

## **Scottish COVID 19 Inquiry**

### **Witness Statement of Jane Ormerod, Long Covid Scotland**

1. My name is Jane Ormerod, and I am 67 years of age. I have provided my home address and personal details to the Inquiry for their records. I currently reside in Aberdeen.
2. I retired about 10 years ago from NHS Grampian. I was a cardiac care nurse, and then moved onto being involved in clinical education and a nurse teacher.
3. I became a self-employed coach facilitator and was involved in volunteer work for around 5 to 6 years.
4. I contracted COVID at the start of the pandemic and in June 2020, I was diagnosed with long COVID. I suffer from it to this day. I had difficulty in even getting a diagnosis in the beginning and had to fight to get one. I felt dismissed and minimised by GPs and access to healthcare was extremely difficult. My experience was one that resonated with many of the long COVID sufferers I have met to date.
5. I am happy to speak today with witness statement takers from the Scottish COVID 19 Inquiry Team and consent to my statement being contained in any reports prepared by the Inquiry and for it to be published.
6. I am happy to provide Oral Evidence if required and have availability throughout 2024, with the exception of July as I have a family wedding.
7. I am currently the Chair of Long COVID Scotland. I joined LCS (Long COVID Scotland) in September 2020, became more involved and was appointed Chair early on in 2022.
8. As Chair, I coordinate and facilitate the LCS Board meetings and organisational activity. However, the Trustees have a shared responsibility for all LCS activity. Decision making about Long COVID Scotland business is a shared activity.
9. Generally, I lead the representation for LCS with meetings with other stakeholders. However, other Trustees may do so as required. Currently with the vice chair we oversee finance activities. We aim to appoint a Treasurer to the Board as soon as we can.

### **Overview of Long COVID Scotland**

10. Long COVID Scotland is a volunteer-led charity run by people living with Long COVID on behalf of those living with Long COVID. We are advocating for rehabilitation, research and recognition for people with Long COVID living in Scotland.

11. It started off as a Facebook group called Long COVID Scotland Action Group with people looking for answers, support and how to best organise themselves. The work that we do is primarily focused on campaigning and advocacy. We are not a support group as such. We will certainly signpost people to support groups and give them direction in relation to advice or counselling services. We are mainly an action and advocacy group and provide peer support to each other. We do not offer support to individuals on a smaller scale. We would require more volunteers to be able to offer individual support. People were having to try to find out where to access services themselves as they had very little information. So, we began to advocate with a view to get ourselves heard by Scottish Government. We split ourselves into action groups in order to facilitate this. Initially these action groups were focused on employment, research, advocacy (comms and media) and volunteer support. The creation of the action groups was more to organise ourselves as it is easier to ask a volunteer to assist with a specific area than to ask for general help.
12. We also collectively advocate on employment and benefits, research and local and national policy. Originally established in 2020, we initially started at the same time as **Long COVID Support**, a successful English charity and campaign with over 55,000 members, represented at Independent SAGE, the ISARIC global research forum, and the All-Party Parliamentary Group on Coronavirus. We looked at the practices of Long COVID Support in the early days and forged good links with them. We continue to do that until this day.
13. We have around 826 members in Scotland, who are involved in doing various tasks in respect of our online action groups. Some of those action groups assisted us in carrying out surveys around employment and impact of the pandemic, which I will refer to later in my statement.
14. Since our inception in 2020, we have worked to establish partnerships with various organisations, including Scottish Government, Health and Social Care Alliance Scotland, Chest, Heart, and Stroke, along with researchers from several UK universities.
15. Later in 2020, Long COVID Scotland had a Trustee/Steering group and four subgroups focusing on advocacy, employment, research and volunteer support.
16. We met with NHS National Health Services Scotland (NSS) pre and post the Long COVID summit in 2021. We wanted to be at the table with them to discuss what services would be available, development and provision there would be for LC sufferers.
17. National Services Scotland provide services and advice to the NHS and wider public sector. Within NSS we communicate mainly with Clinical priorities / Clinical quality Improvement about a number of things e.g., if we want to

meet with a minister, which we have done on several occasions. We did initially 2020/21 have regular meetings with the minister for Health we do not currently. The focus on meeting is to discuss the funding of and provision of care and services for people with Long Covid.

18. The LC Summit in 2021 was an example of an early event we organised to feed into discussions with Scottish Government about problems that people with Long COVID were having, particularly in accessing services. We have a diagrammatic representation of that and what the objectives were, if required.
19. Additionally, we worked with supportive partners to create a Scottish Cross Party Parliamentary group on Long COVID with meetings 3 times a year looking for example, at issues around employment, education and treatment for those with Long COVID. Three MSPs co-chair the Group and LCS provide the secretariat.
20. Since September 2022, we have been a registered charity (**SC052053**). The organisation is currently led by a Board group of seven Trustees, who all have Long COVID, with two elected office bearers. More recently we have become a formal membership led organisation and have just held our first AGM. It has allowed us to be better placed within the third sector and to advocate for rights.
21. We have 187 people registered with our charity as members, at the moment. Being registered with the charity provides people within it to have voting rights at our AGM and on any relevant matters we discuss.
22. Long COVID Scotland do not receive any funding at present and do not have a particular part of Scotland that we support. I would say that we probably represent more women than men, aged between 35 and 65 years old as a demographic. We do not have any statistics for that though.
23. Since 2022, the steering group has become the Board. A reduced manpower availability has also meant we have reduced the number of subgroups to one active subgroup – advocacy and comms. We realised that we did not have the manpower to actively work on all the areas within the action groups so we reduced our focus.
24. Both the board and subgroup group are populated by volunteers from our 826 strong membership bases from across Scotland. Most volunteers have Long COVID, just 2 members do not.
25. Advocating for those with Long COVID has been and continues to be our purpose and passion.
26. Unfortunately, during the pandemic for those who developed COVID, their experience of care provision including rehabilitation, was mixed. Some went

on to recover fully, some went on to develop Long COVID. For the most part and for various reasons, many of those people experienced 'not being heard', when seeking access to appropriate diagnosis, care and treatment.

27. Since Long COVID, in some instances may become a chronic illness, this experience sadly is not a new one. Many people with chronic illness face the same challenge.
28. Through our communication and connection with our members at Conversation cafes and through subject polls/surveys on our social media group, we continue to inform our workplan and validate our purpose. The Conversation cafes were a very useful way to get to know our stakeholders and members.
29. Our members are very clear about what they want; "people with Long COVID need to be listened to and lived experience needs to be at the heart of solutions". We need space and structures to be created so we can inform processes and action, for example a stakeholder panel".
30. We aim for those with Long COVID to be recognised and heard: For Long COVID-informed care: All patient services for investigations, care and rehabilitation must be co-produced with people with Long COVID to better meet their needs. Equitable patient and public involvement (PPI) are also required: As with the design of medical services, people with Long COVID need to be involved in research from its onset, regardless of background, test status, and whether they have been hospitalised, or not these people may have unique pathology and experiences which can inform future treatment. We also seek and help to develop better information for employers, unions, and universities. We are informed by patients, on how to support people returning to or starting work and study.
31. Since 2021, we have worked with several stakeholders to advise and contribute to the development of long COVID Services. In September 2021 the Scottish Government produced the document 'Scotland's Long COVID Service'.
32. The document aimed to achieve the provision of clear information for people with Long COVID at the right time' ..... to 'help people to feel more in control of their condition, and live their lives better, on their terms'.
33. A range of person-centred support and care services delivered by the NHS, social care and the third sector were proposed for people with Long COVID. Some of the services were already in existence and there was an aim to integrate new and existing services.

## **Long COVID**



34. In early 2020, the first cases of COVID-19 were reported in the UK. Quickly, concerns were raised about the spread of this new infection, its severe health risks, the rising numbers of people hospitalised, particularly in intensive care units, and loss of life for many people. Despite the high number of people hospitalised, Government advisors said there was an expectation that most people would experience milder symptoms and could expect a full recovery. However, by the summer of 2020, people started to report longer-term health problems impacting their daily lives. As numbers increased, the term long COVID became widely used to describe these experiences of longer-term illness.
35. Long COVID is defined by the World Health Organization as a condition that occurs in individuals (adults and children) with a history of probable or confirmed SARS CoV-2 infection. Diagnosis is usually three months after the onset of COVID-19, with symptoms that last for at least two months and cannot be explained by an alternative diagnosis.
36. We now understand that long COVID can affect multiple organs and systems within the body, including respiratory, cardiovascular, neurological, gastrointestinal, and musculoskeletal systems. Common symptoms include fatigue, breathlessness, and cognitive dysfunction. Symptoms may also be new following initial recovery from illness. People experience fluctuations and relapses of symptoms that majorly affect everyday life.
37. We need to recognise that the people most impacted by an illness often struggle to have their stories heard, validated, and understood. Consequently, early in 2022 Long COVID Scotland undertook 2 surveys. The first looked at the **Impact of Long COVID**<sup>1</sup> on people's lives. The second looked at **Issues with Employment for people with Long COVID**.<sup>2</sup>
38. Long COVID Scotland also recognised the importance of co-produced, lived experience citizen research. We invited members to discuss the questionnaire design to effectively evaluate the impact that long COVID was having on people's lives. This identified several areas to explore. How did people experience illness? Were they tested for COVID-19? What symptoms do people experience? What has been their experience of healthcare services, and what are the broader impacts of adjusting to a long-term condition?
39. We recognised that asking people living with long COVID to complete a lengthy survey can add to the fatigue they experience. But we felt it was important to give people an opportunity to say what was most important for them about the experience of long COVID. We also suggested that people complete the questionnaire in stages to avoid fatigue. The questionnaire was open for four

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<sup>1</sup> <https://docs.google.com/document/d/1bDA4HxXCofJLHaq9QXUT-cng6puYAjL8SlxEBfUITA/edit?usp=sharing>

<sup>2</sup> <https://drive.google.com/file/d/1w-w8p8A1fP1hIUxbgOWDPJ-FQova-uZN/view?usp=sharing>

weeks in March 2022. A total of 225 people responded to the online questionnaire. Three people did not complete the questionnaire as they lived outside of Scotland, and 222 people completed the questionnaire.

40. 225 people responded to our **Impact on Lives**<sup>3</sup> questionnaire, including parents of children and young people suffering from long COVID. Some of those direct messages are included in this statement. The final survey report is made up of the voices of people living across Scotland from various backgrounds wanting their voices to be heard.

### **Analysis**

41. Long COVID Scotland asked for volunteers from our group to take part in the analysis and write-up of the final report. Taking a thematic approach, each volunteer took a section of the questionnaire to do a first analysis.
42. With 225 responses, including a large amount of free text, there was much information to read. Throughout the process, it was essential to let the personal voices come through in identifying themes and developing the narrative of how we experience long COVID in Scotland.
43. The opening question invited people to say, in their own words, what was most important to them? 172 people answered this, from a total of 252 respondents. From these statements, common themes have been drawn out, building a narrative of long COVID.

### **Our Experience of Long COVID symptoms**

44. In October 2022, the Office of National Statistics (ONS) estimated that 2.3 million people (3.5% of the population in the UK) self-reported long COVID symptoms. Proportionally this could mean at least 175,000 people in Scotland are living with long COVID. Almost three-quarters (73%) of people reported symptoms lasting at least 12 weeks and nearly half (44%) had symptoms more than a year after first becoming unwell.
45. People living with long COVID reported a wide range of cyclical or constant and multi-systemic symptoms, leaving them disabled and debilitated.
46. Commonly, people reported breathlessness, fatigue, cognitive impairments, chest pains, palpitations, joint and muscle pains, sleep problems, skin conditions, upset stomachs and diarrhoea, altered sense of taste and smell.
47. Symptoms often fluctuate and vary in severity, with people reporting that cognitive exertion or physical activity, infections and stress seem to have

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<sup>3</sup> <https://docs.google.com/document/d/1bDA4HxXCofJLHag9QXUT-cng6puYAjl8SlxEBfUITA/edit?usp=sharing>

a negative impact on the severity of the symptoms they were experiencing. As a multi-system illness, symptoms can manifest anywhere in the body.

48. The relapse and remitting nature of system-wide symptoms can cause confusion and misunderstanding, adding to the invalidation for people living with long COVID.
49. The experience of trying to understand and manage a myriad of complicated and fluctuating physical symptoms severely affects people's physical and mental health and all areas of their lives, often putting a strain on their relationships with loved ones and friends. Justifying, explaining, and trying to get symptoms recognised and validated is a big part of people's experience. In seeking treatment or support, people spoke about problems accessing appropriate healthcare, being misunderstood by family or friends, and feeling under pressure from employers to say when they would be well enough to return to work.
50. Almost half of the people who completed the survey said they felt they contracted COVID-19 during the first wave before community testing was available. For some, this seemed to increase their difficulties accessing services or receiving support through employers because they can't prove they ever had COVID.
51. Some symptoms are widespread in the first few months of long COVID. In our study, we found 26 symptoms experienced by more than half of all people responding. Eleven of these symptoms were shared by at least 75% of people, with the top five symptoms being almost universal.
52. Symptoms experienced by more than 75% of respondents showed that many had shortness of breath, brain fog, extreme tiredness and fatigue, feeling tired after cognitive exertion, muscle aches, post exertion malaise, difficulty sleeping, chest pains, irregular heartbeat, joint pain and anxiety.
53. Other common symptoms in the earlier stages of long COVID included tachycardia; depression and low mood, coughs, pins and needles; unexplained sweating or chills; sore throats; altered sense of smell or taste; feeling dizzy or faint; lower back or kidney pains; nausea, weight gain, changes to vision and abdominal pains. 50-75% of people completing the survey reported each of these symptoms.
54. Other symptoms, including speech and language impairments, skin conditions, hair loss, urinary problems, confusion, tinnitus, persistent fever, and weight loss, were experienced by at least 1 in 4 people.

### **Changes and Fluctuations over time**

55. We know that characteristic of long COVID is a pattern of 'fluctuating' or 'relapsing and episodic' symptoms. Fluctuations can often occur within a few



hours or over weeks and months. Other research found that people living with Long COVID sometimes characterise their experiences as unpredictable in nature.

56. However, we also found that the five most reported symptoms were also reported to be the most persistent symptoms: tiredness and fatigue; brain fog and memory impairment; tiredness after cognitive exertion; post-exertional malaise and breathlessness. These constant and ongoing symptoms cause problems for 3 out of 4 people living with long COVID.

57. This does not mean that other symptoms became any less significant over time, and many symptoms continued to be experienced by more than half of all people. Including physical symptoms such as muscle aches, joint pains, headaches, and migraines; chest pains or tachycardia continue to be reported by more than half of people.

58. *"I'm concerned about my brain function, I still forget people's names, leave pots on hob, etc."*

59. There is a significant impact on mental health and well-being, with more than half of people saying that they have developed ongoing symptoms of anxiety and depression. This may result from living with persistent physical symptoms for so long.

60. In our survey, over 50% of women also said they experienced flare-ups or worsening symptoms with their menstrual cycle or menopausal symptoms since developing long COVID. Symptoms included experiencing irregular periods, unusual clotting, worsened premenstrual syndrome (PMS) and an increase in the severity of their long COVID symptoms around the time of their period.

61. Some long COVID symptoms of fatigue, heart palpitations, sweating, and sleep disturbance are also associated with perimenopause and menopause. Not recognising that symptoms could be similar, or overlap could lead to diagnostic overshadowing or misdiagnosis leading to a missed opportunity to provide treatments.

62. For women, there is an urgent need to better understand the inter-relational relationship between long COVID and their reproductive health to develop treatment plans and to reduce further risks to women's health.

### **Survey Themes – Long COVID Impact on our Lives**

63. **Demoralised by illness:** Long COVID's impact on people's lives cannot be ignored or underestimated. People commonly talk about how the devastating and debilitating symptoms of long COVID affect their quality of life. The lack of treatment, adjusting to the uncertainty, worries for the future, and the lack of

understanding and support have made people feel demoralised and disheartened as they face an uncertain future.

64. One of the quotes are: *"It has devastated my life in all areas. I feel unsupported by the mediccpoal and welfare communities. It has been a heart-breaking battle to receive any assistance. I have been unable to return to work since becoming unwell in March 2020."*

### **Impact on our working lives**

65. Many people living with long COVID of working age, were employed before the pandemic. Illness has led to long-term sick leave, reductions in income, reduced working hours, and many leaving employment altogether. Where people have been able to return to work, employers have needed to adjust work settings and routine to provide additional support, which for smaller employers can be costly. However, our members were also experiencing financial difficulty One of the quotes are: *"I'm lucky I've been able to return and that I got sick pay. But it is very difficult fitting work back into a life that is changed beyond recognition. I am up to 15 hours a week as part of a very phased return and on the brink of relapse daily"*.

### **The impact on family life and relationships**

66. When someone has long COVID, it significantly affects other household members and the broader family. We hear people talk about how illness has changed family life. How they cannot tidy the house, do things with their children, or enjoy leisure activities. Added to this were emotional pressures, strains on relationships and dealing with financial pressures, particularly if work has been affected. There are no specific benefits for anyone with Long COVID at present. We want to be recognised as a group with a disability in order that this can change.

67. One of the quotes are: *"I went from being a very active Mum of two, running my own business, to barely able to leave my house. Long COVID has impacted so much of my life. I had to shut my business down, couldn't do any active things that I previously enjoyed, and couldn't even do normal jobs around the house for a very long time. It affected my mental health, but more so the mental health of one of my children, who wanted real Mummy back."*

### **Long COVID and children**

68. There is still an incorrect belief that children are mainly unaffected by COVID. However, evidence is increasingly showing that many children with symptomatic and asymptomatic COVID-19 experience long-term effects months after the initial infection. We have heard parents describing the

devastating impact on their children and the frustration among parents of the lack of support from doctors or education services.

69. One of the quotes from a parent are: *"She is now unable to attend school in person due to her symptoms. She is now unable to access online school due to the cognitive and Neuropsychiatric symptoms which have completely disabled her ..., 2 years in and we've only had one CAMHS appointment and 2 physio appointments or simply inaccessible. There is nothing for children."*

70. Experiences of long COVID can lead to social stigma. Public attitudes toward long COVID remain ambiguous. Misconceptions or misrepresentations of people living with long COVID have led to many people experiencing social stigma and discriminatory behaviours. This can lead to feelings of isolation, stress and anger for people living with long COVID.

71. One of the quotes that reflect this is: *"It's also been a complete eye-opener with regards to the behaviour of family, friends, and the U.K. public. It has caused me very much stress, frustration, and sheer anger at the refusal of people to get vaccinated and the 'it's just a 'cold' brigade."*

#### **Need for better public health messaging.**

72. People with long COVID have been demoralised by poor Public Health messaging. The belief still exists that COVID-19 is mainly a short-term respiratory, flu-like illness. There is a need to address the belief that only people with underlying health conditions can experience long COVID and that anyone can develop long COVID.

73. Some of the quotes that supports this are: *"The community at large remain unaware of long COVID, and this is worrying, I feel let down by the Government who show no urgency in providing help" and "Do they even believe me? 'You look great!' they say. I'm a single parent so the only income I have is my income. I can't do things with my son, and it breaks my heart. I feel so guilty. I have felt so alone at times."*

#### **Living with a myriad of unpredictable symptoms**

74. Long COVID presents as an extensive and "perplexing mixture of symptoms." These can last months after having a confirmed or suspected case of COVID-19. Symptoms can affect your whole system, with symptoms coming and going, new symptoms developing, and people experiencing unpredictable fluctuations and relapses over time with no real treatment plan.

75. One of the quotes to reflect this is: *"So many bewildering symptoms. You may get used to one kind of group of symptoms and how to manage them, when*



*others pop up. There are so many layers to this condition. Debilitating, depressing - it's a very lonely condition"*

### **Recognising the chronic nature of long COVID**

76. Long COVID is a complex multi-system, long-term, and life-changing illness. There is no known cure or commonly understood sickness duration; however, research suggests that it can last for months or even years. Some people have not recovered two years after the pandemic's start. These people carry the longest burden of illness, many of whom continued to provide essential frontline services after lockdown restrictions were announced.

77. *One of the quotes reflecting this is: "I will be 2 years in on 14 March. I know this is a new virus but to still not have a treatment plan in place or any idea of whether I will recover fully - it's not acceptable. I feel I have been abandoned by the medical profession, even where they have been sympathetic".*

### **Problem accessing care and treatment through GP**

78. People with Long COVID often report frustration at accessing care and treatment through GP practices. It can feel like a lottery whether their GPs understand long COVID, with many people saying that they felt let down by their GP practice. One of the quotes reflecting this is: *"My GP has no answers. Test after test after test - normal; 'so that's reassuring' they say. Is it? Feeling like this but there's no apparent cause? Like I am having a heart attack? I'm terrified, not reassured."*

79. There was a delay in supplying fully funded and informed care. On 9 September 2021 the Scottish Government announced a £10 million three year Long COVID support fund.

80. This currently equates to around £16 per person. During the period the Inquiry is covering, many of the boards did not deliver Long COVID care from this resource. During the period of the inquiry and after, additional difficulties were faced by health boards due to the non-recurring nature of funded posts resulting in health boards not using all of the budget allocated to them. This impacted our members in actually accessing care and was symptomatic of the current funding arrangement for Long COVID clinical services being scaled appropriately (Then and now).

### **Increasing GP understanding**

81. In Scotland, the current healthcare pathway for long COVID treatment is through the patient's GP and Primary Care services. There is a need to improve understanding of long COVID and develop more robust treatment pathways, including improving access to hospital-based specialist services.

82. One of the quotes to reflect this is: *“Long COVID feels progressive and totally debilitating, and a life-changing illness. Clinicians and GPs in Scotland need more training to support us”*

### **A systematic approach to investigations**

83. Currently, there is no objective diagnostic test for people with long COVID. This can be problematic, particularly for long-haulers who may not have had a positive COVID-19 test result to receive a diagnosis. Repeatedly we heard people saying that clinical tests they had been sent for were inconclusive or showing results within a normal range, causing patients to question whether they were being believed.
84. One of the quotes are: *“It is important that GPs and medical practitioners are very aware of LC and all its varieties of presentation and effects on organs and that the basic tests do not show its existence but that it is a real physical response to having had the virus. It may be invisible in some tests, but it is there. No one wants to prolong illness.”*

### **Improving care and treatment pathways**

85. The multi-systemic nature of long COVID requires thorough investigation and access to appropriate specialist services. However, very few people said they received ongoing specialist care and treatment. There is a need for all patients to receive a long COVID holistic assessment of their physical, cognitive, psychological, and functional abilities so that they can be referred to the right specialist help.
86. One of the quotes are: *“Lack of referral pathways in the healthcare system. My GP tried to refer me to cardiology, respiratory and infectious diseases but they were refused because I am non-hospitalised long COVID. To get referrals taken I had to get on the front page of a national newspaper then referrals were magically accepted and fast-tracked.”*

### **Exploring the value of alternative therapies**

87. Many people have found support in various alternative therapies accessed privately, often not offered, or prescribed by the NHS. People have reported the positive benefits of alternative and holistic treatments on their symptoms and well-being. However, there are also concerns that people can become victims of ineffective or dangerous remedies promoted through the internet out of desperation.
88. One of the quotes are: *“I discovered a treatment that helps- oxygen therapy. Not one of the many clinicians I’ve seen even mentioned it, not even the ME/CFS clinic. ‘Not enough evidence to support it’. Mindfulness does not work for me yet was repeatedly pushed as if a cure for*



*everything. At times I feel I've been blamed for not getting better. That I'm not trying hard enough. Not explicitly, but subtly."*

### **Let down and disappointed.**

89. Many people with long COVID have expressed dissatisfaction with the Scottish Government's response to long COVID. Many of the people we heard from expressed dissatisfaction, abandonment, and feeling unsupported and unheard by the Scottish Government.

90. One of the quotes are: *"I sit at home all day wondering 'who cares! This is an international issue. Why are those suffering having to fight so hard to be heard, the medical community and Government should be driving this. It could be any one of them who suffers this awful condition next. Some days I wonder how I can go on existing like this and wonder if any one of those lucky to have avoided long COVID after their infection would like to walk in the shoes of any one of us suffering from it for even a day"*.

### **Underlying Health Conditions and Long COVID**

91. The media anti-vax campaigners and poor public health messaging have created a myth that only people with underlying health conditions or disabilities are affected by long-COVID. We know from the many personal accounts that long COVID has destroyed the lives of people who previously had healthy and active lives before contracting COVID-19. In the survey, almost two-thirds (6%) of people reported that they had no underlying health condition or disability before contracting COVID-19.

92. One of the quotes are: *"COVID has affected every part of my life for the worse. From being a fit & healthy professional geologist working around the world, an ultra-runner, with an active social life and a regular volunteer, I was too ill to work at all for over a year, and I'm now only well enough to work half time from home, my income has reduced, and my long term employment depends on my employer continuing to enable me to work remotely, which I have no guarantee of"*.

### **Our experiences of accessing health and social care**

93. Scotland has not invested in Long COVID Clinics. Instead, the treatment pathway advocated by the Scottish Government is through GP practices and Primary Care. The Scottish Government have said: *"Our response to long COVID depends on having a range of well-integrated sources of support, given the wide spectrum of needs that people affected can sometimes have. This range of support is already being delivered by our NHS, social care and third sector across Scotland. We have an approach in place that will strengthen the range of support available within the primary care setting, providing a person-centred response with referrals to secondary care where necessary"*.

94. We found the reality for most people who responded to be very different. Months after becoming ill, people described deep frustrations with primary healthcare and access to secondary specialist services.
95. People described feeling ignored, disbelieved, or not taken seriously by their GPs. This, in many cases, included doctors refusing to give a diagnosis of long COVID, particularly where the person had not tested positive for COVID-19, usually because testing was not available when they first developed symptoms.
96. Others have said that whilst GPs have been sympathetic, their knowledge of Long COVID and what secondary care services are available are limited. Some quotes are: *"I feel let down and forgotten"* and *"Most management techniques have been learnt from patient groups/ private consultants (where the NHS would not run tests or prescribe medication) or self-taught."*
97. Long haulers struggling with complex symptoms including fatigue, pain, tachycardia, and 'brain fog' often said that they felt that symptoms were dismissed or minimised, being told "you have to expect that" with minimal investigation done despite the severe impact these long COVID symptoms are having on the person.
98. Where people reported having had tests and investigations, most were carried out in primary care settings. Commonly these included blood tests, urine samples and liver and renal function tests. Some reported having been sent for chest x-rays or ECGs, with the results going back to the GP. However, results came back as "normal", often with no follow-up to secondary care services.
99. Over the last year, research has found some tests that may be beneficial, such as micro-clot testing. In the UK, testing for micro-clots is not available on the NHS, and nobody in our survey reported having had a micro-clot test. There is no consistent diagnostic pathway for long COVID, and some health professionals are unaware of how to proceed with the appropriate investigation. Even if patients are referred for investigation, it does not mean they will be seen by a specialty or seen quickly; several people reported waiting months after a referral has been made.
100. Some people report having had to turn to accessing private healthcare. One quote in relation to that is: *"Forced to go private and taking out a loan, I am seeing a cardiologist very soon and tests (echocardiogram, MRI) will then follow"*
101. This frustration at the lack of access to testing and investigations has left long COVID patients, especially those from the first COVID wave, desperate to get help. We found 49 (22%) people saying they paid to access tests privately. In health terms, this is a high number of people accessing private health care as roughly only 11 per cent of the UK population has some form of private medical insurance. One woman desperate for treatment described having

taken out a loan she could ill afford to access diagnostics. A quote is: *“I paid about £800 for an echocardiogram as a history of heart issues in my family (including a heart transplant and 5 heart attacks) left me terrified of dying and the NHS waiting list for cardiology, despite knowing this history.”*

### **The impact on our mental health and wellbeing**

102. Survey respondents reported a significant impact on their mental health and well-being because of long COVID. We know that long COVID can cause a prolonged inflammatory and immune response in the body. Such an inflammatory response, particularly in the brain or central nervous system, is also associated with feelings of anxiety and depression. However, this is not the only factor, and there are many reasons why people with long COVID report long COVID affecting their overall feelings of well-being.
103. More than half of the people who responded said they have developed ongoing symptoms of anxiety and depression. Sometimes, this was described as a symptom or a response to other symptoms, i.e., loss of sleep or constant fatigue, which were seen to impact mood.
104. As a new illness, we do not know how long people will suffer from long COVID, when they will recover or even if they will recover. Prolonged and chronic illnesses are known to significantly affect a person’s life, needing to adjust to changes and cope with added stressors.
105. Public attitudes towards long COVID have not helped. These can often be hostile and dismissive, with people facing negative comments or abuse in person or on social media. Negative or unsupportive comments from family and friends, health professionals, employers and co-workers wanting to know when you will be better lead to people feeling isolated, unsupported, and alone.
106. The feelings of social ostracism, rejection and devaluation are likely to affect emotional wellbeing negatively. As society talks about recovery from the pandemic, those impacted by long COVID feel left behind in a society trying to return to life before the pandemic.

### **Long COVID Scotland Employment Survey 2022**

107. There were 232 people living with Long COVID in Scotland that responded to the Employment survey. Overwhelmingly, 82% of people identify as female indicating that Long COVID disproportionately affects women. It affects those of prime working-age with the largest group affected being those aged 45-54 years old. At this age, many people will have made career progressions, possibly worked many years within an industry or for a specific employer, and with regards to women, they may have had to work all the harder for career progression if they had taken an earlier career break or reduced hours to raise a family following maternity leave. As it is, women often face incommensurate

earnings compared to men and are more likely to be single parents.

108. When asked if they were employed 85% of people stated they were, however, 15% of those people had lost their job to either Long COVID or COVID-19. According to the Office for National Statistics Scotland's rate of unemployment has been 3.5%-3.8% during the surveyed period yet the rate of unemployment for people with Long COVID has been almost four times higher than this.
109. *Of the 15% who had lost their jobs some had resigned, others were medically dismissed, retired, or ceased self-employment. With an additional 3% taking a career break or leaving the workforce temporarily. A further 6% were redeployed or worked reduced hours. One of the quotes are: "It is a very uncertain time. If I am off too long, then I know as I have heard from lots of teachers (COVID support group) that have faced dismissal or resigned. Sickness policy also states this could happen." Another quote is : " My workload has actually been increased since my return to work, I believe, to encourage me to resign. Management hasn't supported me, and I feel that I'm not valuable anymore as I dared to say I was struggling with my workload."*

#### **Return to work experiences.**

110. The main barrier identified preventing a successful return to work was a symptom relapse with fatigue, exhaustion, and general worsening of symptoms being most highly cited. Some people had inpatient care because of exacerbations following a return to work. Of the people who sustained working, this was only possible due to working amendments such as reduced hours, working from home, or a change of job/career. Some participants said that the drive or commute to work negatively impacted their symptoms and several people said that lack of support from their employer contributed to their failure to sustain a working pattern. One quote is: *"Each return [to work] led to a massive "crash" making me bedbound once more" and "I'm unable to manage it [symptoms] properly because I need to be at work, and I have two young kids so when I'm not at work I can't rest much either."*
111. Phased returns, when provided, varied enormously and ranged from a basic four-week plan, sometimes to six or eight weeks with the lengthier thus more successful phased returns being over months, often up to six months. The length of a phased return is extremely important as Long COVID is a relapsing and remitting condition with fluctuating symptoms. One quote is *"I am worried about what happens when I reach the end of my phased period as the manager is already talking about areas of work I will 'have' to pick up as 'everyone in the team has to take on areas of work'. I think they have lost patience with my needs."*
112. What became clear in this survey is that Long COVID and its symptoms fit within the description of 'disability' under the Equality Act 2010 and that



reasonable adjustments should be made where possible to support workers returning to employment. However, only two-fifths of people surveyed being newly disabled, know about reasonable adjustments covered within the Equality act 2010.

113. Generally, of those who have attempted or sustained a return to work, a big key to success has been a reduction in hours which unfortunately comes with a reduction in salary. Amended duties have helped in some cases and the inclusion of extra regular breaks has been very helpful.

114. Working from home has been favourable in being able to pace symptom management and regulate workload although it should be noted that frontline workers with public-facing roles who were at the greatest risk working throughout the pandemic are met with greater challenges in attempting to secure home working as a reasonable adjustment given the physical, active nature of the normal role.

115. However, it is clear from the survey and other data that Nurses and Teachers with Long COVID face unique problems regarding registration and updating skills/qualifications. Some quotes are: *"I'm due to renew my registration as a RGN in April but I will be unable to meet the criteria for this. I will therefore lose my registration. Another is: "As a qualified nurse, many of my mandatory training requirements have expired. My registration is now at risk." and: "I can't even begin to think about being the way I am in a nursery environment with 30 children needing my continuous support - physically and emotionally. I'm not sure if I will be able to return to doing the job I love."*

116. Employers need to improve their responses to people with longer term Illness. in this instance Long COVID, to keep valued, experienced, and committed staff employed. Additionally The Scottish Government need to bring their aspirations stated in A Fairer Scotland for Disabled People: Employment Action Plan to fruition. With only 22% knowing about Access to Work and 39% being aware of reasonable adjustments in relation to the Equality Act 2010, these damning statistics openly depict the state of employment for people with Long COVID in Scotland. Immediate measures are needed to stop the estimated 155,000 people, many of whom are key workers, from falling out of employment. The Chartered Institute for Personnel and Development published *Working with long COVID: Research evidence to inform support* yet guidance does not seem to be fully implemented.

## **Conclusion**

117. The issues identified in these surveys still exist 18 months later. There have been some changes and improvements in work to develop care pathways in local Health Boards. However, much more is needed with longer term commitment required to continue funding and work on all areas after 2025. Public health messaging has not improved with few opportunities taken to promote mitigations, such as mask wearing, ventilation of public spaces, for

prevention of COVID 19 disease development and to therefore reduce the possibility of Long COVID in the population.

118. In addition, notification and recording of COVID infections has been stopped. No true picture exists of COVID and Long COVID. It is convenient to suggest it does not exist. Meanwhile we see the burden of Long COVID increasing. Some 200 million people are predicted to develop the disease in the next decade. This is comparable to those who have heart disease. ([Long COVID four years on, 2 December, New Scientist](#)).
119. There is a range of information available in respect of the impacts of Long Covid on people and the wider society<sup>4</sup>.

### **Recommendations for the future**

120. It is nearly four years next since the pandemic began. For many of us who were infected in that first wave, it is our four-year anniversary in March 2024. That is four years of being unwell; four years of relapsing and remitting illness; four years of battling to be heard and trying to access appropriate health care. In many instances, four years of not being heard by the very people who should be helping and supporting.
121. Our members are very clear about what they want; “people with Long COVID need to be listened to and lived experience needs to be at the heart of solutions”. We need space and structures to be created so we can inform processes and action, for example a ‘stakeholder panel’. A stakeholder panel would be made up of a range of people with Lived Experience of long COVID from across Scotland. Panel members would be available to be involved (on behalf of the long COVID community to advise on and in the development, delivery and evaluation of long COVID care services. The panel would work in partnership with a range of stakeholders to ensure the voice of lived experience is truly heard.
122. We aim for those with Long COVID to be recognised, heard, and acknowledged positively. For Long COVID-informed care: All patient services for investigations, care and rehabilitation must be co-produced with people with Long COVID to better meet their needs. Equitable patient and public involvement (PPI) are also required: As with the design of medical services,

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<https://docs.google.com/document/d/1lmqzInVvKQCuncivqtWdWZ6vDtlIqpYC/e dit?usp=sharing&ouid=116284170854606827594&rtpof=true&sd=true>

<https://www.alliance-scotland.org.uk/blog/news/alliance-briefing-for-scottish-parliament-debate-on-long-covid/>

people with Long COVID need to be involved in research from its onset, regardless of background, test status, and whether they have been hospitalised, or not these people may have unique pathology and experiences which can inform future treatment. We also seek and want to help to develop better information and education for employers, unions and universities, This would mean fully informed by patients, on how to support people returning to or starting work and study.

123. The Scottish Government launched the Long COVID strategy network in 2021. Two years later although there has been progress, it is glacially slow. It is an ongoing 'fight' to be heard and taken seriously. Co-production of LC services is an ongoing development. The range, understanding and interpretations of that term is wide. People with lived experience of LC is misunderstood. In terms of the burden this work places upon them as well as their ability to engage in it meaningfully. Our aim is to see this through. Although, that is with a backdrop of job loss, lives on hold and ongoing family lives.

### **Recommendations for the future**

124. Long COVID Scotland noted the Scottish Government's own new programme for Government and Health recovery made no mention of Long COVID. We hope it will implement the recommendations made to it by the Scottish Parliament's Long COVID Inquiry<sup>5</sup> which were not addressed in its previous Long COVID support funding. These include the below mentioned.

125. Start to fully record and monitor data on the prevalence of Long COVID in Scotland and account for the impact that incorrect coding of Long COVID can have on the accuracy of prevalence data.

126. Make progress in collecting data to inform long COVID services has been slow and not enough is being done by the Long COVID Strategic network to address this and deploy data in clinical practice.

127. Fully recognise and address that not enough is being done to help support and treat children and young people with Long COVID with no clinical pathways in existence presently.

128. Address the recruitment and funding difficulties faced by health boards due to the non-recurring nature of funded posts and other pressures which has resulting in health boards not using all of the budget allocated to them.

129. Deliver a substantial public Health campaign on Long COVID.

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<sup>5</sup><https://digitalpublications.parliament.scot/Committees/Report/CVDR/2023/4/26/3f31d972-6497-4e89-b77a-07c03ffa5c10#d0b31edf-9520-46cb-a2ff-e8daf67fbeaf.dita>

130. Fully implement SIGN guidelines to ensure a medical professional oversees Long COVID care within each Health Board, as mandated within the guidelines themselves.
131. SIGN is Scottish Intercollegiate Guideline Network. The network develops, implements and evaluates a range of clinical guidelines for health care professionals, predominantly medical staff. There is a guideline on long COVID care in existence, however few medical staff are aware of it.
132. Evidence continued Dedicated research funding into long COVID – Investment and commitment into treatment trials.
133. Involve those with Long COVID meaningfully in all development work.
134. Make and follow through on a Commitment to continue to fund the establishment and continued work of long COVID services.
135. I have signed and dated my statement as below.

Signed

**Personal Data**

Dated 1 March 204