding to “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”.

**Members may wish to ask:**

- **Is there sufficient knowledge and understanding among health professionals around long COVID in children? Does this impact on diagnosis of long COVID in children?**
- **What pathways and healthcare services are available for children with long COVID in Scotland? How is good practice being shared between health boards?**



- **What support do children with long COVID have when transitioning to adult services?**

## Theme 4: Data

The Scottish Government told the Committee “The Strategic Network is undertaking a work stream to facilitate a consistent national approach to the collection of data relating to long COVID, that allows for comparative analysis across Scotland. A workshop has been held with key stakeholders to identify data collection needs and further activity is planned to determine and agree recording and reporting mechanisms required at local and national levels”.

During the [debate on Long COVID, in May 2022](#), the Cabinet Secretary for Health and Sport said: “we can probably do more on data gathering”. He went on to say:

“I do not think that we have the level of granularity in the detail that we need in relation to those who are suffering with long Covid. We have some of the headline figures but, at a more granular level, when it comes to, for example, how many children, people with disabilities and minorities it affects, that data is not in a place where I would like it to be.”

In response to question [S6O-01872](#), on long COVID data collection, the Deputy First Minister and Cabinet Secretary for Covid Recovery, John Swinney MSP, said:

“We are supporting activity to improve the collection of clinical data on the prevalence and healthcare needs of people with long Covid to inform the planning and delivery of services. Officials are working with NHS National Services Scotland’s long Covid strategic network to improve data collection as a priority. The network is taking forward a dedicated workstream to agree outcomes, indicators, monitoring and evaluation to accelerate progress.”

Long COVID Kids have highlighted its concern about the lack of publicly available data relating to Long Covid in children and young people in Scotland.

Ian Mullen, Covid Action Scotland, told the Committee:

“There is no information about how many staff or pupils have become long Covid sufferers, which is a major issue. It is the same with all the essential workers who worked all the way through the pandemic. There is no data available—I certainly have not seen any—that identifies how many essential workers have suffered through attending work.”

The submission from NHS Greater Glasgow and Clyde noted: “Public Health Scotland is supporting the Long COVID service leads group in understanding prevalence, shifting demand and data trajectories, in determining need and therefore effective service planning”. In its submission NSS said one of the challenges related to “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.”

**Members may wish to ask:**

- **Public Health Scotland, what plans exist to improve the collection of information on the number of people in Scotland that have long COVID? What work is it undertaking with the Long COVID service leads in each health board area?**
- **Are there plans to disaggregate information on long COVID by ethnicity, age, disability etc? If so, will this information be published?**
- **Is it anticipated that information on the prevalence of long COVID will be published? If so, when will it be made available?**

## **Theme 5: Education of healthcare professionals**

The Scottish Government outlined to the Committee that the Strategic Network has developed and is implementing an education strategy to raise awareness of the long-term effects of COVID-19, share education resources symptom management, and share developing knowledge and expertise across healthcare professionals working with people with long-term effects of COVID-19. It noted this has been supported by the establishment of a bi-monthly peer support forum, and will be supplemented by the development of a quarterly multi-disciplinary case conference for complex cases and a central web-based resource for sharing information and signposting to learning resources.

In its submission NHS Education for Scotland (NES) said that 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.

Responding to the response to the Committee by the Scottish Government, Jane Ormerod, Long Covid Scotland, said:

“I noticed a suggestion, in some of the evidence that has been submitted, that there is an education strategy around long Covid. That is news to me. I am not aware of that being the case, and I do not think that any of our members would be aware of that, nor am I aware of them having been asked to be involved in that.”

Members may wish to ask:

- **NHS National Services Scotland (NSS), for an update on the roll out of the implementation of the education strategy?**
- **How is the effectiveness of the education strategy being monitored?**
- **Have people with long COVID been involved in the development of the education strategy and the educational resources?**
- **Are all healthcare professionals receiving training and/ or education on long COVID? What is the update of this? Is it mandatory or optional training?**
- **What has the impact been of the bi-monthly peer support forum and the quarterly multi-disciplinary case conference for complex cases?**

## Theme 6: Learning from other areas

[The Chief Scientist Office's \(CSO\) launched a funding call for applications which aimed to investigate the longer-term effects of COVID-19.](#) Applications were invited for Scottish-led applied research proposals, designed to improve understanding of the longer-term effects of COVID-19 infection on physical and mental health and wellbeing in Scotland, and/or research with the aim of developing effective clinical interventions to support recovery and rehabilitation from COVID-19 infection. [Nine projects received funding and are currently taking place. Further information on each of these is available on the Chief Scientist's Office website.](#)

The Scottish Government's letter to the Committee noted:

“The Strategic Network is facilitating the exchange of regular updates to clinical and service planning colleagues to ensure they have access to up to date and evidence-based information to inform practice and planning, including relevant information from CSO funded studies on the long-term effects of COVID-19. A programme of quarterly knowledge-sharing events has been initiated to achieve this, and will be supported by the publication of a monthly bulletin summarising key updates.”

Other research has been funded by the [National Institute of Health Research](#) into long COVID. The NIHR's research portfolio aims to examine the underlying mechanisms of long COVID, investigate symptoms such as 'brain fog' and breathlessness, and tests possible treatments. It explores whether NHS services, such as long COVID clinics, meet people's needs and looks at what people can do to optimise their own recovery. The NIHR has funded the [STIMULATE-ICP](#) (Symptoms, Trajectory, Inequalities and Management: Understanding Long-COVID to Address and Transform Existing Integrated Care Pathways) a study which aims to

deliver knowledge to clinicians and scientists, evidence to policymakers, and improved care to patients, while collecting real-world data at scale.

Jane Ormerod, Long Covid Scotland said:

“In 2020, nine research projects were funded in Scotland, but there has not been any further funding for Scottish research projects since then. There are a lot of opportunities for further research. I would like to know what the future plan for that is. We want research here to be linked to British and international research. It is said that the time between an initial idea for research and that research producing something that leads to guidelines or treatment can be as long as five to 10 years.”

Sammie McFarland, Long Covid Kids, summed up that:

“I go back to the earlier point about the importance of validation. Of course, we want validation, but validation is not treatment. It is really important that the assessment process rules out other conditions and ensures that patients are not just left with validation but are given options. At the moment, it feels like a lot of stabbing in the dark is going on, with people being sent for tests and diagnostics that will not necessarily be or even prove to be helpful. However, if we were to invest in biomedical research so that we are not wasting those precious resources on unhelpful tests, we could make the most of the resources that are available and serve the people with long Covid, including children and young people, much better.”

**Members may wish to ask:**

- **What work is being undertaken to ensure international good practice and learning is integrated in long COVID services in Scotland?**
- **What networks exist to ensure that leaning from the rest of the UK is considered in service development? For example, findings from studies funded by the National Institute of Health Research, such as STIMULATE-ICP?**

**Lizzy Burgess, Senior Researcher, SPICe**

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The Scottish Parliament, Edinburgh, EH99 1SP [www.parliament.scot](http://www.parliament.scot)

## Annex A: Summary of health board responses (received by 20 February 2023)

NHS Board	Long COVID Service
NHS Borders	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. 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
NHS Dumfries and Galloway	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 8 <sup>th</sup> 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
NHS Fife	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. GP services provide consultation and onward referral for diagnostic testing, and further specialist review.
NHS Forth Valley	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.
NHS Grampian	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. 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.
NHS Greater Glasgow and Clyde	The 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. 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. GGC are completing our recruitment processes to all professional and support worker positions.
NHS Highland	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. There is no long-term Condition Management Service in NHS Highland currently.
NHS Lanarkshire	NHS Lanarkshire has a Long Covid Rehabilitation pathway which includes a single access point to an interdisciplinary team of dietetics, occupational therapy, physiotherapy, psychology and speech & language therapy – the Covid Rehabilitation Team. Funded posts (WTE): 1: Clinical Service Lead (B8), 4.8 Physiotherapists (2xB7 and 3xB6), 1.8 Occupational Therapists (1 xB7 and 0.8 B6), 2 Psychologists (1xB and 1 B7 CAAP), 0.2 Speech and Language Therapist, 0.2 Dietician, 2 Admin and Clerical (B3)
NHS Orkney	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 Shetland	NHS Shetland set out to recruit a specific AHP to lead and co-ordinate this [long COVID] work however the specific challenges of NRAC funding equating to less than a full time role has prevented us achieving this.
NHS Tayside	Proposed: 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. GP with special interest for leadership and co-ordination 0.1 WTE (9 months) 9 months are July – March. Child health resource development 0.2 WTE Band 7 (6 months).

## Barriers and enablers

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

### Barriers

#### *Funding*

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

#### *Recruitment*

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

#### *Capacity*

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

#### *Expectations*

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

#### *National model*

- Siloed approach – difficult to provide holistic service
- Lack of alignment with model and provision in England
- More capacity for Once for Scotland approach
- Limited facilities in smaller boards

- Other operational matters such as establishing electronic pathways, digital screening platform

#### *Research and evaluation*

- Data – little Scottish data available
- Limited studies to evidence education – currently informal
- Initial lack of long COVID research to inform service modelling

## **Enablers/ good practice**

#### *Engagement*

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

#### *Education and resources*

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

#### *National service and leadership*

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

#### *Digital*

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

#### *Multi-disciplinary team*

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