COVID-19 Recovery Committee

Long COVID inquiry

Call for views - summary of responses

Introduction

The COVID-19 Recovery Committee ('the Committee') issued a call for views on its long COVID inquiry, which ran from 12 January 2023 until 10 February 2023 and was then extended until 19 February 2023. The Committee sought views based on three main themes—

- Awareness and recognition
- Therapy and rehabilitation
- Study and research

508 responses were received. The majority of responses (93%) were from individuals with lived experience of long COVID and 36 organisations (7%) also provided a submission. The following organisations responded—

- Aberdeen City Council
- The Health and Social Care Alliance Scotland (the ALLIANCE)
- ASLEF
- British Association of Counselling and Psychotherapy (BACP)
- Chartered Society of Physiotherapy Scotland (CSPS)
- Chest Heart and Stroke Scotland (CHSS)
- The Cheyne Gang - sing to breathe
- Chartered Institute of Personnel Development (CIPD)
- COSLA and Social Work Scotland (SWS)
- Covid Action Scotland (CAS)
- The Educational Institute of Scotland (EIS)
- Inclusion Scotland
- Long Covid Kids (LCK)
- Long Covid Rehabilitation in Scotland study team (LOCO-RISE)
- Long Covid Scotland (LCS)
- Long Covid Support (LCS)
- Long Covid Support Group: Scotland (LCSGS)
- #MEAction Scotland
- Moderna Biotech UK Limited
- NASWUT
- NHS Ayrshire & Arran
- NHS Fife
- NHS Greater Glasgow and Clyde
- NHS24
- Perspectum

- PoTS UK
- Royal College of General Practitioners Scotland (RCGP Scotland)
- Royal College of Occupational Therapists (RCOT)
- Royal College of Paediatrics and Child Health (RCPCH)
- Royal College of Physicians of Edinburgh (RCPE)
- Scottish Women's Convention (SWC)
- Tea in the Pot
- Unite Scotland
- University and College Union (UCU) Scotland
- University of Stirling
- Vitamin D Campaign Group

SPICe have produced a word cloud based on the most common words found in the responses—

This summary is not intended to provide a comprehensive account of all the issues raised by respondents, rather it provides an overview of the main issues and recurring themes raised.

Lived experience - overview

The majority of responses were from individuals with lived experience of long COVID or caring for someone with long COVID. Many respondents highlighted the stigma that exists around long COVID. In relation to their experience of the condition, written responses described the myriad of symptoms, which can number over 200. These include severe fatigue, breathing difficulties, tachycardia, cardio-respiratory, dysautonomia, musculoskeletal pain, neurological symptoms and skin complaints. Almost all said the complexity of the condition had led to delays in diagnosing long COVID and obtaining treatment.

Diagnosis

The responses highlighted some ambiguity around what type of illness long COVID is. Many argued that it is not a respiratory disease, rather a vascular one with neurological aspects, while others considered that it is a respiratory illness. For example, Anna Buchanan said—

> “Recognition of my long covid was long-delayed because I did not display the classic sign of a cough. Yet, by January 2021, medics who were keeping updated about COVID-19 should have been aware that many people with the condition do not present with a cough. They certainly should be aware now, because the research evidence is very clear, that long covid is a condition with more than 200 symptoms that impact on multiple organ systems. It is an incredibly complex condition and many people are more strongly impacted by neurological symptoms than respiratory symptoms.”

Donna Convery, arguing that long COVID is a vascular disease, commented—

> “The NHS (and wider medical profession) are simply not using the cardiovascular, neurological, immunological and haematological abnormalities right tests to look for the right things. After 3 years and 10,000 papers published in reputable journals such as the BMJ, Lancet, etc, it is beyond disappointing that on a daily basis patients are still being told they are anxious or have FND[1] (which is a 'dustbin' diagnosis with no measurable parameters used to gaslight patients with complex symptoms).”

Marie-Claire Grounds also spoke of the lack of understanding of the nature of the illness saying—

> “My impression is that Long Covid is considered to be ‘slow recovery’ after a covid infection, when in fact the reality is that it is a complex multi-system neuroimmune illness, currently with no cure. A paper in Nature published in 2022 found that of those Long Covid patients still sick after 2 months, only 15% had recovered by one year, and of those 33% would later relapse.”

Mental health

Almost all of the individual respondents said they felt frustrated, angry and not listened to or believed. A common phrase used was they felt they were being ‘gaslighted’ by the medical profession.

Long Covid Kids also highlighted that children and young people living with long COVID, and their families often face scepticism from the general public who are unaware of the condition and its potential severity. They said—

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[1] Functional neurological disorder.

> "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."

An overwhelming number of individual respondents spoke of the impact on their mental health, as well as their physical health which had been extremely detrimental. This view was echoed by the ALLIANCE who highlighted its findings 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.

Catherine McCormack summed up her experience—

> "People generally think that it is made up, people don't understand that it comes and goes, some good days some bad and some terrible days. It's exhausting having to explain all the time what you're going through because no one actually knows what it is through no fault of their own. I struggle to understand it at times and I'm the one living with it."

Royal College of General Practitioners Scotland (RCGP Scotland) said it recognised the distress experienced by those self-reporting with Long COVID, and acknowledged that it has had a significant negative effect on their physical and mental health and wellbeing.

Stirling University, on behalf of a team of researchers from the Universities of Stirling, Aberdeen and Oxford, highlighted their COv-VOICES study involving people with Long COVID, family members, healthcare professionals, policy-makers and the general public on what living with long Covid is like in people's own words. They said—

> "Our interviews and analysis clearly show that participants in our study often felt invisible, overlooked, left behind or unheard in much of the public discourse and by healthcare professionals, employers and policy makers…They described their frustration that the devastation of their lives caused by their Long Covid symptoms remained a "hidden illness."

Dr Aileen Grant and Dr Nicola Torrance highlighted their research "Exploring the lived experience of long COVID in NHS workers in Scotland", which suggested that knowledge on long COVID was limited. They said—

> "Our findings suggest there is sometimes a lack of belief around the condition and understanding of the diverse effects of long COVID on body systems. People struggle to get a formal diagnosis (of long COVID or the associated signs and symptoms) which enables access to health and other services, such as occupational health and human resource support."

Awareness and recognition

The overwhelming majority of respondents felt there was not enough awareness and recognition of long COVID by the general public, medical professionals, employers and policy makers in Scotland. A number of reasons were given for this and suggestions made on how to improve awareness among these groups.

PoTS UK summarised that, although there was some awareness of long COVID, this did not necessarily translate into the following—

- recognition of the prevalence and impact of long covid
- ability of patients to find or receive medical care for long covid
- ability of medical professionals to recognise symptoms and diagnose or manage it
- willingness of employers to understand long covid or support affected employees
- willingness of policy makers in Scotland to provide adequate services or other support for affected patients/carers.

General public

As stated, awareness of long COVID among the general public was said to be lacking. Christopher Potter's response was typical when he said—

> "I feel the general public has very low visibility and understanding of the real underlying consequences of Long COVID and its residual effects around an individual and their family's lives. Unless someone has personal or close experience with an individual dealing with the real-life implications of Long COVID, I doubt many would regard this chronic illness with the seriousness that it deserves."

Respondents highlighted problems with misinformation in relation to long COVID on social media channels. A majority of individual respondents complained of not being taken seriously with friends and colleagues believing it to be a 'made up' illness which left them feeling abandoned and extremely isolated. Numerous respondents spoke of the perception that people affected by the condition are simply tired or lazy, rather than suffering from a recognised medical condition. This chimed with what the ALLIANCE heard in it is Long Covid Lived Experience Survey and its commissioned research report, with Chest Heart & Stroke Scotland (CHSS), by E.Miller, 'Accessing social support for Long Covid.'

However, NHS 24 argued there was sufficient information available on its microsite to support the general public's awareness of long COVID, noting that—

> "The microsite also offers a range of other advice on long COVID including brain fog, loss of smell and taste, breathlessness, coughs,

> and other symptoms. People continue to regularly access information on long COVID hosted on the NHS inform microsite, and information should continue to be provided there until the need is no longer identified.”

Suggestions for change

A number of respondents suggested that a national public health campaign should be launched to increase awareness of the condition but also to communicate the risks associated with COVID and developing long COVID. This was supported by Covid Action Scotland who said the Scottish Government and Health Protection Scotland have “a duty of care” to raise awareness through a national campaign. A number of respondents said that a public health campaign should include television adverts outlining the risks of long COVID and raise awareness of the condition. This call for public health messaging was echoed by Long Covid Scotland who said—

> “There is a need to address the belief that only people with underlying health conditions can experience long COVID and increase understanding that anyone can develop long COVID.”

Long Covid Support said—

> “The way to avoid Long Covid is to avoid Covid. This message has been absent in public health messaging, despite being known since the summer of 2020. This may result in behaviours that lead a significant number of people to contract COVID-19, assuming a brief illness with a full recovery, who now maintain episodic or full-time disability as a consequence of infection.”

Many respondents called for information on long COVID to be readily available in the form of online data and leaflets in GP practices and pharmacies to help raise awareness of the condition.

The ALLIANCE made the point that any information produced to raise awareness and recognition must be inclusive and available in a range of accessible formats, including Community Languages, British Sign Language (BSL), Braille, Moon, Easy Read, clear and large print, and paper formats.

Medical professionals

Almost all individual respondents spoke of a lack of awareness among medical professionals, GPs in particular, in terms of assessing patients, diagnosing long COVID and the ongoing treatment options. Many respondents said they did not feel listened to by the medical profession which included responses from those who work or had worked within the medical profession such as Chiara Berardelli, Sarah McDonald, Nichola Hendry, Marie-Claire Grounds, Cass Macdonald, Bruce Watson and Fiona Litman.

A number of respondents highlighted difficulties encountered with their GPs in relation to diagnosis due to the lack of a long COVID test and the wide variety of symptoms. Many spoke of having to undertake their own research in order to get effective treatment. For example, Sarah McDonald said—

> "Long covid for me has been a mixture of two treatable conditions (postural orthostatic tachycardia syndrome) and asthma triggered by Covid. I was only able to access testing, diagnosis and appropriate treatment after self-diagnosing these conditions and securing medical testing and input to confirm mainly due to my personal professional relationships with colleagues. I worry that many with long covid who do not possess the detailed medical knowledge and have the confidence and in my case professional respect that allowed me to obtain diagnosis and treatment."

The result of misdiagnosis with conditions such as ME/CFS, depression, anxiety and the menopause was a concern among a number of individuals who responded to the call for views, with a some explaining they felt forced to seek private medical care for the correct assessment and treatment. They made the point that this could result in a two-tier health system, given this is not affordable for everyone.

Many respondents argued that the level of awareness among GPs varied across the country with a number referring to a 'postcode lottery' when going to your GP with long COVID symptoms. One respondent said—

> "Medical professionals are not being consistently taught about Long Covid symptoms/appropriate testing and management options and even commonly known diagnostics are not being used."

Marie-Claire Grounds said—

> "I am an NHS Doctor, and was asked to give a presentation about my personal experience of Long Covid at a Royal College of Physicians Edinburgh event in summer 2022. The overwhelming response from colleagues was that they had no idea of the severity of the illness nor it's impact on day to day function. This demonstrated to me the enormous gap in knowledge within the medical profession towards not only Long Covid, but other related illnesses such as ME/CFS, POTS and dysautonomia. As such, my medical colleagues are unaware of what advice to give their patients."

Long Covid Kids commented that the lack of awareness in the medical profession of the appropriate management of Long COVID in children leads to increased suffering and in some cases causes further harm. They said—

> "The absence of a diagnosis results in failure to access appropriate treatment for commonly associated conditions, such as POTS, MCAS, PANS, ME/CFS etc…. Families frequently report being prescribed graded exercise therapy, which, supported by the updated NICE

> guidelines for ME/CFS and similar energy-limiting conditions, is the wrong approach which can cause further harm and injury.”

The Royal College of Physicians of Edinburgh (RCPE) expressed concern regarding the prevalence of long COVID in particular population groups, namely people aged 35 to 69 years, females, people living in more deprived areas, those working in social care and in particular those with another activity-limiting health condition or disability. On awareness within the profession, they said—

> “Our understanding of the pathophysiology and mechanisms underlying it remains primitive with ongoing research. Treatment in general is limited. “

Suggestions for change

The vast majority of respondents argued for more education and training for medical professionals on long COVID with time being made available for training and continuous professional development, which some respondents said was not always the case. Bruce Watson said—

> “As a healthcare professional myself I am aware of the lack of up to date understanding and recognition of the condition by other healthcare staff. Unless you are affected by the condition personally as a sufferer or close relative, friend, colleague etc then I think most don't have a real understanding.”

NHS Greater Glasgow and Clyde (NHSGGC) highlighted current guidelines developed by SIGN, the National Institute for Health and Care Excellence (NICE) and the Royal College of General Practitioners which have been cascaded through GPs and primary care teams. They pointed out that these are aligned with the principles and recommendations of the Scottish Government Recovery and Rehabilitation Framework 2020.

These guidelines were also highlighted by NHS Fife who said awareness and recognition of long COVID is ever increasing although “NHS Scotland could do more.” On training they said—

> “There are no educational resources available for training, but we believe that NES is presently exploring this. “

NHS Ayrshire & Arran also highlighted that all health professionals have not had training in the management of Long COVID and that the NSS Long Covid Steering Group are developing resources for Primary Care Team training.

Chest, Heart and Stroke Scotland (CHSS) pointed to its Long Covid Action plan which calls for better awareness and resources for clinicians. It highlighted current training provision and that need for more to be done—

> “RCGP have provided training modules on Long Covid, which have helped many GPs understand this condition, and have addressed harmful misconceptions around mental health. SIGN Guidelines on Long Covid have been available since 2020. However, there is a clear need for more work in this area.”

COSLA and Social Work Scotland (SWS) said it was not represented on COVID Strategic Network. They highlighted that the group’s membership includes NHS Board members, clinical experts and that, given the Network has recommended supporting the education of healthcare staff on the identification, assessment and management of people with long COVID, its membership should include representation from Local Government to ensure the impact to ensure the impact on social care and other local services is fully recognised. They argued that network groups on long COVID should also involve SWS in discussions.

It was suggested that medical professionals involved in assessment of Long COVID should share their information and knowledge with consultants and GPs as a matter of course.

It was also suggested that guidance should be issued to all healthcare providers on recognising long COVID in patients and what appropriate actions should be prescribed.

Stirling University’s COv-VOICES study found that the “importance of keeping an open mind, being professionally curious and learning from patients’ experiences” were common themes in relation to medial professionals’ awareness and recognition.

Employers

Many individual respondents spoke of having to take long periods of sick leave and subsequently some had lost their jobs and others felt unable to continue in employment so resigned or took early retirement. The uncertainty regarding their employment and the financial implications, in addition to dealing with the condition, was highlighted as a common source of additional stress.

Unite highlighted a TUS report on report workers’ experiences of long Covid which found—

> “Respondents also described the poor treatment that they experienced at work because they had long Covid. Over half (52 per cent) had experienced some form of discrimination or disadvantage. Workers were faced with disbelief and suspicion, with around one fifth (19 per cent) having their employer question the impact of their symptoms and one in eight (13 per cent) facing questions from their employer about whether they had long Covid at all.

> Respondents were also concerned about what the future might hold for them at work given the amount of sick leave they had been forced to take due to their long Covid symptoms. For around one in six respondents (18 per cent), the amount of sick leave they had taken had triggered absence management or HR processes and one in 11 respondents (9 per cent) had used up all of their sick leave and had been told there would be negative consequences if they took more. One in 20 respondents (5 per cent) had been forced out of their jobs because they had long Covid.”

Long Covid Kids highlighted the difficulties continuing with employment faced by parents of children with long COVID as a result of caring responsibilities. They spoke of employers’ inflexibility forcing families to resign from roles, reduce employment hours or move to part time and/or hybrid working which causes financial difficulties.

Long Covid Support, commenting on the national picture, said—

> “An increasing number of people of working age are being left unable to work at all or to their previous capacity as a result of their Long Covid. Analysis of the results of our recent Long Covid clinics survey show that 81% of respondents have had a change to their employment status - 22% of whom were on sick leave, 21% had left work, 24% had reduced their working hours.”

The NASUWT highlighted the Wellbeing at Work survey 2021 which found that 17% of those respondents in Scotland with Long COVID had not disclosed this to their employer, suggesting a lack of trust and support.

HR Policies

Many respondents said that, despite having an understanding line manager, their employers’ awareness of long COVID and its symptoms was lacking. It was argued that that employers’ human resources policies such as return to work and absence management policies were not fit for dealing with long COVID as they assumed a steady improvement in symptoms over time which is unrealistic in long COVID cases.

Respondents said employers should be engaged and encouraged to adopt remote and flexible workplace practices to facilitate the ability of people with long COVID to remain in work more easily.

The Chartered Institute of Personnel Development (CIPD) commented that employers should promote understanding and awareness of long COVID among managers, and ensure they have sickness absence, return-to-work and health and wellbeing policies that encourage a flexible and individualised approach to managing fluctuating long-term health conditions.

Guidance produced by CIPD for HR professionals, line managers and colleagues to support employees with long COVID was highlighted by one respondent however, it was felt that this guidance was not widely known.

CIPD confirmed they had produced a series of reports and guides aimed at helping its members, line managers and employers understand the impact of long COVID and steps that can be taken to support employees. It referred to research undertaken by Affinity Health at Work and the University of Sheffield which found that employees with long COVID "often face the triple burden of having unclear rehabilitation pathways, colleagues and family/friends are worn out by the pandemic and pressure on the healthcare system which means that often people are waiting a long time for diagnosis and treatment."

In addition, it highlighted CIPD's 2022 Health and Wellbeing at Work report, which found that 12% of organisations include COVID-19 as a top 3 cause of long-term absence (4 weeks or more) and 26% also include long COVID as a top 3 cause. It said—

> "The scale and prevalence of long COVID in the workplace is therefore a significant concern. There is a need for a public policy response that addresses this and recognises that long COVID poses a considerable challenge - and is likely to continue to do so for the foreseeable future."

NHS Fife highlighted the Health & Safety Executive (HSE) commissioned study which looked evidence on the impact of Long COVID on work, the workplace, and return to work interventions. The study made recommendations within guidelines to facilitate return to work and NHS Fife said it was unclear how well these guidelines have been disseminated or adhered to by both public sector and private sector employers.

On a related point, it was also argued that businesses should be made aware that the best way to future proof their buildings by installing air filtering or ventilation (HEPA) systems against a future virus and Long Covid Scotland called for investment in HEPA air filtration in public buildings.

Key workers

A large number of individual responses were from people who work for or had worked for the NHS and argued that, as key workers, they should be compensated for contracting COVID and long COVID while at work. Some argued that long COVID should be treated as an industrial disease.

Marie-Claire Grounds said there was no flexibility with regard to the standard phased return policies, making it incredibly challenging for healthcare workers to return to the workplace whilst still living with this illness. She said—

> "As per the Scottish Government guidelines (Once for Scotland Attendance Policy), my pay is about to be halved, and will cease altogether in September 2023 if I am not able to return to work. It remains unclear whether my job would be terminated at this point.

> Having caught covid working on the front line in the first place, it feels unjust that healthcare workers like myself should be so harshly impacted having put ourselves at risk in order to care for others."

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

The NASUWT said it had been urging schools and local authorities in Scotland to recognise Long COVID amongst teachers and provide the necessary support. It said—

> "The Union's appeal followed data from the ONS which shows that teachers and school staff are one of the most likely professions to be affected by Long COVID, only just behind health and social care workers, and many of these individuals will have contracted COVID-19 through their employment."

It argued for an entitlement to reasonable adjustments, flexible working, and access to ill-health retirement and financial compensation for teachers left unable to teach as a result of contracting COVID at work.

Educators

Many respondents highlighted the need for educators to be more aware of the condition and adapt their access and learning policies to help support children and young people with long COVID.

To help prevent children and young people from infection and reinfection, some respondents called for better ventilation in public spaces and NASUWT argued for additional funding and direction to schools to improve ventilation. It said that HEPA air filtration devices should be provided to all schools to help prevent covid and long COVID infection in schools.

Stirling University highlighted research findings which showed the importance of education to children and young people with Long COVID and that attending school/college/university was a valued part of normal life they had lost. Participants of their study described being absent from school/college/university as stressful and isolating, leaving them feeling like they were falling behind academically and socially. They also said that returning to education, albeit on reduced timetables, often caused "crashes" or relapses, leading children and young people to need to find ways of balancing school/college/university and symptoms, such as prioritising attendance and rest over other aspects of their lives.

The Royal College of Occupational Therapists (RCOT) noted that schools may not feel equipped to support students experiencing long COVID and may not recognise the complexity and fluctuating nature of children's symptoms.

Long Covid Kids highlighted the Children and Young People's Healthcare Experiences: Preliminary findings (Jan 2023) which looked at healthcare experiences of children and young people in the UK living with Long COVID. The survey found that 49% of children and young people reported 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.

Policy makers

Some respondents argued that governments should highlight the risks associated with long COVID and mitigations which should be taken to prevent people getting COVID and long COVID. There was an acknowledgment that prevention measures such as mask wearing is no longer a requirement however there were calls for governments to do more on ventilation and clean air strategies.

A number of respondents questioned the policy decision to remove COVID-19 protection measures, such as mask wearing in public places and building ventilation measures. They said that they felt that governments had decided COVID was over and was no longer a risk which they believed was the wrong message. They argued that this did not help with raising awareness of the dangers and impact of COVID, which could develop into long COVID, and the dangers of reinfection for those who already have long COVID. Ruth Finegold said—

> "The government policy now is to get covid. It feels as though they are willingly forgetting about long covid, and perfectly happy for people to get it. Vaccines are protecting certain groups from being hospitalised or killed from the virus (to an extent), but they don't protect against long covid, and there is no recognition for that in policy as the only government strategy remaining is vaccinating vulnerable groups."

This was echoed by Lulu Cotton who commented—

> "There is minimisation of COVID-19 as a disease as part of the Scottish Government political narrative, with lack of raising the importance of long COVID by professional advisors such as the CMO. Given this national de-promotion of the importance of long COVID it is not surprising that employers and general public are not aware of the devastating impact of long COVID."

CIPD referred to its long-held position asking for the UK Government to introduce paid carer's leave and acknowledged the support provided by the Scottish Government's Carer's Assistance. They commented—

> "We know one of the key issues with carers' benefits is their uptake, so spreading awareness of eligibility among those caring for people with long COVID is crucial."

The ALLIANCE recommended that government should prioritise improving Long COVID care and support should be prioritised that the Scottish Government should work 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.

Long Covid Kids also argued that long COVID awareness raising exercises should be led by Government through its strategic frameworks to accelerate the communication and development of the support systems and treatment regimes needed. They said—

> “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.”

Moderna Biotech UK Limited said the Scottish Government’s commitment to a care coordination service model, and the action taken so far, such as the Long Covid Support fund, is encouraging, however it said more needs to be done on improving coordination across the country. It also said the Scottish Government should continue to raise awareness around the benefits of vaccination against Covid-19 through public health communications.

Therapy and rehabilitation

Long COVID clinics

There were mixed responses to the use of long COVID clinics. The call for views asked for thoughts on the use of long COVID assessment clinics and a large number of individual respondents simply said they were in favour but added no further information.

Many said that the use of long COVID assessment clinics could be useful, however, the key point emphasised was the need for improved assessment and diagnostic services across all health boards, consistency of services and greater understanding of long COVID among the medical profession more generally.

NHS 24 said that it was is aware from its staff who talk and listen to people with lived experience of long COVID that many of them say that they would welcome the use of long COVID assessment clinics.

However, most of the substantial submissions provided details of what types of long COVID assessment and diagnostic services are required rather than focusing on where these services are based.

Many respondents called for a joined-up approach to treating people with long COVID to be adopted, which should include Multi-Disciplinary Teams (MDTs) of medical professionals who are experts on long COVID are able to provide assessment, diagnosis and treatments for patients. The point was also made that these MDTs could develop expertise in long COVID and would have up-to-date knowledge of relevant ongoing research studies. The Chartered Society of Physiotherapy Scotland (CSPS) agreed that access to MDTs were essential but it was not clear that this approach was being adopted across all health boards and this was believed to lead to delays in diagnosis, referral and treatment.

For example, whilst not commenting on clinics specifically, Dr Aileen Grant and Dr Nicola Torrance said their research showed a need for long COVID management services with a multidisciplinary team approach and individually tailored care pathways.

The Cheyne Gang - Sing to Breathe commented on the use of long COVID clinics in England as a 'one stop shop' for diagnosis, symptom management and follow up. They said—

> "There are good guidelines for medics from NICE and SIGN but these are not much use if there are no specific Long Covid clinics that people in Scotland can be referred to…Primary and secondary care doctors have to refer patients to varying consultants dependent on their symptoms so many patients end up being seen by respiratory, cardiology, gastroenterology etc and, with the current state the NHS is in, it can take many months to get appointments. "

RCOT noted the potential value of long COVID assessment clinics but felt strongly that these clinics would require a multidisciplinary approach and that it would be essential that clinics included rehabilitation and are not limited by medical model processes. This point was echoed by CSPS. NHS Fife also supported the use of specialist clinics in principle, but said—

> "However, the cost-effectiveness of this needs to be assessed and balanced against other service and health needs to identify the potential opportunity costs. The current pressures mean the workforce may be difficult to recruit and there may be sustainability issues that should be considered."

A lower number of respondents were not in favour of clinics saying long COVID should be assessed and diagnosed by GPs following referrals to specialists to rule out other conditions. Some also argued that the cost of setting up these clinics would not represent efficient use of NHS funding, which they believed is already under extreme financial pressure.

RCGP Scotland argued that long COVID patients should be managed within general practice. It said—

> "However, there are severe pressures in general practice and those with Long Covid may require repeated evaluation. There is some

> variability in direct access investigations available to GPs and outpatient waiting times for specialist evaluation can be long."

RCGP Scotland also said that the shortage of MDT professionals presents a major barrier to the possibility of establishing long COVID clinics. It also questioned whether the long COVID clinics set up in England represented the most cost-effective and appropriate service provision for long COVID patients.

There were also mixed views on the use of long COVID clinics from Stirling University's research study. Those in favour of clinics spoke of providing 'joined-up' care services involving of healthcare professionals, such as specialists in neurology, cardiology, respiratory medicine, physiotherapy, occupational therapy, and psychology. Participants said that this would address the challenges and exhaustion associated with having to repeat recent medical histories in a range of medical settings and the difficulties of accessing appointments.

However, according to their study, some people who had long COVID clinics set up in their area and were not in favour, complaining that appointments were often held remotely, but they would have appreciated the opportunity to be seen in person. Some found their initial appointment disappointing and not useful because they were not offered any further tests, referrals, or follow-up appointments. Some people who were referred to other specialists by the clinic said this meant being placed onto another long waiting list.

Long Covid Kids were in favour of assessment clinics saying they were vital to providing comprehensive long covid services for all ages although noted that the two clinics in Scotland (Edinburgh and Lanarkshire) do not provide services for under 16-year-olds. It called for long COVID assessment clinics in each health board area comprising of multidisciplinary teams of specialists, which should include paediatric specialists. It argued that this would ensure a consistent approach to diagnosis and treatment across Scotland and allow robust prevalence data to be captured.

Moderna Biotech UK argued that the introduction of clinics could ease the workload burden on GPs, enabling them to focus on other patients who require their attention.

Long Covid Support expressed concerns that there was an over-focus on self-management, psychological support, and rehabilitation, resulting in the potential for "watered-down" versions of NHS Long Covid clinics that do not provide thorough physical assessment of patients.

CSPS pointed out that centralised long COVID clinics may not be accessible to everyone, particularly in remote and rural areas.

The Long Covid Rehabilitation in Scotland Study Team highlighted its study of Long Covid Rehabilitation (LOCO-RISE),[2] where many of the people interviewed reported that specialist Long Covid assessment clinics would enable greater integrated holistic care from services and avoid multiple referrals to various secondary care/specialist services. They did say however for this to occur, the assessment clinics would require to be multidisciplinary and have easy referral routes to specialist clinical areas, noting—

> "A single profession assessment clinic would be unlikely to meet the needs of most Long Covid patients."

NHS Fife, RCGP and RCPE all called for an evaluation of the clinics set up in England. RCPE said—

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

Sharing good practice and coordinated approach

There was a general consensus among individuals that there was not the correct mix of services in place in Scotland to help people who have long COVID. In a number of areas examples of good practice were highlighted, such as the work being done by CHSS, but it was believed this good practice was not being shared across all health boards.

CHSS outlined its services to people with long COVID, which provides and advice line to support those with long COVID and works with NHS Lothian to deliver integrated, collaborative care.

Long COVID clinical pathway

Moderna Biotech UK Limited commented that effective referral programmes such as the Long Covid Pathway, a partnership between NHS Lothian and CHSS which could be replicated across the health boards and that further action needs to be taken to develop a national Long Covid Pathway.

Concerns were expressed regarding the lack of clear long COVID medical pathways and associated support systems. Lynsay Gracie's point was typical—

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[2] A collaboration of researchers (Robert Gordon University, University of Stirling, University of Dundee), people with lived experience of long covid, and NHS clinicians conducting a study to evaluate models of service delivery for long covid rehabilitation in Scotland, funded by the Chief Scientist Office

> “Long covid pathways must be developed at NHS Board level that begins with the GP & leads to a multi disciplinary team as well as peer support. “

CHSS argued that a coordinated approach is required with access to multiple specialities for treatment and diagnostics including integrated referrals to third sector self-management and support. On the lack of coordinated care, CHSS said—

> “People living with Long Covid often feel abandoned and frustrated by the lack of coordinated care. They tell us that care is uncoordinated and difficult to access. Furthermore, many people can’t access the vital self-management support they need to live with this chronic condition. “

It called for a national long COVID service saying—

> “a national service is essential. Specialist assessment clinics could be part of this national service, providing diagnosis and coordination between different specialties.”

COSLA and SWS expressed concern regarding the lack of involvement of local government in long COVID service provision development. They said—

> “Local authorities and Integration Authorities are responsible for commissioning publicly funded social care services and have a statutory duty through the Public Bodies (Joint Working) (Scotland) Act 2014 to work in partnership with NHS health boards to deliver a joined-up approach to health and social care services. Despite this, within the current guidance, “Coronavirus (COVID-19): Scotland's Long Covid service” produced by the Scottish Government in September 2021; there seems to be a lack of consideration to the crucial role local authorities play in service delivery planning and workforce capacity to support those with long COVID.”

Claire Jones who leads the Long Covid Service in North Wales outlined their service provision—

> “We provide medical assessment (from advanced practitioners and GP), incorporating a holistic, biopsychosocial approach, with provision of focused multi-disciplinary support for symptom management. Our service also has the ability to request further relevant tests in-house, and to treat or recommend treatment based on symptoms, e.g. treatment of POTS, MCAS and overlapping hormonal symptoms. We co-developed this service with people with lived-experience of Long covid through the development of a partnership groups to ensure we would be developing a service which meets the needs of the population and was accessible. This resulted in us being the first service of its kind to allow patients to self-refer, improving accessibility and reducing workload on primary care. It has been a great success, with around

> 80% of our ~1600 referrals being self-referrals and with low rates of inappropriate referral."

Consistency of service provision

Respondents called for a more joined-up approach to treating those with long COVID. There were also complaints regarding the differing approaches adopted across health boards and calls for a more consistent approach to COVID the treatment of long COVID across all health boards. This point was echoed by NHS 24 who said—

> "People with lived experience have expressed that they feel that there is a lack of co-ordination and consistency in services provided."

Respondents highlighted a lack of consistency in the quality of services in primary care settings and lack of cohesion with secondary care services with no clear defined care pathways for people with long COVID. Long Covid Support called for long COVID medical pathways saying it was essential that there is an appropriately funded strategic framework to ensure consistency of service provision and equality of access. They said—

> "The planning of any such framework must be co-developed with lived experience experts and be informed by up-to-date research and best practice clinical provision."

This inconsistency of service provision was highlighted by Dr Aileen Grant and Dr Nicola Torrance who said their research showed—

> "…there is regional variation in service provision across Scotland. Where long COVID service provision is in place it is often temporary, on short term funding. With little research evidence and often inconclusive diagnostic tests GPs are trying to support patients as best they can, often through trial and error. In some areas people are trying to access specialist services via their GP and facing lengthy wait times, if referred. Other patients have given up consulting their GP as they feel there is little, they can do for them. "

There were many calls for a holistic approach to be taken to the treatment of long COVID by both individuals with lived experience and organisations such as the ALLIANCE and CHSS and Long Covid Scotland.

NHSGGC explained it has adopted a person-centred approach in order to provide a comprehensive interdisciplinary approach to Long COVID services. It said—

> "These services will provide integrated care including assessment, interventions that include various rehabilitation strategies for individuals presenting with Long COVID symptoms. This approach primarily focuses on self-management and supported self management

> pathways condition management programmes, utilising and connecting community and locality resources and supports."

RCOT and RCGP argued for the need for more awareness and support around the benefits of rehabilitation in relation to long COVID. CSPS also argued for patients to receive a comprehensive assessment to establish their rehabilitation needs and to put a holistic, personalised rehabilitation plan in place. RCGP highlighted the need for increased and long-term investment in access to therapies based in the community, such as physiotherapy, occupational therapy and specialist rehabilitation which are important resources for patients suffering from Long COVID. CSPS also called for more investment in community rehabilitation services.
CHSS highlighted that, as a multi system disorder it requires multidisciplinary support and that patients should be offered access to rehabilitation and occupational therapy, as well as further support from specialist secondary care and third sector services.

The ALLIANCE commented that its research showed that the desire was for support to 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."

NHS Ayrshire & Arran said that multi-disciplinary teams are being formed around the country but that it was unclear if planned resources are adequate to meet requirements once fully available to the public. They noted a lack of available medical expertise, other than secondary care routine pathways, to support specialist medical review and investigations.

A number of organisations spoke of the challenges in recruiting specialist staff, which can be a barrier when developing MDT service provision for long COVID patients.

RCGP highlighted the need for increased investment in community mental health services for those experiencing the psychiatric and psychological impacts of Covid-19. Long Covid Support also spoke of the need for mental health support—

> "The National Collaborating Centre for Mental Health (2018) asserted that two-thirds of people with a long-term condition will also have a mental health problem, mostly depression and anxiety disorders. It is therefore important to recognise that people with Long Covid may need support with their mental health but that this is a secondary symptom rather than a primary cause of the disease. "

Harnessing patient experience

Long Covid Support highlighted the need for widespread recognition of the patient expertise of many people with Long COVID who are sometimes more familiar with recent evidence. It said—

> “Health professionals have an opportunity to harness this knowledge, to collaborate and co-produce in a meaningful and respectful way with people with Long Covid.”

A number of individuals expressed concern regarding inappropriate medical advice being given regarding their symptoms. Long Covid Support also made this point in relation to graded exercise—

> “It is imperative that patients are not given unsafe advice around exercise when research indicates that a high proportion of people with Long Covid experience post-exertional malaise (PEM) / post-exertional symptom exacerbation (PESE) and have detectable organ damage. Graded Exercise Therapy (GET) has recently been removed from the NICE guidelines for ME/CFS and many people with Long Covid also meet diagnostic criteria for ME/CFS. Exercise rehabilitation is also cautioned against by the WHO.”

This point was echoed by Claire Jones who said—

> “…advice to commence graded exercise and just ‘push through’ can often lead to an increase in symptoms and deterioration.”

It was suggested that the expertise gained by those with long COVID should be used more widely by the medical profession. A number of respondents highlighted that, given those with lived experience had become experts on their condition through personal research and experience that they should be involved in developing appropriate care pathways.

On a related point, one respondent suggested that a long covid task force should be created within each health board who should consider the experiences of those with long COVID when agreeing appropriate care. Moderna Biotech UK Limited also called for the introduction of a dedicated NHS Scotland long Covid taskforce, as seen in other parts of the UK, which it said would help to coordinate efforts and better understand the condition.

Specialist treatment and diagnostic services

Many of individual respondents and organisations mentioned the lack of access to specialist treatments and diagnostics services with a number specifically referring to a lack of services in relation to postural tachycardia syndrome (PoTS) which was said to be experienced by a number of long COVID patients. CHSS also highlighted that specialist resource to support people living with PoTS is not available in Scotland.

The Long Covid Rehabilitation in Scotland Study Team said it found that practitioners who worked in isolation or in remote/rural settings had less confidence in recognising Long COVID and what their role in supporting these patients could be. The study reported that that having access to others with specialist knowledge and opportunities to share experiences and learning would help their recognition of Long COVID and knowledge of how to intervene. It said—

> “Our study of Long Covid Rehabilitation (LOCO-RISE) in Scotland has found that service models for Long Covid Rehabilitation vary across the country. To date many of these have been dependent on short-term funding and staff availability. This has resulted in considerable variation in professional availability and skill mix. A clear patient need for many in this population relates to mental health support. Yet very few services for Long Covid include mental health professionals or have an easy route to access these services.”

Children and young people

RCOT highlighted an increase in children presenting with post covid symptoms and noted that there is an absence of support available for children and young people. They said—

> “Members report referrals to children and young people’s services with new symptoms post covid ranging from upper limb pain and inflammation impacting on functional tasks, post covid fatigue and chronic pain. This has potential impacts on children and young people’s ability to complete activities of daily living and attend school which may have longer term impacts on development.”

The Royal College of Paediatrics and Child Health (RCPCH) also highlighted that there is no specific service aimed at children and young people in Scotland, noting—

> “Paediatricians have consistently highlighted the lack of services and referral options available for children and young people presenting with symptoms of chronic fatigue syndrome.”

Private healthcare

A number of individual respondents said they felt forced to seek private medical care due to a lack of appropriate services provided by their GP. They also noted that this option was not open to all sufferers given the financial implications.

This was echoed by RCOT who said it members reported anecdotal evidence of individuals receiving improved levels of care and support from private health care providers when experiencing symptoms of long COVID. They said—

> “It is imperative that all of Scotland’s citizens have access to the correct medical support and rehabilitation, regardless of their financial position. Clear guidance and standards of best practice would be beneficial to support health and social care professionals providing services for

> those living with long COVID. This will require the sharing of best practice across locations and sectors.”

Long Covid Scotland also commented—

> “We are also aware of a number of people paying, sometimes when they are already financially struggling, to access private medical care for tests and expertise they have not been able to access via the NHS. This is reflective of the growing health inequalities between people living with Long COVID, with the poorest and most vulnerable often being unable to access the specialist care that has helped those who can afford it.”

Support for people who are supporting or caring for people with long COVID

A majority of responses called for financial support for those people supporting or caring for people with long COVID in addition to more mental health and practical respite care support, as highlighted earlier in this summary.

Financial

The financial implications for those unable to work was commented on my many individuals. Concern was raised regarding sick pay and the fact that many people with long COVID have not qualified for disability benefits and carers allowance.

Concerns were raised regarding the ability to access Personal Independence Payments (PIP), which are designed to help with extra living costs if an individual has both a long-term physical or mental health condition or disability and difficulty doing certain everyday tasks or getting around because of their condition. While some respondents were able to access PIP, a number complained of the complicated application process and there were others who said they could not access the payments at all.

Many respondents, including Aberdeen City Council, called for Carers Allowance and the need for respite both in the form of paid carers coming in on a regular basis as well as overnight and longer breaks.

There were numerous calls for long COVID to be considered as a disability given the debilitating and long-term nature of the symptoms. It was argued that this would offer protection for those people and access to disability benefits.

It was also highlighted by many that applying for benefits was an extremely difficult process, which was not made any easier by long COVID symptoms, such as ‘brain fog’ and difficulty with concentration. CHSS also commented on the lack of workplace support and the difficulty in accessing benefits to support people living with Long COVID.

The Cheyne Gang - Sing to Breathe commented—

> "Many employers are woefully unaware of the impact of Long Covid on patient's health and many people have lost their jobs as a result. There is also little in the way of benefit support for sufferers as their condition is not recognised in the same way as a Long Term Condition (LTC) like chronic obstructive pulmonary disease (COPD) or clinical depression might be so people are unable to access benefits when they are off ill or have lost their regular income."

A large number of respondents argued for long COVID to be recognised as a disability under the Equality Act. ASLEF called for the government to recommend a best practice guidance for employers which outlines that long-COVID can be seen as a disability under the equality act and outline the need to find reasonable adjustments for employees with long-COVID before taking any further action. NASUWT also made this point.

Long Covid Support argued that many people with Long COVID qualify as disabled under the Equality Act 2010 definition, yet they are struggling to receive appropriate accommodations or to access disability benefits. It noted that in other countries Long COVID has been recognised as an occupational disease, a point raised by other respondents.

Families

The ALLIANCE said commented on the 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. They recommended that such support is co-produced with unpaid carers, families and people with lived experience.

Long Covid Kids spoke of the lack of support for children and families with long COVID in the following areas—

- 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.

They said they were unaware of any families in their support groups that have been able to successfully access social care support, although some families have identified a clear need for it. In addition, they also highlighted the difficulties associated with accessing financial support, saying—

> "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."

For those families with children with long COVID, RCPCH Scotland recommended that support should be holistic with the child and family at the centre. It said that additional support should include support groups for a range of ages and the use of social prescribing should be considered to allow young people to attend activities that support their recovery.

The use of supports groups which have been set up by those with lived experience was praised by many individual respondents as a great source of mental health support and information on the condition. A number of respondents called for a helpline telephone number which people could call for advice and support.

RCGP Scotland said it witnessed the significant burden placed on some carers and supported efforts to improve support for carers of people with long COVID saying they should have the same rights as other carers. It called for further research into the specific or unique challenges faced by carers for those with Long COVID, which could be helpful and assist with the provision of effective holistic care for those suffering from the condition.

CSPS said a 'once for Scotland' approach is needed to produce a resource pack to support those caring for people with long COVID.

NASUWT said it is clear that being absent from work with Long COVID is having a substantial and detrimental impact on teachers' finances. Additional financial support for those caring for people with Long COVID would be beneficial. Equally, those undertaking a caring role will also require signposting to appropriate health, wellbeing and mental health supports.

Study and research

Individual respondents called for more research into the causes of long COVID and for biomedical research into diagnosis possible treatments. For example, Sarah McDonald said identifying potential treatment targets and testing therapies should be priorities for research and study. She said—

> "There is already sufficient evidence to justify initial studies on treatments for mast cell activation (H1 and H2 antihistamines), anticoagulants (in some cases) and treatments for autonomic dysfunction. There is potential to better understand known conditions and their treatment. For example there is some evidence available for POTS but it has major gaps, particularly when it comes to early intervention and potential resolution given average time to diagnosis pre-covid for patients with POTS was 5 years. By this time 85% of patients had been told their symptoms were caused by anxiety so the attrition rate of patients who either recovered before diagnosis or gave up seeking help is likely high. Given the massive increase in POTS patients post-covid and the fact most are early in their illness or

> currently undiagnosed there is potential to learn about early intervention and track recovery in a way that has not been possible before.”

There were many suggestions of areas for future research and study, for example, Dr Janet Scott suggested the following areas for further study and research into developing diagnostic techniques and imaging e.g., Xenon Gas MRI and ImmunoPET and into treatment strategies.

Some of these points were also raised by the ALLIANCE who highlighted that respondents to its survey 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.

A number of individual respondents called for research into the parallels between other conditions, often displayed in long COVID patients, such as ME/ CFS/ PVFS/MCAS. #MEAction Scotland commented that emerging research suggests that more than 40% of people with long COVID are meeting the criteria for ME.

There were a number of calls from individuals for specific research into the presence of microclots in patients with long COVID and pointed to research being carried out in other countries including Germany. CHSS said—

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

There were also calls for further research into understanding the effectiveness of rehabilitation services. RCPE also called for more research into understanding the mechanisms leading to long COVID and potential drugs, which may impact quality of life.

There were a number of calls for further research into the impact of long COVID on children and young people. Stirling University suggested this could include a comparison of experiences by age, gender, social class and ethnicity to identify where interventions could be focussed.

NHS Fife and RCOT also identified a lack of research or guidance on the impact of long COVID on children and young people. This point was echoed by Long Covid Kids who recommended ‘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.’ COSLA and SWS also commented on this saying—

> “Further research is required to determine the long-lasting effects of the condition on young people, however, common symptoms relate to fatigue, anxiety and depression. Long COVID could result in loss of education through extended absence and impact on mental health welfare during this time. This may impact on local authorities' educational services, including mental health support and funding requirements for in-school counsellors, if those with long COVID require additional support.”

A number of respondents spoke of the prevalence of long COVID in women including #MEAction Scotland and University and College Union Scotland. The Scottish Women’s Convention said that as women are more likely to be carers for those people with Long COVID there should be more research into the gendered aspects of long COVID saying—

> “Due to the prevalence of women working in health and social care, as well as making up the majority of retail and hospitality workers, women were more likely to contract the COVID-19 virus. It is, therefore, vital that future study and research into the impact of COVID considers the gendered element of the virus, and if women are more likely to experience long COVID as a result.”

NASUWT also commented on the fact that women aged between 35 and 69 are most likely to experience Long COVID and that some racial or ethnic minority groups and people with disabilities can also be at greater risk for developing post-COVID conditions. It said—

> “Counter-intuitively, the ONS figures show a much lower prevalence rate in non-white populations, which is illogical, given the higher impact the virus has had on Black people. This suggests significant underreporting in Black people. It is essential that study and research into Long COVID takes an intersectional approach and considers impact by protected characteristic.”

Stirling University called for further research in a number of areas including how experiences of Long COVID vary by factors such as ethnicity, socioeconomic status, gender and age, and exploring how inequalities can be addressed through interventions.

Dr Aileen Grant and Dr Nicola Torrance called for further research into the impact of health inequalities and deprivation on people effected by long COVID. They said—

> “…these people were disproportionally affected during the pandemic: relative deprivation was associated with higher rates of infection and mortality due to Covid-19. Evidence suggests there is likely to be unmet need in more deprived areas.”

NHS Fife also called for further study into understanding impact of co-morbidity and inequalities.

British Association for Counselling and Psychotherapy (BACP) called for more analysis of the psychological impacts of Long COVID, upon both those with Long COVID and their families and support networks.

Jill Austin suggested research into the co-occurrence between long COVD (and ME/CFS) and neurodiversity (ADHD/autism) and research into the link between long COVID and menopause. The need for research into the overlap between symptoms of menopause and perimenopause and Long COVID was also highlighted by Claire Jones.

Data

Many respondents spoke of the lack of data on the prevalence of long COVID across Scotland, including COSLA and SWS. Stirling University found that there was insufficient data publicly available on the prevalence of long COVID in Scotland and RCOT and RCPE said that clear data should be made public on this which should include demographic data on those most affected. Dr Aileen Grant and Dr Nicola Torrance noted—

> "…there is very little publicly available data on the prevalence of long COVID in Scotland (although we are aware that there are large data linkage studies underway)."

A number of respondents commented on the usefulness of the ONS data, including CHSS, NHS 24 and NHS Fife. CIPD noted its limitations, explaining—

> "The experimental dataset published monthly by the ONS provides a good indication of the longer-term trends around long COVID. However, it does not allow Scottish policy-makers more granular analysis of the prevalence of long COVID among different age groups, differences in reported symptoms or any differences by industry and sector. That being said, it is unlikely that these would be significantly different in Scotland compared with the UK-wide breakdowns, which the ONS provides. "

NHS Fife, on the ONS data and Scottish Health Survey, explained the limitations of both these estimates arise because they are from a sample of the population (so may not be representative) and from people who have self-reported having Long COVID. It noted—

> "More robust population-level estimates will be available through the EAVE II study, which will draw on GP records to estimate the prevalence in Scotland. However, the study excludes children. Another limitation of the data will be that it only captures those accessing health services."

Dr Janet Scott highlighted that she was undertaking research on long COVID prevalence, and, although true prevalence is difficult to calculate, she expects to publish the results soon.

Coding

A number of respondents believed that cases of long COVID were not being coded correctly within primary care settings and considered that some GPs are reluctant to diagnose long COVID. Dr Aileen Grant and Dr Nicola Torrance noted—

> “There is a need for robust epidemiological data on the prevalence of long COVID and for awareness of the need for coding in electronic health records.”

There were numerous calls for a requirement on GPs to log long COVID to help ascertain its prevalence. NHS Fife said there has been a variation in how long COVID is coded in primary care, which could lead to under reporting in figures drawn from medical records.

NHSGGC commented that the National Strategic Network recognised the challenge of the available data due to current systems and the inconsistent use of SNOMED coding and prevalence data within Scotland. Concern around the lack of appropriate coding by medical practitioners of long COVID cases was echoed by many individual respondents.

To improve the availability and accuracy of data, Long Covid Kids recommended improving awareness and application of standard medical codes for Long Covid in NHS patient databases and improvement of search functions on medical databases to facilitate efficiency in correct coding practices.

NHS 24 said it heard that there is a lack of central sharing and collaboration between different professional bodies in relation to long COVID research data and that there was no clear route for individuals to participate in research, and to include lived experience as an integral part of research and shaping research priorities.

COSLA and SWS stated—

> “It is important to note that any request for data collection should, where possible, connect to the existing data being provided by local authorities. Data collection must be appropriate, consistent, and proportionate. A data strategy for health and social care is due to be jointly published by Scottish Government and COSLA will support the consistent use of data across health, social work and social care.

Committee clerks
Scottish Parliament
6 March 2023