

# COVID-19 Recovery Committee

## 3rd Meeting, 2022 (Session 6), Thursday 9 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 first formal evidence session of the inquiry, in which the Committee will focus on awareness and recognition through lived experience, although it is expected there will be discussions around the other themes in the inquiry. The Committee will take evidence from the following panel of witnesses—
  - Rob Gowans, Policy and Public Affairs Manager, Health and Social Care
  - Alliance Scotland (the ALLIANCE);
  - Ian Mullen, Covid Action Scotland;
  - Sammie Mcfarland, CEO and Founder, Long Covid Kids;
  - Jane Ormerod, Chair and Stuart Mclvor, Long Covid Scotland;
  - Michelle Powell Gonzalez and Donna Convery, Long Covid Support Group: 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. SPICe will produce an updated blog prior to this evidence session, which will be published on the Parliament's website.

## Scottish Government position

1. On 9 September 2021, the Scottish Government announced a [£10 million Long COVID Support Fund](#), which is 'designed to maximise and improve the co-ordination of a broad range of existing services across the health and social care system and Third Sector in response to the condition.' In announcing the fund, the Scottish Government said it is 'engaging with NHS Boards as they co-ordinate pathways across primary, community and secondary care services to support patients through long COVID recovery.'
2. The Scottish Government also published [Scotland's Long Covid](#) service on 30 September 2021. This sets out its approach to supporting the health and wellbeing of people with long COVID and explains the approach is based on four key elements—
  - Supported self-management
  - Primary care and community-based support
  - Rehabilitation support
  - Secondary care investigation and support
3. 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

4. The Scottish Government's [response](#) has been published on the website and is attached at **Annexe A**.
5. 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.
6. The Committee asked for a response by 10 February. Responses received thus far from NHS Borders and NHS Orkney have been published on the [website](#).

## Engagement

7. Given the nature of the inquiry, the Committee was keen to speak to people with lived experience of long COVID at the outset of the inquiry.
8. On 12 January 2023 the Committee spoke with four 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 read on the [website](#).
9. On 2 February, the Committee held an informal online discussion with six participants from Long Covid Kids, a note of the discussion will be published in due course.

## Written evidence

10. The Committee issued a call for views, which closes on 10 February 2023. To date the Committee has received 290 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?

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

- The Alliance
- Covid Action Scotland
- Long Covid Kids
- Michelle Powell Gonzalez, Long Covid Support Group: Scotland

## **Next steps**

12. The Committee will continue to take evidence on the inquiry at its meetings on 23 February, 2 March, 9 March and 16 March.

**Committee Clerks**  
**February 2023**

# ANNEXE A

Cabinet Secretary for Health and Social Care  
Humza Yousaf MSP



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20 December 2022

Dear Convener

Thank you for your letter of 25 November 2022, requesting information in relation to the Committee's forthcoming inquiry into long COVID. I have provided information on each of these areas below, which I hope is helpful for yourself and the wider Committee.

## **1. Further information on the £2.5 million supported nine research projects commissioned by the Scottish Government into long COVID;**

As part of the Scottish Government's response to the pandemic, the Chief Scientist Office (CSO) launched a funding call in October 2020, seeking applications for research to investigate the longer-term effects of COVID-19. Following an independent expert review process, nine projects were funded with a total funding commitment of around £2.5 million. The funding outcome was [announced](#) in December 2020 and includes projects to better understand the symptoms of, and factors associated with, long COVID, to examine effects on cognitive function, and to evaluate rehabilitation approaches.

The nine projects are all progressing and are at around the mid-point stage of their 22 to 24 months duration. The full outputs from these projects are expected once they have been fully completed. However, some have reached a stage where it has been possible for the research teams to publish initial findings in peer-reviewed scientific journals, including a number of papers describing the nature of, and factors associated with, long COVID. These include results suggesting that asymptomatic infection is not associated with adverse outcomes and that COVID-19 vaccination may be associated with reduced risks of some symptoms.

I can share some examples of the papers which have been published:

- Hastie *et al.* (2022) Outcomes among confirmed cases and a matched comparison group in the Long-COVID in Scotland study. Nature Communications. [Outcomes](#)

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[among confirmed cases and a matched comparison group in the Long-COVID in Scotland study | Nature Communications](#))

- Hayes *et al.* (2021) More Than 100 Persistent Symptoms of SARS-CoV-2 (Long COVID): A Scoping Review. *Frontiers Medicine*. [Frontiers | More Than 100 Persistent Symptoms of SARS-CoV-2 \(Long COVID\): A Scoping Review \(frontiersin.org\)](#)
- Healey *et al.* (2022) Symptoms and signs of long COVID: A rapid review and meta-analysis. *Journal of Global Health*. [Symptoms and signs of long COVID: A rapid review and meta-analysis — JOGH](#)

## **2. Details of funding allocations of the £10 million long COVID support fund to date and future investment plans for addressing long COVID;**

We have made an initial £3 million available from our £10m long COVID Support Fund over the financial year 2022-23 to provide NHS Boards and partners with additional resource to respond to the needs of people with long COVID in their areas.

The table below outlines the organisations to which funding has been made available for 2022-23, and the associated amounts.

<b>Organisation</b>	<b>Funding amount made available (£)</b>
NHS Ayrshire and Arran	187,554
NHS Borders	50,727
NHS Dumfries & Galloway	79,426
NHS Fife	178,051
NHS Forth Valley	142,020
NHS Grampian	254,847
NHS Greater Glasgow and Clyde	595,169
NHS Highland	119,641
NHS Lanarkshire	320,007
NHS Lothian	372,215
NHS Orkney	14,716
NHS Shetland	13,676
NHS Tayside	194,620
NHS Western Isles	19,988
NHS National Services Scotland	370,000
Thistle Foundation	87,343
<b>TOTAL</b>	<b>3,000,000</b>

Further detail on the initiatives that this funding is being used to support can be found in Annex A.

We remain committed to delivering the £10m Long COVID Support Fund and the 2023-24 budget published on 15 December 2022 outlines that £3m will be made available from the fund over the financial year 2023-24.

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### **3. 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;**

To complement activity already taking place at a national and individual NHS Board level, the Scottish Government commissioned NHS National Services Scotland to establish an expert short life working group on managing the long-term effects of COVID-19.

The short life working group met in September and November 2021, and recommended that the most appropriate model to support the development and implementation of the approach outlined in the Scottish Government's publication '[Scotland's long COVID Service](#)' would be the establishment of a National Strategic Network. This recommendation was agreed by NHS Board Chief Executives on 11 January 2022.

The National Strategic Network 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 Strategic Network structure is composed of:

- A strategic oversight board
- A steering group
- A clinical and subject matter expert group
- A service planning group
- A lived experience planning group

### **4. 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**

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**

As outlined in response to question 2, 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.

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.

#### **Support for professional education**

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 related to

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symptom management, and share developing knowledge and expertise across healthcare professionals working with people with long-term effects of COVID-19.

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.

### Consolidation of clinical pathways

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.

### Ongoing engagement with people with lived experience

The Strategic Network has established a lived experience planning group to co-ordinate activity to support the engagement of people with lived experience, and ensure their views inform development of pathways of care and support.

The Health and Social Care Alliance Scotland (the ALLIANCE) has been commissioned to facilitate a lived experience network to gather views from a range of people with experience of long COVID, and those supporting them. This network was launched in August 2022, and has completed a survey exercise to identify priorities from people with lived experience of long COVID.

### Evidence and innovation

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.

### Data and intelligence

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.

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## **5. Further details on the £370,000 supported national programme of improvement work led by National Strategic Network**

In May 2022, a total of £370,000 was made available within the long COVID Support Fund for 2022-23 to support the delivery of the national level activities outlined in response to question 4.

This included making £200,000 available to support the procurement and supply of a digital tool to support the collection of patient reported outcome measures, and £170,000 to support the operation of the Strategic Network. The costs of the Strategic Network mainly reflect the staffing costs to deliver the programme of work, including costs for providing sessions for clinical leadership where required.

## **6. How the Scottish Government is meeting the [recommendations of NICE](#) around long COVID service provision.**

The clinical guideline on managing the long-term effects of COVID developed by the Scottish Intercollegiate Guidelines Network (SIGN), the National Institute for Health and Care Excellence (NICE) and the Royal College of General Practitioners (RCGP) makes the following recommendations in relation to service organisation;

*Agree local, integrated referral pathways between primary and community care, rehabilitation services and specialist services, multidisciplinary assessment clinics (where available) and specialist mental health services.*

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.

*Share knowledge, skills and training between services to help practitioners in the community provide assessments and interventions, such as 1-minute sit-to-stand tests and breathlessness training.*

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 related to symptom management, and share developing knowledge and expertise across healthcare professionals working with people with long-term effects of COVID-19.

*Provide integrated, multidisciplinary rehabilitation services, based on local need and resources. Healthcare professionals should have a range of specialist skills, with expertise in managing fatigue and respiratory symptoms (including breathlessness). Additional expertise may be needed depending on the age and symptoms of the person. The core team could include, but not be limited to, the following specialist areas:*

- *occupational therapy*
- *physiotherapy*
- *clinical psychology and psychiatry*
- *rehabilitation medicine.*

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The Scottish Government has made resource available to NHS Boards through our long COVID Support Fund which is being used to augment and provide access to the services outlined in the guideline recommendation above. For example, many Boards are using the funding to introduce rehabilitation pathways providing 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 individual needs.

*Provide access to multidisciplinary services, if available, (these could be 'one-stop' clinics) for assessing physical and mental health symptoms and carrying out further tests and investigations. Services should be led by a doctor with relevant skills and experience and appropriate specialist support, taking into account the variety of presenting symptoms.*

The rationale in the guideline related to this recommendation notes that due to geographical factors and the differing needs and resources of areas "one model would not fit all areas" and that 'one-stop' clinics "might not be feasible for all services or wanted by all patients".

As noted as an option within the clinical guideline, NHS Scotland Boards are providing assessment and support for people with long COVID through integrated and co-ordinated primary care, community, rehabilitation and mental health services, with referral for further investigation in secondary care settings where clinically necessary.

## **7. Clarification on its position on long COVID clinics and information on which, if any, health boards have established them;**

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 needs.

## **8. Details of those people who have accessed Chest, Heart and Stroke Scotland's 'long COVID support services'**

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.

## **9. Whether the Scottish Government believes long COVID should be treated as a disability under the Equality Act 2010;**

The subject matter of the Equality Act 2010 is largely reserved to the UK Government. A person is disabled under the Equality Act 2010 if they have a physical or mental impairment

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that has a 'substantial' and 'long-term' adverse effect on their ability to do normal day-to-day activities.

If long COVID has this effect on an individual they would meet the definition of disability in terms of the Equality Act 2010.

I hope you find the information outlined in this letter to be helpful.

Yours sincerely,

**HUMZA YOUSAF**

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## **ANNEX A – 2022-23 Funding made available through long COVID Support Fund and initiatives this funding is supporting**

### **NHS Ayrshire and Arran, £187,554**

- Development of a long COVID multidisciplinary rehabilitation pathway delivering 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.
- Liaison with primary care, third sector community support services and where required, onward referral to specialist clinical pathways via normal routes and triage processes.
- Support is currently being provided to people who require this due to long COVID via services already established in the community depending on their symptoms. For example, this may include primary care services, secondary referral to specialist services e.g. respiratory or cardiology pathways, or referral to intermediate care or rehabilitation services. Staff in these services have received specialist training in the management of long COVID, and there is a small cohort of staff supporting people deemed at most need by their general practitioners on a case by case basis, dependent on availability of staff.
- Support is also being provided to NHS staff who are experiencing symptoms of long COVID. This is primarily provided in occupational health by a specialist physiotherapist, using a long term conditions rehabilitation approach.

### **NHS Borders, £50,727**

- Development of clear and easy to access pathways for those requiring support for long COVID. These pathways will be developed by an advanced practice occupational therapist based in primary care alongside clinicians from other specialties.
- Support is currently being provided for those with long COVID through existing services in line with presenting symptoms. This may mean support from GP, cardiology, respiratory, physiotherapy, occupational therapy or psychology services as appropriate.

### **NHS Dumfries and Galloway, £79,426**

- Establishment of a small team of experts to lead on the long COVID Rehabilitation Service development. This includes a Lead GP, AHP, Psychologist and Public Health Practitioner.
- Support is currently being provided for people with long COVID by services which were established for people suffering from ME/CFS/Fibromyalgia. GPs can refer to psychology, AHPs and, if necessary specialist secondary care services. In due course the Board intend to unify these services into a more bespoke, streamlined service.

### **NHS Fife, £178,051**

- Development of a long COVID rehabilitation pathway, delivering a point of access for assessment and co-ordinated support from services including nursing, physiotherapy,

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occupational therapy, and others depending on what is most appropriate for a person's needs.

- Support is currently being provided to people who require this due to long COVID via services already established in the community depending on their symptoms. For example, this may include community rehabilitation teams, chronic fatigue service, pulmonary rehabilitation and other services.

### **NHS Forth Valley, £142,020**

- Development of a screening service for people referred with long COVID and recruitment of an Allied Health Professional long COVID Coordinator, a Clinical Associate in applied Psychology, a full-time Respiratory Physiotherapist and a part-time Psychologist.
- The screening sessions will provide screening and signposting as well as offering supported self management groups.
- The long COVID Coordinator will be responsible for the mapping of services and supporting healthcare professionals' understanding of referral pathways available to support patients with long COVID. The Coordinator will support the development of local networks, and the organisation and delivery of training, to ensure that guidance, tools and pathways are shared throughout General practice, primary and secondary care.
- A long COVID pathway is already in place to support referrers in decision making when people present with long COVID symptoms. There is access to supported self management resources and referral to specialist services based on people's specific and individual needs.

### **NHS Grampian, £254,847**

- Development of a long COVID rehabilitation pathway embedded within existing services, including supported self management, specialist advice for patients and other professionals, onward referral to appropriate services for investigation or treatment, and may include a single point of access for assessment and co-ordinated support, depending on what is most appropriate for a person's needs.
- Identifying and responding to training needs of the wider workforce in health and care in relation to managing long COVID.
- Support is currently being provided to people who require support due to long COVID via existing services in secondary care, primary care and in the community depending on their symptoms and needs. For example, this may include General practice, occupational therapy, physiotherapy, psychology or specialist services.

### **NHS Greater Glasgow and Clyde, £595,169**

- Development of a long COVID rehabilitation pathway, implementing a single point of access for assessment and co-ordinated support. This service model is focussed on Occupational Therapists delivering specialist assessment to those presenting with the common symptoms of long COVID.
- This service will be a primary care service, accessed via referral from GPs and secondary care. As such, it will liaise closely with primary care and community health and locality services referring to specialist services where required.

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- Interventions provided will include virtual and telephone assessment, signposting to online and digital resources and support to utilise these, as well as virtual and face to face group sessions and where required individual virtual or face to face appointments.
- Support is currently being provided to people with long COVID via services already established in the community ,depending on their symptoms. For example, this may include General practice, primary care services, rehabilitation services, the Centre for Integrative Care and specialist clinical services such as cardiology and respiratory medicine.
- The Board has a dedicated resource to support staff with long COVID to remain in or return to work.

### **NHS Highland, £119,641**

- 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 Lanarkshire, £320,007**

- Delivery of a single access point to a long COVID rehabilitation pathway, supported by a team of occupational therapy, psychology, physiotherapy, dietetics and speech & language therapy. The team can assess and help with physical, mental or social difficulties people may have that are related to long COVID.
- The funding made available through the long COVID Support Fund is contributing towards paying for the multi-disciplinary staff supporting the pathway.
- It will support the implementation of a digital, app based tool that allows people with long COVID to measure and monitor their symptoms. This information supports the assessment, intervention and evaluation of their care.

### **NHS Lothian, £372,215**

- 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.

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- 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.

### **NHS Orkney, £14,716**

- Support for a specialised physiotherapist who assesses and supports long COVID cases as a significant part of their job plan. This is in addition to support being provided via services already established in the community depending on people's specific symptoms.

### **NHS Shetland, £13,676**

- Facilitation of a local pilot to examine whether the the implementation of an Allied Health Professional Care-Coordinator role improves outcomes for people living with long COVID.

### **NHS Tayside, £194,620**

- Enhancement of the Tayside long COVID rehabilitation pathway. This pathway will be accessed via an individual's GP in line with SIGN guidelines to deliver an accessible point of access for assessment, support and co-ordination.
- At present, people can be supported by national NHS Inform self management and the Chest, Heart & Stroke Scotland advice line as well as local services already established across within the community depending on their symptoms. People can also access the community listening service for support.
- Where required, services such as psychology, secondary care teams and local specialist rehabilitation teams, embedded within local communities (including physiotherapy, occupational therapy, psychology, dietetics and speech & language therapy) can be accessed via GPs, depending on what is most appropriate for a person's needs.

### **NHS Western Isles, £19,988**

- Facilitation of Public Health intelligence activity to establish the incidence and need related to long COVID across the Western Isles.
- At present, support for people with long COVID is accessible via general practice, with multiple options available for onward referral in line with individual clinical need.

### **Thistle Foundation, £87,343**

- Delivery of a 'Good Conversations' training programme for Allied Healthcare Professionals in Scotland.

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## **NHS National Services Scotland, £370,000**

- A total of £370,000 has been identified to support NHS National Services Scotland to undertake national level actions to improve care and support for people with long COVID.
- This includes the operation of a National Strategic Network for long COVID, and the once-for-Scotland procurement of a digital tool to assist the screening and evaluation of care for people with long COVID.

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# ANNEXE B

## Health and Social Care Alliance Scotland (the ALLIANCE)

Call for Views: Long Covid

3 February 2023

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### Introduction

The Health and Social Care Alliance Scotland (the ALLIANCE) welcomes the opportunity to respond to the COVID-19 Recovery Committee's Call for Views on Long Covid.<sup>1</sup>

This response draws on findings from core pieces of work undertaken by the ALLIANCE in relation to Long Covid. In May 2022, the ALLIANCE and Chest Heart & Stroke Scotland (CHSS) published a commissioned research report by E. Miller, 'Accessing social support for Long Covid', which aimed to build understanding of the life circumstances of people with Long Covid in Scotland, as well as their experiences of accessing social support.<sup>2</sup>

In July 2022 the ALLIANCE established the Long Covid Lived Experience Network, in partnership with Asthma + Lung UK and CHSS.<sup>3</sup> The Long Covid Lived Experience Network forms part of the Scottish Government's 'Long Term Effects of COVID-19 Strategic Framework' and was established to gain views from a wide range of people to directly inform service delivery. Throughout September 2022, the Long Covid Lived Experience Network launched the 'Long Covid Lived Experience Survey' which aimed to gather feedback from individual living with Long Covid, or unpaid carers caring for individuals with Long Covid, about their priorities for Long Covid services and health care provisions in the future.<sup>4</sup>

Additionally, in September 2022 the ALLIANCE published an anthology of Opinions about people's experiences of Long Covid, spanning people with lived experience of Long Covid, those researching supports and treatment options, and people working within the third sector to support people with Long Covid.<sup>5</sup>

### **Question 1. 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.

The ALLIANCE has heard consistently across our work on Long Covid that there is limited public awareness of the life circumstances of people living with Long Covid in Scotland. 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. A respondent to the Long Covid Lived Experience Survey summarised their experience as follows:

“[Long Covid] is life changing. Sometimes it feels like we are invisible”.<sup>6</sup>

This was echoed in the research report published by the ALLIANCE and CHSS, in which participants were keen to see the lack of public awareness of Long Covid remedied:

“Along with the fatigue the other biggest thing is attitudes. The more education there is – education is so important – and with that maybe it would be a bit more recognised.”<sup>7</sup>

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 situation was summarised by one contributor to the anthology of opinions about people’s experiences of Long Covid:

“It is disappointing [...] that despite the information we now have on Long Covid people are still struggling to have their voices heard. I’ve lost count of the number of people who have told me they were dismissed by their GP and other healthcare professionals, being told that they were suffering from anxiety and they should get out and exercise more. People in employment are also struggling with their employers, with many being forced to go back to work when they’re not ready or facing disciplinary action. Dealings with the Department for Work and Pensions have also added to the pressure people are already facing, particularly with PIP [Personal Independence Payment] applications, with people giving up on claiming benefits they are entitled to because the claims processes are far too exhausting for them.”<sup>8</sup>

Findings have also highlighted that a lack of recognition and awareness of the symptoms of Long Covid, can have a significant impact on individual health and wellbeing with people reporting feelings of depression and isolation.<sup>9</sup>

More broadly, participants of the Long Covid Lived Experience Survey called for a greater awareness in the general public on the potential longer-term impacts of COVID-19 infection, and the importance of pacing recovery to prevent symptoms deteriorating:

“[It is important to] make it clear to people in the early stages of COVID-19 infection that, if they are suffering fatigue, not to try and push through or go

back to work too early. I'm almost certain this is what has set me back. This has to be an official position so that people don't feel pressured to return to work too soon and employers should be supported to allow this for their employees."<sup>10</sup>

It should be noted that there are positive examples of progress being made to support those living with Long Covid, including some health boards in Scotland establishing their own care pathways for people living with Long Covid,<sup>11</sup> people being well supported from their employers,<sup>12</sup> and people having access to third sector organisations and peer support networks.<sup>13</sup> However, it is clear that these experiences are inconsistent and varied across Scotland, with participants acknowledging their own positive experiences as 'unusual'.<sup>14</sup>

## **Question 2. What more could / should be done to raise awareness and recognition of Long Covid?**

Across our research and evidence in relation to Long Covid, participants have suggested key measures which would help to raise awareness of living with Long Covid condition. To ensure that action taken to improve recognition is grounded in evidence and lived experience, the ALLIANCE suggests that the following recommendations are co-produced with people living with Long Covid, their families and unpaid carers. Some key actions are summarised below:

- In Long Covid Lived Experience Survey, 48.67% of respondents said that government legislation to specifically improve Long Covid care and support should be prioritised.<sup>15</sup> Development of law, policy and guidance is needed to respond specifically to the challenges raised by Long Covid.
- Further recognition is needed on the impacts of Long Covid on people of all ages, including children and young people. ALLIANCE members, Long Covid Kids, have provided essential and tailored support and resources to thousands of children and young people living with Long Covid, and the people who care for them.<sup>16</sup> The ALLIANCE suggests that the Scottish Government works in partnership with organisations such as Long Covid Kids to ensure children, young people, and those who care for them are provided with accessible, up to date guidance on the impacts of Long Covid and appropriate methods of support.
- People living with Long Covid have highlighted the need for a consistent level of understanding about what Long Covid is both within the healthcare profession, and across the general public. It is important that the latest research findings on Long Covid – including information on symptoms, medical treatment options, and available social support – is shared with

healthcare professionals, people living with Long Covid, and the general public.

- Information to raise awareness and recognition must be inclusive and available in a range of accessible formats. Accessible information should follow the Six Principles of Inclusive Communication,<sup>17</sup> and should be publicly available in multiple inclusive formats, including Community Languages,<sup>18</sup> British Sign Language (BSL), Braille, Moon, Easy Read, clear and large print, and paper formats. The ALLIANCE recommends involving relevant experts – including BSL and language interpreters – at the earliest opportunity to ensure communication and information provision is inclusive for all.

### **Question 3. What are your thoughts on the use of Long Covid assessment clinics?**

The ALLIANCE supports the use and establishment of Long Covid assessment clinics. In the Long Covid Lived Experience Survey, a range of views were expressed as to how a Long Covid clinic might look, but generally respondents pointed to the Long Covid clinics being established in England and Wales – a centre or clinic which provides multidisciplinary care, but where all practitioners have specialist knowledge.<sup>19</sup>

The provision of holistic support for people living with Long Covid was a key theme in the research published by the ALLIANCE and CHSS. Participants who took part in a focus group to inform the research discussed how the development of Long Covid ‘hubs’ or ‘one stop shops’ could be useful as a central point for coordinating support, connecting with others, for reassurance and for signposting.<sup>20</sup> This was seen as particularly important for people who need to conserve limited energy when seeking support. Participants welcomed the idea of a central point that would cover a range of life areas and the whole breadth of a person’s health and wellbeing, including physical healthcare, emotional support, self management guidance, advice on social security entitlements, career, income, family, and relationships.

Participants were also clear that support should be practical, ongoing, and long term, and linked directly to research on Long Covid, recommending that support services themselves also act as research hubs, whereby learning can be captured and used to directly inform service delivery:

“Linking research to care centres, then there’d be staff who’d begin to learn about the condition, see patterns. It goes hand in hand with research.”<sup>21</sup>

“Why not appoint someone who is responsible for Long Covid? Researchers could put their questions to medical centres, whoever is responsible for Long Covid in that centre knows the questions to ask... So many people with Long

Covid could be reassured about being taken seriously. Effects of that research could be put into practice very quickly.”<sup>22</sup>

However, considering the current pressures on the NHS, it is important that such a resource would be able to provide quick responses to people when they need it. This was highlighted by one participant who explained that, “people tend to go to these things when at their lowest ebb, and the last thing they need is to be told we can give you an appointment in three weeks’ time”.<sup>23</sup>

#### **Question 4. Do you consider that the correct mix of services are in place to help people who have Long Covid?**

No.

Across our engagement, people with lived experience of Long Covid have highlighted key challenges in accessing appropriate care and support for Long Covid. Some of the key challenges and areas for improvement are summarised below.

Our engagement with people living with Long Covid suggests that there is a lack of consistency in quality support in primary care settings. While there are pockets of good practice, our evidence suggests that this is limited and variable across the country. This was highlighted in the findings of the Long Covid Lived Experience Survey where people shared positive personal experiences of support from their GPs, but recognised that such support is inconsistent.<sup>24</sup> Participants also expressed their frustration that there is currently “no defined pathway of care” after a GP appointment and “no post diagnosis care plan from GPs”. As highlighted in our response to Question 1, greater awareness among primary care staff, including GPs, is much needed and could improve this issue.

In the Long Covid Lived Experience Survey, people living with Long Covid highlighted key issues with a lack of integration between services and support, noting that “nothing is joined up” and describing current Long Covid care as “slow, patchy and ineffective”.<sup>25</sup> 60% of respondents stated that consistent care pathways should be prioritised, and a holistic approach should be taken to care and support services which takes account of every aspect of people’s individual needs. Participants also highlighted that more could be done to improve signposting to wider support services.

The research report published by the ALLIANCE and CHSS also called for wider social support for those living with Long Covid, including access to supported self management, employment support, financial support, community support (including support from family and friends, peer support, and third sector support), and mental health support.<sup>26</sup>

### **Question 5. What support could or should be available for people who are supporting or caring for people with long COVID?**

Participants of the research published by the ALLIANCE and CHSS highlighted families and friends as key supports, particularly in the context of restricted services and the ability to see others during the pandemic:

“My husband has been amazing. I don’t know how we would have coped otherwise. He is so patient and emotionally reassuring – he knows what to say. I also prefer socialising with him as he will say, “stop – don’t do that.” It’s easier when someone else tells you.”

“My mum has had to be a surrogate mum for my kids. I couldn’t talk to them when they go in from school.”<sup>27</sup>

However, it was also highlighted that key family supports were also struggling with their own health conditions, and in some cases the pressures of taking on a caring role. There is a pressing need for adequate and tailored support, advice and guidance for family members who are adjusting to new caring roles supporting people with Long Covid, including young carers. The ALLIANCE recommends that such support is co-produced with unpaid carers, families and people with lived experience.

### **Question 6. What should be the main priorities for study and research into Long Covid?**

Further research should be carried out into the causes of Long Covid, as well as treatment options. Respondents to the Long Covid Lived Experience Survey expressed that they felt that there was not enough research or clinical trials being done to explore medical interventions for Long Covid, and called specifically for biomedical research and clinical trials to take place.”

Future research must also prioritise the voice of lived experience to ensure that learning is captured and used to inform and improve care and support for people living with Long Covid. Participants in the research published by the ALLIANCE and CHSS outlined that they were keen to continue to be involved in research, and to co-create channels within services for their voices to shape support and services.<sup>28</sup>

Additionally, further research and engagement is needed on the impact of Long Covid on children and young people with Long Covid, and their parents or guardians. As highlighted by a contributor to the anthology of opinions about people’s experiences of Long Covid, “we do not know what the impact of reinfections will be. We do not yet know if, like Polio, further problems may occur in years to come.



There is still much we need to learn, and the World Health Organisation has identified it as an area for priority research".<sup>29</sup>

The ALLIANCE suggests that the Scottish Government should prioritise further research and engagement in this area to fill the knowledge gap about children and young people's experiences of social support, in order to ensure that policy and practice responds to their needs.

As outlined in our response to Questions 1 and 2, it is imperative that research on Long Covid is utilised and communicated to health care professionals, including GPs. Respondents to the survey shared that it often feels like existing research is not being utilised, or communicated, either with the general public, people living with Long Covid, or with healthcare practitioners. Additionally, as outlined in our response to Question 3, it is important that research is linked directly to practical support, for example, by support services themselves also acting as research hubs, whereby learning can be harnessed to directly inform how things are done at ground level.

#### **Question 7. Is sufficient data publicly available on the prevalence of Long Covid in Scotland?**

No. The latest data from the Office of National Statistics estimate 2.1 million people in the UK are living with the condition, which equates to over 187,000 people in Scotland.<sup>30</sup> However, as outlined in our response to Question 1, people currently living with Long Covid have shared concerns that the condition is not sufficiently acknowledged or recognised. As a result, Long Covid prevalence is not prominent in discussions about risks from the pandemic, and the statistics of people living with Long Covid in Scotland are likely to be higher.

#### **Question 8. Do you have any other comments?**

No.

#### **About the ALLIANCE**

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of

Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

## Contact

**Gillian McElroy, Senior Policy Officer**

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<sup>1</sup> The Scottish Parliament, 'COVID-19 Recovery Committee, Long COVID'. Available at: <https://www.parliament.scot/chamber-and-committees/committees/current-and-previous-committees/session-6-covid19-recovery-committee/business-items/long-covid>

<sup>2</sup> The ALLIANCE, 'Research report: Accessing social support for Long Covid' (1 June 2022). Available at: <https://www.alliance-scotland.org.uk/blog/news/research-report-accessing-social-support-for-long-covid/>

<sup>3</sup> The ALLIANCE, 'New Long Covid Lived Experience Network' (13 July 2022). Available at: <https://www.alliance-scotland.org.uk/blog/news/new-long-covid-lived-experience-network/>

<sup>4</sup> The ALLIANCE, 'Long Covid Lived Experience Survey Insight Report published' (25 January 2023). Available at: <https://www.alliance-scotland.org.uk/blog/news/long-covid-lived-experience-survey-insight-report-published/>

<sup>5</sup> The ALLIANCE, 'Living with Long Covid – an anthology' (5 September 2022). Available at: <https://www.alliance-scotland.org.uk/blog/news/living-with-long-covid-an-anthology/>

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- <sup>6</sup> The ALLIANCE, 'Long Covid Lived Experience Survey Insight Report published' (25 January 2023). Available at: <https://www.alliance-scotland.org.uk/blog/news/long-covid-lived-experience-survey-insight-report-published/>
- <sup>7</sup> The ALLIANCE, 'Research report: Accessing social support for Long Covid', p.15. (1 June 2022). Available at: <https://www.alliance-scotland.org.uk/blog/news/research-report-accessing-social-support-for-long-covid/>
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- <sup>9</sup> The ALLIANCE, 'Research report: Accessing social support for Long Covid', p.14. (1 June 2022). Available at: <https://www.alliance-scotland.org.uk/blog/news/research-report-accessing-social-support-for-long-covid/>
- <sup>10</sup> The ALLIANCE, 'Long Covid Lived Experience Survey Insight Report published' (25 January 2023). Available at: <https://www.alliance-scotland.org.uk/blog/news/long-covid-lived-experience-survey-insight-report-published/>
- <sup>11</sup> The ALLIANCE, 'Living with Long Covid: an anthology', p.7. (5 September 2022). Available at: <https://www.alliance-scotland.org.uk/blog/news/living-with-long-covid-an-anthology/>
- <sup>12</sup> The ALLIANCE, 'Research report: Accessing social support for Long Covid', p.24. (1 June 2022). Available at: <https://www.alliance-scotland.org.uk/blog/news/research-report-accessing-social-support-for-long-covid/>
- <sup>13</sup> The ALLIANCE, 'Research report: Accessing social support for Long Covid', p.33. (1 June 2022). Available at: <https://www.alliance-scotland.org.uk/blog/news/research-report-accessing-social-support-for-long-covid/>
- <sup>14</sup> The ALLIANCE, 'Research report: Accessing social support for Long Covid' (1 June 2022). Available at: <https://www.alliance-scotland.org.uk/blog/news/research-report-accessing-social-support-for-long-covid/>
- <sup>15</sup> The ALLIANCE, 'Long Covid Lived Experience Survey Insight Report published' (25 January 2023). Available at: <https://www.alliance-scotland.org.uk/blog/news/long-covid-lived-experience-survey-insight-report-published/>
- <sup>16</sup> Long Covid Kids, 'Home'. Available at: <https://www.longcovidkids.org/team>
- <sup>17</sup> Inclusive Communication, 'Six Principles of Inclusive Communication'. Available at: <https://inclusivecommunication.scot/the-six-principles-of-inclusive-communication>
- <sup>18</sup> Community Languages are languages spoken by members of minority groups or communities within a majority language context. Examples in Scotland include: Arabic, Hebrew, Hindu, Makaton, Punjabi, Polish, Urdu.
- <sup>19</sup> The ALLIANCE, 'Long Covid Lived Experience Survey Insight Report published' (25 January 2023). Available at: <https://www.alliance-scotland.org.uk/blog/news/long-covid-lived-experience-survey-insight-report-published/>
- <sup>20</sup> The ALLIANCE, 'Research report: Accessing social support for Long Covid', p.22. (1 June 2022). Available at: <https://www.alliance-scotland.org.uk/blog/news/research-report-accessing-social-support-for-long-covid/>
- <sup>21</sup> The ALLIANCE, 'Research report: Accessing social support for Long Covid', p.23. (1 June 2022). Available at: <https://www.alliance-scotland.org.uk/blog/news/research-report-accessing-social-support-for-long-covid/>
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- <sup>24</sup> The ALLIANCE, 'Long Covid Lived Experience Survey Insight Report published' (25 January 2023). Available at: <https://www.alliance-scotland.org.uk/blog/news/long-covid-lived-experience-survey-insight-report-published/>
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- <sup>26</sup> The ALLIANCE, 'Research report: Accessing social support for Long Covid'. (1 June 2022). Available at: <https://www.alliance-scotland.org.uk/blog/news/research-report-accessing-social-support-for-long-covid/>

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<sup>27</sup> The ALLIANCE, 'Research report: Accessing social support for Long Covid', p.31. (1 June 2022). Available at: <https://www.alliance-scotland.org.uk/blog/news/research-report-accessing-social-support-for-long-covid/>

<sup>28</sup> The ALLIANCE, 'Research report: Accessing social support for Long Covid', p.31. (1 June 2022). Available at: <https://www.alliance-scotland.org.uk/blog/news/research-report-accessing-social-support-for-long-covid/>

<sup>29</sup> The ALLIANCE, 'Living with Long Covid: an anthology', p.4. (5 September 2022). Available at: <https://www.alliance-scotland.org.uk/blog/news/living-with-long-covid-an-anthology/>

<sup>30</sup> Office for National Statistics, 'Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 5 January 2023'. Available at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/5january2023>

# **Covid Action Scotland**

## **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?

Unfortunately, not. This is mainly due to the lack of information from Health Protection Scotland and the Scottish Governments fundamentally flawed decision to withdraw all restrictions, recording and reporting of positive case. Those seriously impacted include those in previous shielding category, vulnerable, immunosuppressed and different characteristics including the BAME community. Placing the economy before public health. GPs and other medical practitioners are stretched to the limit and have inconsistent understanding of long COVID. Employers are forcing staff back to workplaces without reasonable adjustments, support, access to Occupational Health or the option flexibly from home. Employers should be encouraged to sign the Indie SAGE COVID Safety Pledge:  
<https://www.independentsage.org/the-new-covid-19-safety-pledge/>

What more could / should be done to raise awareness and recognition of long COVID? HPS and the Scot. Gov. have a Duty of Care to raise awareness through a national campaign. Employers from the public, private and voluntary sector need clear and concise guidance on the effects of long COVID, fatigue syndrome and other side effects. There need to be robust support mechanism put in place including no loss of pay.

What are your thoughts on the use of long COVID assessment clinics? I don't believe there has been enough work done on these clinics, with sufferers being wrongly diagnosed. Properly resourced and funded clinical research is critical to assess the long term health of long COVID sufferers. With an estimated 10,000 NHS staff diagnosed with long COVID along with other front-line staff, they're feedback is vital as are assessment clinics.

## **Therapy and rehabilitation**

Do you consider that the correct mix of services are in place to help people who have long COVID? Definitely not.

What support could or should be available for people who are supporting or caring for people with long COVID? Properly resourced and funded health and social care provision. Not by the private sector who hand back contracts to local authorities if they start to lose money or are refused additional funding, they are unaccountable. In these cases, it falls back on LA staff with heavy workloads, low pay and recruitment and retention issues. There should also be additional financial assistance for carers.

## **Study and research**

What should be the main priorities for study and research into long COVID? As above, however if you are asking this question now then you are too late, it should have been asked and actioned 2-years ago.

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

Do you have any other comments? Encourage employers to sign the COVID Safety Pledge. Re-instate restrictions especially in public buildings. Start a national campaign on the effects of long COVID.

5 February 2023



**By Email**

Dear Convener and Committee Members,

**Re: COVID-19 Recovery Committee Long Covid Inquiry; Evidence from Long Covid Kids.**

Long Covid Kids welcomes the Long Covid Inquiry being undertaken by the Covid-19 Recovery Committee. It is vital that people with lived experience are actively engaged in this Inquiry and we appreciate the Committee taking the time to meet with and listen to parent/carer's lived experience of Long Covid in their children at the informal meeting on 2nd February 2023.

Below, we have responded to the specific questions set by the Committee. We hope the following information and recommendations are useful for your Inquiry and we would be happy to provide further details or any clarifications that may be required.

In addition, the Committee may be interested in the findings from recent pieces of research that Long Covid Kids have undertaken:

- **What happens when people with Long Covid get reinfected?:** Long Covid Support and Long Covid Kids published (Sept 2022) the first data on the effect of COVID reinfections on adults and children living with Long Covid.

**Headline findings:**

- Reinfection worsens the symptoms of Long Covid in the majority of children who are still symptomatic.
- Reinfection causes a recurrence of Long Covid in 58% of children who were in recovery or remission.



- **Children and Young People’s Healthcare Experiences:** [Preliminary findings](#) (Jan 2023) from a survey undertaken in collaboration with University of Derby, looking at healthcare experiences of children and young people in the UK living with Long COVID.

Headline findings:

- 50% of CYP who received support from healthcare settings were ‘very dissatisfied’ or ‘dissatisfied’ with the level of care they received.
- 73% highlighted their experience has not met their expectations with;
- 51% of those using private healthcare or looking abroad for treatment options.
- 49% report that their persisting Long COVID issues have and continue to impact their education and are now unable to complete standard full-time education. A further 23% have had to leave full-time education.

## Awareness and Recognition

### Q8. 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?

Since the emergence of Long Covid as a related sequelae of post Covid-19 infection there has been a consistent lack of recognition of the condition and practical actions across Government, Education and the Health Sector to support children and their families. Evidence existed since 2020<sup>12</sup>, that children develop Long Covid and the [research](#) base has continued to grow. Even so, the inaccurate perception and narrative that children are not badly affected by Covid infections continues to be perpetuated across all strata of Government and Government services.

This lack of awareness and recognition has and continues to create significant problems for children, young people and their families. This is compounded by the response of key groups including:

- **Potential sufferers:** 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.
- **General Public:** Children living with Long Covid, and their families often face scepticism and derision from the wider community who are unaware of the condition, the potential severity of the condition and the impact it has on the child, their family and wider relationships. This further isolates the child and their family, increasing the likelihood of mental health issues and increasing the pressure on the family unit, sometimes leading to family breakdown.

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<sup>1</sup> Lokugamage, A, Simpson, F, October 2020, [Counting Long Covid in Children](#), British Medical Journal

<sup>2</sup> Di Sante, G, Buonsenso, D, May 2021, [Immune profile of children with post-acute sequelae of SARS-CoV-2 infection \(Long Covid\)](#), MedRxiv.

- **Medical professionals:** For many clinicians and allied health professionals, the general lack of awareness and knowledge, and lack of support to update learning on Long Covid means they are not recognising Long Covid symptoms in young people and are failing to refer patients to appropriate care, where this is available. This can lead to patients' concerns and symptoms being minimised or dismissed leading to misdiagnosis or a failure to provide a definitive diagnosis. This has consequential implications for data collection, with an underreporting of the prevalence of long covid across the community and the assumption that paediatric Long Covid is not of significant concern.

The absence of a diagnosis results in failure to access appropriate treatment for commonly associated conditions, such as POTS, MCAS, PANS, ME/CFS etc. In some cases the lack of awareness of the appropriate management of Long Covid in children leads to increased suffering and in some cases causes further harm. Families frequently report being prescribed graded exercise therapy, which, supported by the updated NICE guidelines<sup>3</sup> for ME/CFS and similar energy-limiting conditions, is the wrong approach which can cause further harm and injury.

- **Employers:** Many of the families in our support services report difficulty continuing with employment due to new care responsibilities for their unwell children. Inflexibility of employers sometimes results in families having little choice but to resign from roles, reduce employment hours or move to part time and/or hybrid working. Households have had to make difficult financial decisions often reducing household income which is further compounded by the current cost of living crisis. Single parent families in particular report having to choose between caring for their children or retaining employment which often results in previously financially self-reliant families relying on benefits, accessing food banks and attempting to engage overwhelmed social care services for support.
- **Policy Makers:** As Covid-19 was a completely new disease, policy makers and advisors have continually reviewed the evidence and provided the best advice available to protect the economic situation across the UK, clearly demonstrated by the evolving policy environment during the outbreak. Yet, this was not reflected in policies for children where policy consistently disregarded the evidence and failed to develop effective policies leading to inaction across Government agencies and actually contributing to the incidence of Long Covid by placing children at greater risk of harm. The impacts can be evidenced in the following areas:
  - Lack of clear public health campaign to inform people about:
    - the risks of children experiencing longer term health issues as a result of a (often mild or asymptomatic) acute SARS-CoV-2 infection,
    - the symptoms of Long Covid to look out for in children and young people
    - how and where to access information, advice and support for children and young people experiencing Long Covid.

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<sup>3</sup> NICE, Oct 2021, [Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management](#), NICE website.

- A lack of investment in paediatric research to improve understanding of Long Covid and to identify potential treatments.
- A lack of health and educational services and support for children and young people affected by Long Covid.
- A lack of preventative action to make indoor spaces safer and reduce the risks of infection amongst children and young people.
  - Unlike many other countries, children in Scotland who are under 5 years old still do not have the option of accessing vaccine protection, despite one being approved for that age group by MHRA last year.
  - The Scottish Government have failed to protect young people and school staff by not undertaking a policy of clean indoor air as is recommended by RCPCH<sup>4</sup>.
- A lack of awareness amongst employers and a lack of awareness of the impact of caring for a child with Long Covid has on their employees leading to requests for reasonable adjustments, reduced hours and/or flexible working arrangements.

#### **Q9. What more could / should be done to raise awareness and recognition of long COVID?**

Awareness raising needs to be led by Government, so that agencies respond to the needs of the children suffering from the condition and policymakers can benefit from strategic frameworks (e.g. Health in all policies, Getting it Right for Every Child) to accelerate the communication and development of the support systems and treatment regimes needed.

Families in our support groups tell us they would like to see a multi-faceted approach being taken to raising awareness and recognition of Long Covid. This should include:

- **Strengthening mechanisms to engage children and young people with lived experience of Long Covid and their families in policy and practice development:** The experiences of children and young people affected by Long Covid and their families will be critical to understanding the priorities and focus for any actions. Policy makers and professionals need to place children and their families at the centre of designing and developing awareness raising initiatives, understanding the impact of Long Covid and the priority agencies and professionals requiring early engagement. Stronger engagement with lived experience would be in line with the ambitions of the [Christie Commission](#) and should build on good practice and lessons learned from other recent policy developments which were developed to put user experience first, such as [The Promise](#) and the [Social Security Experience Panels](#).

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<sup>4</sup> Royal College of Paediatrics and Child Health, Jan 2020, [The inside story: Health effects of indoor air quality on children and young people](#), RCPCH website.

- **Education and training for healthcare professionals encompassing elements such as:**
  - What Long Covid is and the impact it can have on individuals and families.
  - How to identify Long Covid in children and young people.
  - The importance of taking a person-centred, whole family approach to working with children, young people and families affected by Long Covid.
  - What role they can play in supporting and delivering better outcomes for children, young people and families affected by Long Covid.
  - What treatments are available for the associated conditions. Although there is not yet a cure for Long Covid itself, there are established protocols to treat associated conditions, such as POTS, MCAS, PANS, ME/CFS etc., that, where applicable, can be applied to improve quality of life and provide some relief from symptoms.
  - Sources of further information and support which families they are working with may benefit from accessing.
  - How to stay up-to-date with this emerging field of medical research.
  - Practical measures they can take to reduce Hospital (and other healthcare setting) Acquired Infections (HAIs) of Covid-19, including the use of measures to reduce airborne transmission.
  
- **Education and training for other professionals, including social care and education staff, so they understand:**
  - What Long Covid is and the impact it can have on individuals and families.
  - Signs of potential Long Covid in children and young people and where to refer children and young people to for appropriate assessment and support.
  - The importance of taking a person-centred, whole family approach to working with children, young people and families affected by Long Covid.
  - What role they can play in meeting needs and supporting and delivering better outcomes for children, young people and families affected by Long Covid. This may include the provision of flexible/hybrid/virtual education solutions that meet basic needs so children can continue to learn, grow and flourish as they seek to recover.
  - Practical measures they can take to improve indoor air quality and reduce the risk of more children and young people being affected by Long Covid.
  - Sources of further information and support which families they are working with may benefit from accessing.
  
- **An awareness raising campaign for the general public to provide information about:**
  - How to identify potential Long Covid in children and young people/ What symptoms may be associated with Long Covid.
  - Where people can go for help and support.
  - Preventative actions that can be taken to prevent Long Covid.
  - What Long Covid is, and the impact it can have on individuals and families.
  - What we do and do not know about the long term impacts of Covid infection at this stage of the pandemic.

- **An awareness raising campaign for employers, to help employers understand:**
  - What Long Covid is and the impact it can have on individuals and families.
  - Good practice in supporting parents and carers so they are able to continue in employment with reasonable adjustments whilst fulfilling additional caring responsibilities that may arise from having a child with Long Covid.
  - Practical measures they can take, such as improving indoor air quality on their premises and encouraging employees to stay at home when they are unwell, to reduce the chances of employees spreading Covid-19 to children, young people and vulnerable family members.

**Q10. What are your thoughts on the use of long COVID assessment clinics?**

Long Covid assessment clinics are a vital part of a comprehensive suite of services desperately needed by Long Covid sufferers of all ages in Scotland. At present, we are only aware of two Long Covid rehabilitation assessment clinics in Scotland; one in Edinburgh and one in Lanarkshire, with both of these only available to people aged 16+ years. Given the age restriction and limited geographical availability, an NHS postcode lottery is rapidly developing and disproportionately impacting families outside of Scotland's central belt. However it is prudent to note that whilst rehabilitation is a valuable aspect of recovery, Long Covid patients cannot rehab their way out of a condition with untreated underlying pathology.

Evidence from families in our support services indicate that GPs are still unsure of the condition, reluctant to diagnose and unaware of referral pathways for Long Covid in both adults and children.

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.

Additionally, 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.

Scotland-based families in the Long Covid Kids support services report:

- A lack of awareness across all clinical levels and departments of NHS staff.
- The lack of clear information, education, support and training for GPs especially for paediatric patients and support to be able to identify potential Long Covid in children.
- A lack of awareness and confusion in primary care around referral pathways.
- Difficulty accessing appropriate specialist paediatric care, community care and other appropriate services due to referral refusal or long waiting lists.
- Disjointed care if/when able to access multiple specialist services.

We would like to see a Long Covid assessment clinic in each health board area, with a multidisciplinary team that brings together different specialists, including paediatric specialists. The development of assessment clinics will ensure a consistent, evidence based approach to the diagnosis and management of Long Covid, allow the capture of robust prevalence data and become the focal point for a broader spectrum of Government services to assist the child and their family.

## Therapy and Rehabilitation

### **Q11. Do you consider that the correct mix of services are in place to help people who have long COVID?**

Long Covid presents as a multi-system condition in children of all ages with parents/carers currently unable to consistently access services to appropriately diagnose and manage the condition. 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.

Currently, families represented by Long Covid Kids have identified a number of potential issues with existing healthcare services for paediatric patients, with concerns being raised that children's rights are not being met under the [UN Convention on the Rights of the Child \(UNCRC\)](#). Article 24 of UNCRC sets out a requirement that;

*“State Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.”*

It is only by employing persistence and determination by parents/carers to navigate the NHS to find care for their children, that some families are being referred to rehabilitation services (e.g. physiotherapy, occupational therapy). Whilst these have an important role to play, they do not address the underlying pathology of chronic illness. Further, we are concerned that children and young people are often being denied supportive psychological care, which can be beneficial to sufferers of chronic long-term ill health, because they are not meeting perceived severity threshold

levels to access CAMHS and other mental health services that may benefit them. This gap in service provision urgently needs to be addressed.

We suggest that, in addition to a structured approach to the development of services, a more cost-effective approach be adopted to broader training and education of clinical staff using the best-practice model similar to the [National Trauma Training Programme](#). This would build a Long Covid informed and responsive workforce, that is capable of recognising when people are affected by Long Covid, that is able to respond in ways to prevent further harm and support recovery and can address inequalities and improve outcomes and life chances.

Finally, the inquiry should recognise that, unlike the acute phase of Covid-19 that is being effectively addressed through vaccination, Long Covid will continue to present as vaccines have minimal protection<sup>5</sup> against the development of Long Covid, and repeat exposure to SARS-CoV-2 increases the likelihood of developing Long Covid in the future.

## **Q12. What support could or should be available for people who are supporting or caring for people with long COVID?**

The impact of Long Covid on children and families is significant and wide ranging, evidence from families represented by Long Covid Kids indicate persistent and multiple failures across all agencies. These failures can be seen:

- In education, with children unable to access tuition and support.
- In social care with families struggling to cope and unable to access appropriate support.
- In healthcare, with limited or no access to a diagnosis or treatments.
- Across Government, where a lack of consistent, evidence based and practical policy making is failing children and young people in Scotland.

Supporting and/or caring for children and young people with Long Covid 24/7 can be emotionally and physically exhausting, and some parents/carers have Long Covid themselves. Peer support, such as that offered by Long Covid Kids and Long Covid Scotland, is invaluable to families and can play an important role in offering a safe space to be heard as well as moral support and practical assistance to families affected by Long Covid. Families tell us it can be a very isolating experience, with little awareness amongst family, friends and wider society about Long Covid or the impact it can have on children and young people and their families. A better understanding in society would be enormously helpful for families.

We are unaware of any families in our support groups that have been able to successfully access social care support, although some families have identified a clear need for it. Several are on waiting lists for a caseworker, although the level of current demand means that waits can be long as services lack the capacity to take on additional cases. Some families are now reporting waits of over a year.

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<sup>5</sup> Al-Aly, Z et al., May 2022, [Long COVID after breakthrough SARS-CoV-2 infection](#), Nature Medicine Journal.

Families can also suffer financial impacts as a result of having a child with Long Covid, due to a loss of income or experiencing additional costs associated with care and support. Parents or carers may need to reduce their working hours to meet increased caring responsibilities and many families in our support group are now a one-income household as a result. Some single parent families now have to rely solely on state benefits. The lack of awareness and understanding amongst employers has meant that requests for reasonable adjustments, flexible working, home working, time off to attend medical appointments or changes to contracts to enable them to fulfil new care commitments have not been met, which has resulted in them having to leave employment. Current benefit applications are incredibly long and repetitive which makes it very difficult to complete, and parents and carers are struggling to find the time to apply in between looking after their child.

A rapid survey of families in our Scottish support services found that over 60% of families had not applied for Child Disability Payment because the form was too complicated and the lack of clarity from policymakers, professionals and advisers made it virtually impossible to receive the support necessary.

## Study and Research

### Q13. What should be the main priorities for study and research into long COVID?

Although there is research underway in Scotland, the needs of children are under-represented with no research study actually considering Long Covid in children. Some investment has occurred; in March 2020, the Scottish Government invested £2.5m into the [longer term effects of COVID-19 infection](#). Nine research projects were funded and focused on;

- Symptom tracking
- Impact on quality of life
- Risk modelling
- Rehabilitation modelling

Only one research project seeks to understand treatment options for symptoms, but specifically targeted to cognitive symptoms alone and none of the research projects plans to investigate the underlying mechanisms or pathology of Long Covid.

Most concerningly, one research project aims to understand the impact of resistance exercise on people with Long Covid. The updated NICE guidelines for ME/CFS<sup>6</sup> states that exercise protocols for energy-limiting conditions should not be prescribed to avoid further harm to the patient and avoid triggering Post Exertional Malaise (PEM) and/or Post Exertional Symptom Exacerbation (PESE).

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<sup>6</sup> NICE, Oct 2021, [Myalgic encephalomyelitis \(or encephalopathy\)/chronic fatigue syndrome: diagnosis and management](#), NICE website.



Long Covid Kids are unaware of Patient and Public Involvement (PPI) in any of the funded projects.

We recommend immediate investment into high quality biomedical research in children and young people to better understand the underlying pathology and mechanisms that cause Long Covid, so as to develop appropriate treatment protocols to improve health and wellbeing outcomes.

#### **Q14. Is sufficient data publicly available on the prevalence of long COVID in Scotland?**

During the Long Covid debate on 19th May 2022, Cabinet Secretary Humza Yousaf stated,

*"I don't think we have the level of granular data we need in relation to those who are suffering with Long Covid. We have some of the headline figures but on a granular level, when it comes to children, people with disabilities, how many minorities does it affect, etc, I think that data, frankly, is not at a place I would like it to be."*

The [latest ONS figures](#) suggest that in the UK 58,000 young people aged 2-16 years old are living with Long Covid, 40,000 of those have been suffering for longer than 12 months. We do not have data specific to Scotland.

To improve the availability and accuracy of data will require:

- Clear definitional framework for Long Covid, especially for children and young people.
- Better diagnostic services consistently applying guidelines to capture and recognise Long Covid.
- Improving awareness and application of standard medical codes for Long Covid in NHS patient databases (In the summer of 2020 Dr Amy Small brought this issue to the attention of the Scottish Government and the issue has been discussed at length in subsequent Roundtable meetings)
- Improve search functions on medical databases to facilitate efficiency in correct coding practices.

In addition to the lack of granular detail in the data, we also have more general concerns about the lack of publicly available data relating to Long Covid in Scotland. As far as we are aware, despite being one of the significant health harms arising from Covid infections (along with hospitalisations and deaths), a Long Covid indicator has never been included on the Scottish Government's [dashboard of Covid Harms](#).

In response to a [written question](#) about this in December 2021, the Cabinet Secretary stated that such an indicator was unnecessary because data on Long Covid was available in a separate weekly Scottish Government [Coronavirus \(Covid-19\): modelling the epidemic](#) series of publications. This separate series of publications stopped reporting on rates of Long Covid in Scotland in February 2022. For a number of weeks, the publication stated that, *"A report on the rate of long Covid has not been included in this issue. We will report the long Covid projections again once updated estimates of self-reported long Covid prevalence amongst those infected with the less severe Omicron variant become available."* By May 2022 (Issue 100), this statement had

been removed and, since then, there has been no data on the rate of Long Covid included within the weekly report.

We have particular concerns about the lack of publicly available data relating to Long Covid in children and young people in Scotland. Looking back at various publications, the Scottish Government's wording around the risks that Covid-19 poses to children and young people appears to have subtly shifted over time, moving:

- from "[very low risk of health harm from Covid-19](#)" in September 2021
- to "[low risk of direct health harms](#) [from Covid-19]" in February 2022
- to "[relatively low risk of direct Covid-19 harm \[compared to adults\]](#)" by April 2022.

Public health experts have noted that describing the risks to children relative to the risks to adults is bad practice and a form of childism, the term used to describe institutional prejudice and systemic injustice against children. (See, for example, Alwan. N. (2021) [We must call out childism in covid-19 policies | The BMJ](#) and Ashish K. Jha, the White House Covid-19 Response Coordinator, [Twitter thread](#)). In line with good practice, we would welcome an updated assessment from the Scottish Government of the risks to children and young people's health (including the risk of health harms over the longer term) as a result of a Covid infection or reinfection.

Whilst it is important to understand the scale of the problem of Long Covid in Scotland, debating the prevalence of Long Covid in children and young people is unhelpful given we already know that families in Scotland are currently struggling to access services for their children. Long Covid Kids continues to welcome new families to our support services every day suggesting that this is an ongoing and escalating issue that requires urgent attention and immediate action.

### **Q15. Do you have any other comments?**

Long Covid Kids was founded in October 2020 by people living with Long Covid. In 2021, LCK became the first registered charity advocating for families, children and young people living with Long Covid anywhere in the world. With support from our [Long Covid Kids Champions](#), the [Long Covid Kids Team](#) currently support over 12k families with over 200 of those residing in Scotland.

LCK's vision is to achieve recognition, support and recovery for Long Covid and related illnesses in children and young people. Our mission is to increase understanding, aid early diagnosis and improve response and intervention. LCK volunteers have worked tirelessly to raise awareness and effect change throughout the pandemic. [Our Annual Report 2021-2022 spotlights our impact.](#)

LCK's award winning guidebook '[Shining a light on Long Covid in Children. A Guide to Recognition. Support. Recovery](#)' was created in response to the increase in demand for our support services. The guide contains practical and helpful information for health and education professionals, and families, designed to support and inform on recovery alongside our popular resources; [Pacing Penguins](#) and [Cautious Tortoise](#).

In summary, Long Covid Kids' recommendations are:

**Collaboration.** Involve people with lived experience.

**Listen.** Hear the experiences of CYP & implement change.

**Educate.** Provide information to educational staff & healthcare professionals for early intervention.

**Apply.** Use the precautionary principle. Take heed of emerging research and lived experiences.

**Needs.** Provide flexible education that meets basic needs so children can learn, grow & flourish.

**Air Quality.** Prevention is key. Clean the air we share. Invest in air filtration in educational settings.

**Identify.** Consider global research, best clinical practice & granular level data collection.

**Improved Public Health Messaging.** Prevent infection/reinfections & raise awareness.

**Recovery.** Invest in paediatric biomedical research for treatment options.

Long Covid Kids stands ready to assist the Scottish Government in creating positive change and improved health, social care and education policy for families in Scotland whose young people are living with the life-changing impacts of Long Covid.

Yours faithfully,

Helen Goss

COO & Scotland Representative

Long Covid Kids & Friends

# **Michelle Powell Gonzalez**

## **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, not at all. There is a dangerous ignorance surrounding Long Covid by medical professionals, policy makers (The Government) , employers and the general public.

The messaging from the government has been silent surrounding the dangers of Long Covid throughout the pandemic. Now all mitigation measures, which could easily be put in place to protect people, have been scrapped giving people the idea that Covid is no longer a risk. This is totally unacceptable.

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

First off, Long Covid needs to be legally classified as a disability. People need to understand that when getting Covid, even if they are young and healthy and fit they run the risk of getting Long Covid. Policy Makers need to implement mitigation measures such as mask wearing in busy indoor places and better air filtration mechanisms (such as HEPA filters) in all classrooms at all schools in Scotland to protect our children and the rest of our community. There needs to be clear guidance for employers to help support workers with Long Covid. The NHS needs to take the time to create joined up treatment centres that are Long Covid patient informed with the tools available to actually help us. Medical professionals (GPs) need to understand the mechanisms of Long Covid and be briefed on easy testing options for Long Covid's most prevalent symptoms so they are able to actually treat us and resolve some of our ongoing pathological conditions.

Basically, we need public health messaging communicating the ongoing risks of Long Covid from contracting COVID. Throughout the pandemic there has been little to no messaging including Long COVID the messaging has always focused on infections and deaths leaving out LONG COVID completely. Doctors need to be trained and sent some information about LONG COVID. Shockingly most Doctors still have no idea about Long Covid and there are a few who don't even believe it exists.

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

I have not had a good experience with the Long COVID assessment clinic. I have found it to be severely lacking. In my view they are not the solution as they are being implemented at the moment. The NHS needs to consult with those of us with LONG COVID and start implementing clinics that actually focus on treating us and our many ailments.

## **Therapy and rehabilitation**

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

No. I feel people with Long Covid are being forced to go private if they want any real treatment options and doctors who will actually look into what is happening to them. The NHS has not created the correct pathways to treat Long Covid. The system has locked us out and we are being forced into existing structures when our illness is more complex and needs a joined up response. Specialists need to talk to each other and if and when there are actual Long Covid clinics I have many recommendations. These MUST be Long Covid patient informed.

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

Mental Health support as it's very hard to watch your loved one suffer from Long Covid. Also, financial help as supporting someone with Long Covid can be a full time carer's responsibility. It would also be helpful for the carer to be briefed on how to better support and help.

## **Study and research**

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

Doctors and specialists need to understand that Long Covid isn't in just one area of the body. There are many areas of the body affected. There needs to be medical professionals from different specialities working together to find what mechanisms are involved in causing the continued illness in the body. At the moment you have many different doctors looking at very specific areas and researching one part of the body. We need the entire body to be looked at as this is multi-system.

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

Not at all. Now that testing is a thing of the past we have no idea of the prevalence of COVID and with that Long COVID. People don't understand that this will continue to persist and the problem of LONG COVID will only grow bigger and bigger, disabling more and more people, a lot of them of working age or pushing others to early retirement.

### **Do you have any other comments?**

I got COVID in April 2020 and have gotten my vaccinations and boosters as I was allowed to as per my age group. Now I am no longer qualified for any more boosters because I am under 50 yet I have been so severely affected by COVID I am now disabled. I feel that people with Long COVID should

automatically qualify for the COVID vaccinations and boosters. I have been trying to get a booster since September 2022 to no avail. How is it possible someone with LONG COVID does not qualify for yearly COVID boosters?