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The Scottish Parliament
Pàrlamaid na h-Alba

COVID-19 Recovery Committee

Long COVID

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COVID-19 Recovery Committee

To consider and report on matters relating to COVID-19 falling within the responsibility of the Cabinet Secretary for COVID Recovery and other Scottish Ministers where relevant, including—

(a) Cross government coordination of COVID-19 recovery policies and strategic review;

(b) the operation of powers under the Coronavirus (Scotland) Act, the Coronavirus Act and any other legislation in relation to the response to COVID-19;

(c) any secondary legislation arising from the Coronavirus (Scotland) Act; and

(d) and any other legislation or policy in relation to the response to COVID-19.

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Committee Membership

Convener
Jim Fairlie
Scottish National Party

Deputy Convener
Murdo Fraser
Scottish Conservative and Unionist Party

John Mason
Scottish National Party

Stuart McMillan
Scottish National Party

Alex Rowley
Scottish Labour

Brian Whittle
Scottish Conservative and Unionist Party

Membership

1. The following changes to the membership of the COVID-19 Recovery Committee (the Committee) took place since the inquiry was launched—

   Siobhian Brown MSP (SNP) was a member from 17 June 2021 and Convener from 23 June 2021 until 30 March 2023.

   Stuart McMillan MSP (SNP) became a member from 18 April 2023.

   Jim Fairlie MSP (SNP) became Convener from 20 April 2023.

Background

2. The National Institute for Clinical Excellence (NICE) in conjunction with the Scottish Intercollegiate Guidelines Network (SIGN) and the Royal College of General Practitioners (RCGP) has produced guidance on managing long-term effects of COVID-19 (updated November 2021). This defines ongoing symptomatic COVID-19 as “signs and symptoms of COVID-19 from four to 12 weeks”. Post COVID-19 syndrome is defined as “signs and symptoms that develop during or after COVID-19 and continue for more than 12 weeks and are not explained by an alternative diagnosis”. For the purposes of this report, references to "Long COVID” refer to both conditions. [1]

3. There are many symptoms associated with Long COVID, these can include respiratory, cardiovascular, neurological and musculoskeletal symptoms. The Office for National Statistics (ONS) reported that fatigue continued to be the most common self-reported symptom of Long COVID (71%), followed by difficulty concentrating (52%), shortness of breath (48%) and muscle ache (47%). [2]

4. Individual respondents to the call for views spoke of their experience of the condition, where they described the myriad of symptoms which can number over 200. These included severe fatigue, breathing difficulties, tachycardia, cardio-respiratory, dysautonomia, musculoskeletal pain, neurological symptoms and skin complaints.

5. According to the latest ONS figures, an estimated 1.9 million people are experiencing self-reported Long COVID in the UK (2.9% of the population). In Scotland it is estimated that 172,000 people have self-reported Long COVID (3.3% of the population). [3]

6. As a proportion of the UK population, the prevalence of self-reported Long COVID is greatest in people aged 35 to 69 years, females, people living in more deprived areas, those working in social care, those aged 16 years and over who were not working and not looking for work, and those with another activity-limiting health condition or disability**.** [3]

7. The Scottish Parliament’s Information Centre (SPICe) produced a blog [4] to support the inquiry which notes that fatigue continues to be the most common self-reported symptom of Long COVID (72%), followed by difficulty concentrating (51%), muscle

ache (49%) and shortness of breath (48%) according to the ONS.

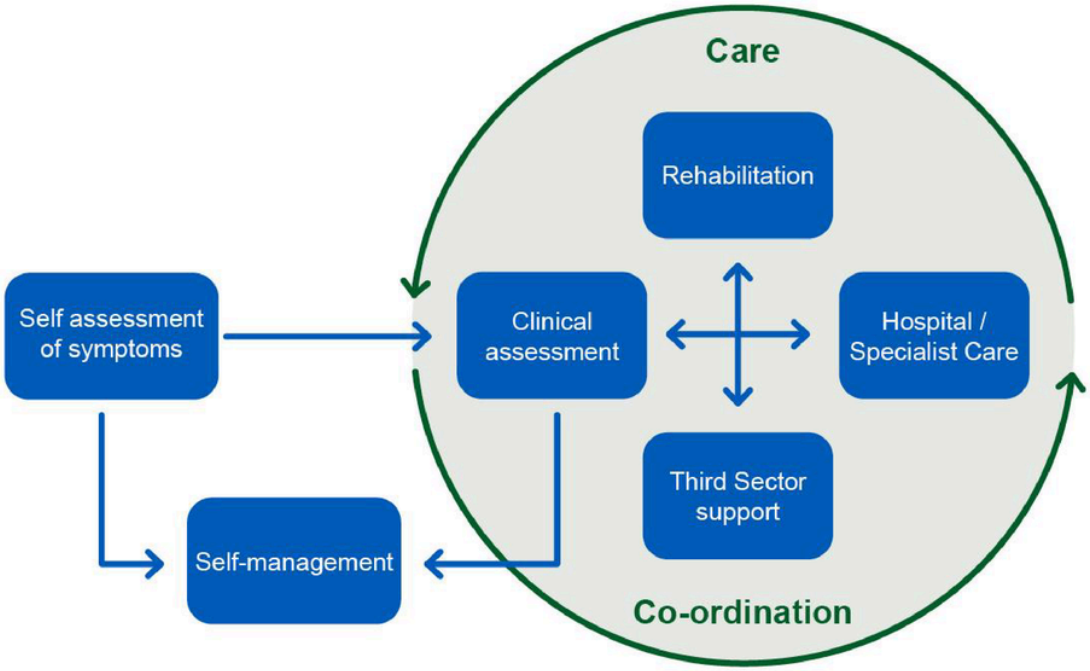
Scottish Government position

8. On 9 September 2021, the Scottish Government announced a £10 million Long COVID Support Fund, which is 'designed to maximise and improve the coordination of a broad range of existing services across the health and social care system and Third Sector in response to the condition.' In announcing the fund, the Scottish Government said it is 'engaging with NHS Boards as they co-ordinate pathways across primary, community and secondary care services to support patients through Long COVID recovery. [5] In May 2022, the Scottish Government announced an initial allocation of £3 million of the Support Fund. [6]

9. In September 2021, the Scottish Government also published Scotland's Long COVID Service [7] which sets out the key elements that underpin its approach to care and support for people with Long COVID. This notes that its approach is based on four elements—

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

Scotland's Long COVID service



Source: Scottish Government

10. At the outset of the inquiry, the Committee wrote [8] to the Scottish Government seeking further information on the following—

- Further information on the £2.5 million supported nine research projects commissioned by the Scottish Government into Long COVID;
- Details of funding allocations of the £10 million Long COVID support fund to date and future investment plans for addressing Long COVID;
- Further details on the £370,000 supported national programme of improvement work led by National Strategic Network;
- An update on the implementation of the recommendations of the National Strategic Network on the initial priority areas for improvement in relation to Long COVID;
- Details of those people who have accessed Chest, Heart and Stroke Scotland's 'Long COVID support services';
- Clarification on its position on Long COVID clinics and information on which, if any, health boards have established them;

- Further details on the expert group set up to identify the capacity needs of NHS Boards and staff in supporting people who have Long COVID;
- Whether the Scottish Government believes Long COVID should be treated as a disability under the Equality Act 2010; and
- How the Scottish Government is meeting the recommendations of NICE around Long COVID service provision.

11. The Scottish Government responded [9] in December 2022 providing further details in relation to each of these points, including a breakdown of organisations to which funding has been allocated for 2022-23. It highlighted that the Scottish Government had established a National Strategic Network in March 2022 to provide national support for building the capacity, capability and co-ordination of health and social care services for people with long-term effects of COVID-19.

Scottish Government funding allocations

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

Source: Scottish Government

12. Immediately prior to the final evidence session with the Scottish Government, the then Cabinet Secretary for Health and Social Care (The then Cabinet Secretary) wrote to the Committee providing an update on the funding made available through the Long COVID Support Fund within the financial year 2022- 23. The letter explained that, as some NHS Boards had experienced delays in recruiting to posts and therefore not fully used their allocated funding for 2022-23, the Scottish Government has now reallocated those unspent funds to support ten initiatives being led by third sector organisations up until the end of the financial year 2022-23 [10].

Scottish Government funding allocations

Organisation	Amount	Description
Chest Heart & Stroke Scotland	£28,904	Integration of the Long COVID support application within Chest Heart & Stroke Scotland's case management system. This aims to improve the patient experience by reducing time between the acceptance of support and the onboarding of patients into the CHSS system, and improve reporting methods and data collection.
Covid:Aid	£48,745	Development of an online support community specifically for people in Scotland with Long COVID, providing access to advice, information, peer support and webinar events.
Covid:Aid	£57,600	Delivery of Covid Aid/ Let's Get on With it Together (LGOWIT) Self-Management Programme, providing free access to online course which aims to support people in the management of impacts associated with Long COVID.
Covid:Aid	£27,750	Development of mobile phone application for the Covid Aid Support Community.
Covid:Aid	£10,000	Delivery of Long COVID advertising and signposting activity, aiming to increase awareness of Long COVID amongst the general public in Scotland.
Health and Social Care Alliance Scotland (The ALLIANCE)	£27,750	Delivery of a pilot programme of Long COVID Support Groups within the Glasgow City and West Dunbartonshire Health and Social Care Partnership areas, facilitated by Senior Community Links Workers.
Long Covid Scotland	£25,000	Investment in systems and equipment required by the organisation to widen its impact and reach more people. Administrative capacity to support the development of educational resources for healthcare staff.
Scottish Ballet	£3,035	Delivery of the 'Emerge' programme designed through consultation with people with lived experience of Long COVID and medical professionals. Aims to help people living with Long COVID to manage symptoms, build resilience and offer time for participant dancers to connect with others with lived experience.
Scottish Opera	£86,892	Expanding course capacity on the 'Breathe Cycle II' project which delivers an online programme of gentle vocal training and breathing exercises designed to re-build physical and mental resilience.
Thistle Health and Wellbeing	£19,000	Expansion of a national Self-Management and Rehabilitation programme, delivered through both 1:1 support and group-based activities facilitated by Wellbeing Practitioners and Peer Volunteers to help participants understand stress, pacing, sleep management and exercise.
Total	£334,676	-

Source: Scottish Government

13. When asked if the Scottish Government intends to increase the £10 million Long COVID Support Funding given the increased number of people with Long COVID since 2021, the then Cabinet Secretary said he would look to see where the Scottish Government could possibly increase funding for Long COVID specifically. He said— [11]

> In my role, I am more than happy to explore that, and I am certain that whoever is in this role after me will look to explore whether that funding can be increased.

Health boards

14. The Committee also wrote [12] to all health boards (and the Thistle Foundation and NHS Education for Scotland) seeking further information on the following—

- details on the current services available including information on how the Scottish Government funding has been used;
- any barriers to service development and provision;

- any examples of good practice; and
- details of future plans for Long COVID service provision in the short and medium term.

15. All the responses have been published on the website [13] and SPICe produced a summary [14] of responses which had been received which showed a variety of approaches to Long COVID service provision across health boards. This is discussed later in the report.

Introduction

16. The Committee launched this inquiry to consider what action the Scottish Government is taking to address Long COVID and post COVID syndrome.

17. The inquiry focused on the following three themes—

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

18. The Committee issued a call for views based on these themes which ran from 12 January 2023 until 19 February 2023. It received 508 responses, mainly from individuals with lived and living experience of Long COVID, and a summary of responses was published on the website. [15]

19. The Committee took evidence from witnesses during five evidence sessions on 9 February 2023; 23 February 2023; 2 March 2023; 9 March 2023; and 23 March 2023. A list of the additional written evidence that was submitted by witnesses is provided in the annexe to this report.

20. The Committee was keen to speak with people with lived and living experience of Long COVID to hear what issues they faced and what more could be done to support them. People contacted through Long Covid Scotland met with the Committee informally at the launch of the inquiry on 12 January 2023 and on 2 February, the Committee held an informal online discussion with people who were contacted through Long Covid Kids. A note of the discussion from these engagement activities is provided in the annexe to this report.

21. The Committee would like to thank everyone who participated in the inquiry, in particular, those with lived and living experience. The discussions it held and the evidence it received helped shape this inquiry and the Committee's recommendations to the Scottish Government.

Awareness and recognition

22. Both in written and oral evidence, the overwhelming message was that there was not enough awareness and recognition of Long COVID by the general public, medical professionals, educators, employers and policy makers in Scotland. The Committee heard of the stigma associated with Long COVID and the negative impact this lack of awareness has had on people with Long COVID or those caring for people with Long COVID.

23. The summary of written responses [16] highlights views and experiences of the level of awareness in each of these groups in greater detail. During oral evidence, the Committee focused on understanding the impact of the lack of knowledge and awareness of the condition on people's experiences of seeking treatment or support. It also focused on awareness and recognition among the medical profession, in particular, primary care. It should be noted that the Committee considered issues relating to awareness among employers as part of its recent road to recovery inquiry: the impact of the pandemic on Scotland's labour market. [17] The Committee received a response from the Scottish Government to its recommendations in March 2023. [18]

Stigma

24. The Committee heard of the frustration felt by people with lived and living experience who said they did not feel listened to or believed when seeking treatment or support for their condition. A common phrase used by respondents to the call for views was they felt they were being 'gaslighted' by the medical profession.

25. Bryony Graham was typical when she said [19] —

> With Long COVID being an invisible illness/disability, there can often be a stigma from medical professionals or the general public that you are not or should not be entitled to the support you need and often it is a true fight to have your struggles be recognised.

26. 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. It said [20] —

> 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.

27. During evidence, Sammie Mcfarland representing Long Covid Kids said [21] —

> Stigma is a huge issue, as is bullying, for children who are living with Long COVID. That goes back to the lack of awareness and training in educational settings. We really need to focus on that area, because if children and young people and educators had better awareness, stigma and bullying would be reduced.

28. These points were echoed during informal discussions with parents of children with Long COVID. [22]

29. Stuart McIver representing Long Covid Scotland and Rob Gowans representing the ALLIANCE argued that lessons had not been learned from the stigma associated with myalgic encephalomyelitis (ME). Stuart McIver said [21] —

> Unfortunately, Long COVID sufferers are becoming aware of the prevailing attitudes around that condition. Education is central to that. I have witnessed horrific abuse of Long COVID sufferers online, with people being attacked for having Long COVID. For some reason, Long COVID seems to be fair game whereas cancer and other illnesses— which are devastating in their own way—are not.

30. Jane Ormerod agreed with this point saying [23] —

> Surely now is the time to say, “Stop. Let us realise that and do something about it”, rather than continuing with groundhog day, which we risk doing with Long COVID just as we have done with ME.

31. Ian Mullen representing Covid Action Scotland also highlighted the stigma attached to those who are immunosuppressed. He said [24] —

> I have colleagues in Covid Action Scotland who have barely been out their door in three years now. One of them has written a lot of articles about the open abuse that she has received over that period of time because she has been very vocal.

32. The stigma associated with Long COVID highlighted by witnesses and respondents to the call for views was echoed in a recent study which found that 95% of people with Long COVID reported experiencing stigma related to their condition. [25]

33. This issue was also highlighted in an article in the British Medical Journal, "The stigma is real for people living with Long COVID," which commented [26] —

> Stigma drives people underground and away from health services, contributes to psychological distress and mental illness, and by doing so compromises long term physical health outcomes. Non-engagement with health services and ill health are further stigmatized, perpetuating a vicious cycle of further stigma and sickness. Research on Long COVID stigma is still lacking, but emerging testimonies point to two important facets: institutional discrimination and internalized stigma.

34. The Committee is deeply saddened to hear of the stigma faced by those with Long COVID and greatly appreciates their input and direct engagement throughout this inquiry.

35. The Committee was concerned to hear of the apparent lack of any lessons being learned from other chronic illnesses such as Myalgic Encephalomyelitis/ Chronic

Fatigue Syndrome (ME/CFS) in raising awareness of Long COVID and avoiding stigma around the condition, and would ask the Scottish Government whether it has any plans to look at this given the evidence the Committee has heard.

36. The Committee considers that the stigma associated with the condition must be addressed to enable those people suffering from Long COVID to receive the recognition and support they need and deserve.

General public

37. A majority of individual respondents reported not being taken seriously by friends and colleagues who consider that Long COVID is 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.

38. During evidence, Stuart McIver highlighted the limited recognition of the effects that Long COVID has on people and the risk of multiple infections. He commented [27] —

> The fact that people have caught Long COVID, not having been aware of it as an illness or of the extent to which they had put themselves at risk, is an issue that has been fed into some of our groups. Unfortunately, it is now too late.

39. An overwhelming number of individual respondents spoke of the detrimental impact that this lack of awareness had had on their mental health. 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. [28]

40. Catherine McCormack summed up her experience [29] —

> 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.

41. Participants during informal discussions with the Committee highlighted that Long COVID has had a huge detrimental impact on the mental health of children with Long COVID, leading many to develop depression and other mental health conditions. [22]

42. During evidence, Ian Mullen representing Covid Action Scotland called for the mental health of people with Long COVID to be considered more seriously. [30]

43. The then Cabinet Secretary disagreed that there was a lack of awareness among

the general public of Long COVID citing a YouGov poll of 1,001 members of the public on February 2023 which found that 94 per cent of people had heard of Long COVID and that 76 per cent of people agreed with the statement that "Long COVID is a serious condition for those that experience it." He said that this poll suggests 'there is good public awareness of Long COVID, at least at a high level'. [31]

44. The then Cabinet Secretary did say he understood the significant impact of Long COVID on adults, children and young people's physical and mental health explaining [32] —

> Indeed, I have heard as much myself in my meetings with people with Long COVID and from those in our national health service who support them. For those who are severely affected, life can be extremely challenging.

45. The Committee was concerned to hear that the lack of recognition and awareness of Long COVID can often have a significant negative impact on an individual's mental health and wellbeing.

46. The Committee notes the overwhelming evidence that there is a lack of awareness of Long COVID among the general public and that it is important that the Scottish Government acknowledges the evidence received throughout this inquiry.

National public health campaign

47. In Scotland's Long COVID Service [33] , the Scottish Government committed—

- £40,000 to deliver a targeted Long COVID marketing campaign in conjunction with community pharmacies across Scotland.
- To develop and distribute a communications toolkit for primary care teams, NHS Boards and other partners. The toolkit will include key messages, campaign assets and relevant information on Long COVID ensuring clarity and consistency of information available.

48. The Scottish Government's Long COVID Awareness Campaign [34] highlights the symptoms of Long COVID, has information on self-management and information on sources of support.

49. The Scottish Government has focused its awareness campaign on people who are already ill (i.e. people attending a pharmacy or primary care setting), rather than aiming it at all members of the public.

50. However, despite the Scottish Government's commitment to a targeted Long COVID marketing campaign in community pharmacies and primary care settings, the Committee heard there was still very little awareness and recognition of Long COVID.

51. Respondents highlighted problems with misinformation in relation to Long COVID

on social media channels. A number of respondents suggested that a national public health campaign should be launched to increase awareness of the condition among the general public but also to communicate the risks associated with COVID and developing Long COVID.

52. 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. [35]

53. 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 [36] —

> 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.

54. 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. [37]

55. In its most recent letter to the Committee, the Scottish Government explained it has made £10,000 in funding available for the delivery of Long COVID advertising and signposting activity, aiming to increase awareness of Long COVID amongst the general public in Scotland. [38]

56. The Committee notes the Scottish Government's £40,000 funding announced in September 2021 to deliver a targeted Long COVID marketing campaign in primary care settings and community pharmacies and its Long COVID Awareness Campaign. However, given the concerning evidence heard by the Committee of the lack of awareness and recognition of Long COVID and the impact this has had on individuals, the Committee considers a public health campaign is needed to address this.

57. The Committee welcomes the additional £10,000 funding for the delivery of Long COVID advertising and signposting activity and recommends that the Scottish Government speaks directly to those with lived and living experience, including Long Covid Scotland, to help inform its future public health campaign activity. In addition, the Committee requests that the Scottish Government provides further clarity on how this funding will be spent.

COVID-19 and Long COVID prevention

58. On the 23 February, the Scottish Government wrote to the Committee announcing the decision to suspend the Covid-19 threat level in Scotland noting that 'the 4 Harms Group takes the view that it is not effective to treat Covid-19 as a separate entity, when this is now just one element of the combined pressure the NHS is under at this time.' [39]

59. In July 2022, the Joint Committee on Vaccination and Immunisation (JCVI) recommended the following groups should receive a COVID-19 vaccination or booster vaccination— [40]

- residents in a care home for older adults and staff working in care homes for older adults
- frontline health and social care workers
- all adults aged 50 years and over
- persons aged 5 to 49 years in a clinical risk group
- persons aged 5 to 49 years who are household contacts of people with immunosuppression
- persons aged 16 to 49 years who are carers

60. Some respondents to the call for views argued that governments should highlight the risks associated with Long COVID and mitigations which should be taken to prevent people getting COVID and developing Long COVID. They argued simply that the best way to avoid getting Long COVID was to avoid getting COVID.

61. 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-19 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-19, which could develop into Long COVID, and the dangers of reinfection for those who already have Long COVID. Ruth Finegold said [41] —

> 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.

62. Moderna Biotech UK said the Scottish Government should continue to raise awareness around the benefits of vaccination against COVID-19 through public health communications. [42]

63. However, during evidence, Michelle Powell Gonzalez was concerned that people with Long COVID were not eligible for booster vaccinations saying [43] —

> I wanted to get the booster before Christmas last year. I am not old enough to get it, but I have been severely affected by Covid. For the past three years, I have been disabled from Covid, but I cannot get the Covid booster. As standard practice, people with Long COVID should be offered the booster every year, or however many times the doctors see fit, without any issues.

64. On preventing Long COVID, both Dr Melissa Heightman, Clinical Lead, Post Covid Service, University College London Hospitals and North Central London Respiratory

Network, National Specialty Advisor, Long COVID Program, NHS England, and Dr John Harden, Deputy National Clinical Director, told the Committee that vaccination reduces the likelihood of getting Long COVID. [44] [45]

65. The then Cabinet Secretary agreed that reducing the numbers of people suffering from COVID-19 would hopefully reduce the numbers of people impacted by Long COVID and highlighted that the uptake for booster vaccinations was high in the older population and those in residence in care homes however there has been a drop-off in uptake among the 50 to 64 age group.

66. He said that vaccination must be front and centre of the Scottish Government's response to COVID-19 and that there is also continued work to do on ventilation in educational and work settings. [46] He also highlighted the Scottish Government's Covid Sense campaign, 'which reminded people of measures they can take to and what to do if they had Covid symptoms—it highlighted good hygiene, ventilation and so on and it will continue to make the case for vaccine uptake.' [47]

67. The Committee notes the evidence received that the best way to avoid developing Long COVID is to avoid getting COVID-19, and that the booster vaccination programme is key to reducing the number of people who will develop severe symptoms and Long COVID. The Committee also notes that the Scottish Government follows the advice from JCVI on who to vaccinate.

68. The Committee welcomes the comments from the then Cabinet Secretary regarding the Covid Sense campaign and publicising the current booster vaccination programme. The Committee recommends the Scottish Government reviews its current publicity strategy for the booster vaccination programme to ensure its effectiveness in raising awareness of the programme and reducing apathy around booster vaccinations.

Medical profession

69. Almost all individual respondents to the call for views spoke of a lack of awareness among medical professionals, GPs in particular, in terms of assessing patients, diagnosing Long COVID and providing treatment options. Many respondents said they did not feel listened to by the medical profession, which included a number of responses from those who work or had worked within the medical profession. [48]

Diagnostic difficulties

70. 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.

71. The Committee heard of a lack of knowledge among GPs of Long COVID and other related illnesses such as ME/CFS and Postural Orthostatic Tachycardia Syndrome (PoTS) and of misdiagnosis due to lack of awareness. For example Marie-Claire

Grounds said [49] —

> 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 its 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.

72. Sarah McDonald also expressed concern regarding obtaining correct diagnosis and treatment saying [50] —

> 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.

73. 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. It said [51] —

> 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 8 guidelines for ME/CFS and similar energy-limiting conditions, is the wrong approach which can cause further harm and injury.

74. On a related point, Dr Claire Taylor also commented that around 50 percent of Long COVID patients have PoTS. Dr Taylor explained that she was not aware of others, apart from herself, who are doing work in this area and noted that there are no PoTS services in Scotland, a point echoed in a number of written submissions. [52]

75. In its submission, the RCGP commented on the NICE guidelines developed by them and SIGN and said that these were highlighted to GPs and on awareness of Long COVID GPs said [53] —

> GPs - as they do for any emergent condition - have had to learn about the manifestations of Long COVID and possible management approaches. We suggest therefore that there is reasonable awareness amongst most GPs.

76. Many people told the Committee they have had to become an expert in Long COVID either as a patient or as a carer for a child with Long COVID because their GP's awareness of the condition and treatment options is low.

77. The Committee notes there appears to be a disconnect between what clinicians are saying about awareness of the condition within the medical profession and what patients, including people who have Long COVID and work in the NHS, are experiencing.

Private medical care

78. Due to this lack of awareness and recognition within the medical profession, a number of respondents to the call for views spoke of having to seek private medical care in order to receive proper diagnostic and treatment services. They highlighted that this was not an option open to all given the financial implications and that this could result in a two-tier health system.

79. During evidence Stuart McIver said the only improvements he has had to his condition was following private consultations with specialists who offered him treatment. [54]

80. This was echoed by the Royal College of Occupational Therapists (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 [55] —

> 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.

81. Long Covid Scotland also informed the Committee that it was aware of a number of people accessing private medical care for tests and expertise they have not been able to access via the NHS. [56]

82. When asked about the number of people who had said they felt they had no option but to seek private medical care, which could result in a two-tier health care system, the then Cabinet Secretary said he did not want a two-tier system and that he wants everybody to be able to access NHS services saying [57] —

> ..of course I do not want people to feel that their only option is to go private. That is why we need to improve the services that we have.

83. The Committee is concerned by the number of people who said they felt they could only get proper diagnosis and treatment by seeking private medical care which is not an option to those who cannot afford to do this. The Committee considers it imperative that access to appropriate diagnosis and treatment should be available to all through NHS services.

Education and training for medical professionals

84. The letter from the Scottish Government stated that the National Strategic Network has developed and is implementing an education strategy 'to raise awareness of the long-term effects of COVID-19, share education resources related to symptom management, and share developing knowledge and expertise across healthcare professionals working with people with long-term effects of COVID-19.' It said that [58] —

> this has been supported by the establishment of a bi-monthly peer support forum, and will be supplemented by the development of a quarterly multi-disciplinary case conference for complex cases and a central web-based resource for sharing information and signposting to learning resources.

85. During evidence, Janis Heaney representing NHS National Services Scotland (NSS) and the Associate Director of National Strategic Networks, which includes the Long COVID National Strategic Network, elaborated saying that one of the key principles of the national strategic network is a focus on education in the workforce. She commented— [59]

> We have developed an education strategy—it is fairly high level, to be fair—and engaged with clinicians who are supporting people with Long COVID to identify what education and development they feel they need. A lot of what they are saying is about being able to signpost appropriately to the right resources and about peer support and being able to come together as a multidisciplinary team to discuss what the approaches could and should be.

86. However, the vast majority of respondents to the call for views argued for more education and training for medical professionals on Long COVID. It was also noted that medical professionals need to be given time to undertake continuous professional development, which some respondents said was not always the case. For example, Bruce Watson said [60] —

> 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.

87. The RCGP highlighted its eLearning course on the long term effects of COVID-19 and Post-COVID-19 syndrome. This aims to teach people how to describe the various presentations of Post-COVID syndrome, understand the current guidance and understand the impact on patients. [53]

88. NHS Greater Glasgow and Clyde [61] (NHSGGC) highlighted current guidelines developed by SIGN, NICE and the RCGP which have been cascaded through GPs and primary care teams. It pointed out that these are aligned with the principles and recommendations of the Scottish Government Recovery and Rehabilitation Framework 2020. [62] 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.” [63]

89. Chest, Heart & 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 [64] —

> 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.

90. During evidence, Jane Omerond representing Long Covid Scotland argued that, although there are a range of accredited professional resources including from the RCGP and the SIGN guidelines, it is unclear how these are disseminated among health professionals. [65] She also made the point that any approach to educating healthcare professionals should involve people with Long COVID in the development of educational resources. She said [66] —

> There are plenty of online resources, but there are also plenty of people with lived and living experience who would be happy to be involved in further development and work to educate GPs—in fact, we are about to embark on a small piece of work on that.

91. Involving people with lived and living experience was also raised by Michelle Powell Gonzalez representing Long COVID Support Group: Scotland who said [67] —

> All that we are asking is for the Scottish Government to, please, re-assess the situation and bring us in. We want to help, we want things to get better, we all want to work together and we all want to get better. Please, listen to us.

92. When asked if currently there were any examples of best practice in training for medical professions, Rob Gowans representing the ALLIANCE said [68] —

> There are no examples of good practice. The situation is inconsistent and comes down to individual employers or healthcare professionals.

93. A number of respondents to the call for views mentioned Dr Claire Taylor as someone other medical professionals could learn from given her understanding and approach to Long COVID services. During evidence, Michelle Powell Gonzalez echoed this point saying [66] —

> ...she has an understanding of its mechanisms and the particular issues that we are going through. She would be an amazing asset to help to train and educate other healthcare professionals.

94. Professor Lindsay Donaldson, Deputy Medical Director of NHS Education for Scotland, which is the statutory education and training body for health and social care in Scotland, commented that the General Medical Council's (GMC) 'good medical practice is very clear that, as clinicians, we must keep our continuous professional development (CPD) up to date, so we have guidance on that.' [69]

95. However, David Shackles representing the RCGP spoke of the difficulty in encouraging GPs to undertake CPD into Long COVID as [70] —

> ...the protected learning time initiative was in abeyance, which restricted the ability of GPs and their teams to come together and take part in educational activities. That has had a negative impact.

96. Linda Currie, Associate Allied Health Professions Director for NHS Highland and the board's clinical lead for Long COVID spoke of the specific difficulties in relation to training in NHS Highland where the geographical area and capacity issues pose challenges. She said [71] —

> When a clinical team comes into the board, its priority is to get on and see the patients, so it is about whether there is also the capacity to do that education widely across all of the multidisciplinary team. However, we are doing that. We meet our GPs and GP leadership groups—I have met them a number of times—we meet clinical teams, and I chair the national clinical network, which NSS set up. It is now much more accessible to do the training. It is happening, but it will take us time to get to everyone, and there are so many other pressures in the system, so it is difficult.

97. Heather Cameron, Director of Allied Health Professions at NHS Lothian, spoke of the need for having clear guidance for GPs and highlighted in NHS Lothian they use RefHelp, for support and information. She also suggested the need to harness the knowledge and skills that people already have in managing long-term conditions. [71]

98. On the educational support available for GPs, the then Cabinet Secretary highlighted the Scottish Government's clinical guideline Implementation Support Note [72] which aims to help GPs effectively assess and refer people with Long COVID. He also highlighted the NHS Inform dedicated microsite which contains key information and sources of support for people with Long COVID. [73]

99. Dr John Harden, Deputy National Clinical Director told the Committee that he hoped that people's experience of a lack of awareness from GPs was a minority experience, or that it is not happening now, saying the Scottish Government has done a lot of work with the RCGP and NHS Education for Scotland to raise awareness and education levels among healthcare providers to make sure that they have the knowledge to recognise the symptoms and signs. [74]

100. The then Cabinet Secretary said he was concerned to hear of patients being dismissed by GPs which is why so much work has been done on educational tools for front-line primary care workers and the Implementation Support Note. He said [75] —

> I would be really disappointed if I was to hear of a recent example of someone being dismissed in the way that you describe.

101. When asked about giving GPs the time to undertake CPD, the then Cabinet Secretary highlighted work that has been ongoing with the British Medical Association on CPD for GPs. He explained that as a result of the pandemic and pressures on the NHS, time allocated specifically for GPs to undertake CPD had not been able to be maintained and another model is being considered in conjunction with the BMA and the RCGP. He said [76] —

> For me, practitioners having protected learning time for CPD is absolutely pivotal. It is important for all of them, but it is especially important in giving our trainee doctors the confidence to progress in their roles as general practitioners…. I give my commitment to the RCGP and the BMA to see what more we can do to support them in that regard.

Sharing information

102. When asked how the medical profession shares learning, Dr Heightman mentioned the RCGP's training webinars and e-learning content however she argued there needs to be investment into GP leadership on Long COVID and that everything must be done to support them in respect of training. [77]

103. Dr Strain, Senior Clinical Lecturer at the University of Exeter Medical School, Lead on Long-Covid at the British Medical Association and Member of the NHS Long-COVID Taskforce, made the point that some GPs have upskilled and become experts in Long COVID where their skills are being used by others and shared among medical professionals, however not all GPs have had the time or opportunity to do this upskilling. He argued [78] —

> Not every GP needs to be an expert in everything. The whole concept of GPs knowing everything about everything cannot exist in today's medicine. I am talking not about full specialist interests but about having different, flexible degrees of specialties and, importantly, GPs networking among themselves so that they know to tell a patient that they are probably not the right GP to look after them and to suggest that they see a different GP. That is about generating a degree of professionalism among GPs, for want of a better term.

104. A similar point was made by Dr Janet Scott, Consultant in Infectious Disease (NHS Highlands) and Affiliate Senior Clinical Lecturer, MRC-University of Glasgow Centre for Virus Research who said [79] —

> I also see HIV patients. I do not expect every GP to keep up with all the HIV literature, but that is part of my job as an infectious disease physician. It should not be the job of every GP to keep up with all the Long COVID literature; it is the job of specialists to keep up with that literature, sift through it and provide appropriate guidance to those in primary care.

105. Dr Amy Small pointed out that Long COVID clinics in England are working in networks to share education and learning and this is not happening in Scotland. She said [80] —

> Dr Claire Taylor has learned lots about this, but she has no one to share it with because there are no networks in Scotland to share the information that she has learned about how to use common medications in an unconventional, but totally safe, way to treat the sequelae of Long COVID.

106. Claire Jones, Advanced Clinical Practitioner and Long COVID Therapy Lead at Betsi Cadwaladr University Health Board, said in Wales there are a number of GPs with specialist interest in Long COVID who link in with the Long COVID network in England. She said there is a lot of variation among GP surgeries in Wales in relation to awareness and there is a need to focus on sharing information about what Long

COVID services are available. [81]

107. On sharing information, Dr Heightman highlighted national networks such as an allied healthcare professional network and NHS England supported clinical network but called for a UK clinical society, to allow for sharing learning and research into Long COVID. She said [81] —

> At the moment, we have to tag on to other societies, and we are not always very popular with them, so we need our own grouping, and we hope that we can stimulate discussion of that as part of the transition planning, so that we are not siloed between England, Wales and Scotland, which seems very odd.

108. Dr Strain echoed Dr Heightman's comments where he spoke of the benefits of informal networking but called for the processed to be formalised. [82]

109. Manira Ahmad, Chief Officer at Public Health Scotland (PHS), highlighted the National Strategic Network's monthly bulletins which provide concise information that can be cascaded through the network and sub-groups. [83]

110. Both Linda Currie and Janis Heaney agreed that the bulletin was very useful and Linda Currie also noted the LOCOMOTION study which is a UK wide multidisciplinary team consortium optimising Long COVID treatments and services across the NHS. She explained that this is a National Institute for Health and Care Research 10-site study and that NHS Highland recently joined as the Scottish board representative, which links the board directly into the National Strategic Network and to the learning from nine English and one Welsh site. [83]

111. The Committee welcomes the National Strategic Network's education strategy aimed at raising awareness of Long COVID among medical professionals. However, the evidence in relation to awareness and recognition among health professionals suggests that the implementation of this strategy has not been fully effective thus far. The Committee draws the Scottish Government's attention to the evidence it has received that many patients are still encountering GPs who are not aware of Long COVID in this regard. The Committee is disappointed by the lack of progress in this area, particularly bearing in mind the length of time since Long COVID first emerged as a disease.

112. The Committee recommends the Scottish Government works with the National Strategic Network and NHS Education for Scotland as a matter of urgency to develop and implement its education strategy in relation to the awareness and recognition of Long COVID within the medical profession. This work should consider the evidence heard by this committee in relation to—

- allowing time for GPs to undertake CPD on Long COVID;
- learning from medical professionals such as Dr Claire Taylor who have developed expertise in Long COVID;
- sharing best practice among health professionals;
- involving people with lived and living experience in a meaningful way; and

- harnessing existing informal networks both in Scotland, across the UK and internationally.

Financial support - access to benefits

113. The Committee also received evidence about the impact that a lack of recognition of Long COVID is having on individuals' personal finances and ability to access benefits. Many individuals highlighted that they were unable to work due to Long COVID or caring for someone with Long COVID. Concern was raised regarding sick pay and the fact that many people with Long COVID have not qualified for disability benefits and carers allowance. A large number of respondents argued for Long COVID to be recognised as a disability under the Equality Act 2010.

114. 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.

115. 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.

116. During evidence, Dr Strain also highlighted the difficulties with accessing disability support for patients with brain fog and fatigue symptoms and called for a more simplified core route to accessing this support. [84]

117. Many respondents, including Aberdeen City Council, called for people to be able to access the Carers Allowance and the need for respite for people caring for a person with Long COVID, both in the form of paid carers providing support on a regular basis, as well as overnight and to allow the primary carer to take longer breaks. [85]

118. Long Covid Kids commented that they were unaware of any families in their support groups that have been able to successfully access social care support and highlighted the difficulties associated with accessing financial support, saying [86] —

> 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 25 policymakers, professionals and advisers made it virtually impossible to receive the support necessary.

119. As the SPICe blog explains, a person is disabled under the UK Equality Act 2010 if they have a physical or mental impairment that has a 'substantial' and 'long-term' adverse effect on their ability to do normal day-to-day activities. Only three conditions are specifically included in the Act: cancer, multiple sclerosis and HIV

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

120. The Equality Act 2010, in the main, is reserved under Schedule 5 of the Scotland Act 1998 but there are some exceptions. These are the encouragement of equal opportunities, and the power to impose duties on Scottish public authorities to meet equal opportunities requirements. [87]

121. In its letter to the Committee, the Scottish Government explained that revising the conditions specified as a disability under the Equality Act 2010 is reserved to the UK Government. It too highlighted that a person is disabled under the Equality Act 2010 if they have a physical or mental impairment that has a 'substantial' and 'long-term' adverse effect on their ability to do normal day-to-day activities. The Scottish Government noted therefore if Long COVID has this effect on an individual they would meet the definition of disability in terms of the Equality Act 2010. [88]

122. The then Cabinet Secretary reiterated this during evidence highlighting it is the debilitating impact of a condition rather than the condition itself that has to be prescribed. He said 'therefore, the effects of Long COVID could mean that someone has a disability that would affect their ability to get certain benefits, including social security benefits.' [89]

123. The Committee notes that conditions defined as a disability under the UK Equality Act 2010 is a reserved matter. The Committee also notes that, if an individual with Long COVID has a physical or mental impairment that has a 'substantial' and 'long-term' adverse effect on their ability to do normal day-to-day activities, they would meet the definition of disability in terms of the Equality Act 2010.

124. The Committee notes however the difficulties described by respondents to the call for views in accessing disability support which can be exacerbated given common symptoms of Long COVID such as brain fog and fatigue. The Committee recommends that the Scottish Government works with the relevant social security agencies to identify means to make the applications process more accessible and any additional support which would help individuals with Long COVID when applying for disability benefits, such as Carers Allowance and PIP.

Therapy and rehabilitation

Current service provision

125. The letter from the Scottish Government outlined how Long COVID services are currently organised in Scotland and where funding has been made available to NHS Boards and partners to develop Long COVID services. The letter provided a synopsis of the Long COVID services provided across health boards in the annexe. [90]

126. In March 2023, during Jackie Baillie's members' business debate on Long COVID, the then Minister for Public Health, Women's Health and Sport confirmed that at present, six health boards have Long COVID pathways up and running and NHS Greater Glasgow and Clyde, and NHS Ayrshire and Arran, have indicated that their pathways are expected to open in March 2023. [91]

127. On Long COVID service provision, the then Cabinet Secretary explained that the Scottish Government is not favouring a specific model rather, through the Long COVID Support Fund, it is supporting health boards to plan services based on local needs and infrastructure. The Scottish Government explained that the Long COVID Support Fund will be allocated and spent over the three financial years (2022-23, 2023-24, 2024- 25). Mr Yousaf told the Committee [32] —

> The Long COVID support fund is targeted additional resource for NHS boards to increase the capacity of existing services, to develop them into more clearly defined pathways and to provide a more co-ordinated experience for those accessing support. We have heard time and again from Long COVID sufferers that that is what is needed. The approaches being tested include looking at ways of achieving those outcomes through having a single point of access for assessment and co-ordinated support from services, including physiotherapy and occupational therapy.

128. The then Cabinet Secretary explained to the Committee that the current clinical guidance recommends the provision of treatment for people's specific symptoms, where possible, or a rehabilitative approach to help people manage the impacts of their symptoms on their day-to-day lives. Mr Yousaf explained [32] —

> That care and that support are being provided through the full range of services delivered across our NHS. People can access general practitioner assessment in a setting close to their home, and GPs can then make referrals to community rehabilitation services or secondary care pathways such as respiratory care or cardiology, where appropriate. Those individual services are best placed to investigate and support people who have as a result of Long COVID symptoms that might require support.

129. The Committee was keen to explore in more detail how services are being developed across health boards and what witnesses and those with lived and living experience felt should be key elements of Long COVID service provision. This is discussed later in this report.

Self-management- third sector support

130. The Scottish Government's Long COVID Service highlights the role that self-management plays for people with Long COVID. It states [92] —

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

131. To support this the Scottish Government has provided funding to CHSS's Long COVID Support Service which includes an advice line. [93] This aims to enable people with Long COVID to speak to nurses who are trained in managing some of the most common Long COVID symptoms, such as breathlessness and fatigue. CHSS also works closely with NHS Lothian to deliver integrated, collaborative care where GPs refer routinely to CHSS teams, who provide advice and self-management support to patients with Long COVID on a case management basis. It also runs a peer support group for anyone living with Long COVID and a Kindness Volunteer scheme, providing regular calls for emotional support.

132. As part of the Self-Management Fund [94] , administered by the ALLIANCE, the Thistle Foundation has also developed a remote self-management programme, with a specific focus on supporting people living with Long COVID.

133. The letter to the Committee from the Scottish Government reported [95] —

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

134. During evidence, Jane-Claire Judson representing CHSS highlighted the support it provided for self-management however due to the referral process and lack of integration with NHS services, the service is not being used to its capacity. She said [96] —

> We set up our service to be integrated with the NHS. We did not want to be stand-alone and off to the side doing our own thing in a way that was not integrated and did not help to free up capacity, but that is exactly what we now have. We must sort that out.

135. Dr Amy Small representing CHSS Scotland highlighted the additional capacity within the third sector which is currently underutilised. She said [97] —

> We in Chest Heart & Stroke Scotland have time to spend with patients. The advice line team has, on average, about an hour per patient. Patients cannot be offered that sort of time in primary care. GPs do not have that time to give to patients, but we have the ability to do that.

136. Linda Currie, told the Committee of the work been done in NHS Highland with multi-

disciplinary teams working together with the third sector Let's Get On With It Together group. [98]

137. Professor Edward Duncan, Nursing Midwifery and Allied Health Professions Research Unit at the University of Stirling commended the funding of self-management strategies however he said self- management should be viewed in the wider context of a number of rehabilitation therapies available. His research found that in one rehabilitation services case study where people were triaged to self-management, individualised therapies and group therapies, very few of the people who had been referred to the services had been suitable for the self-management strategies. He said [99] —

> That begs the question of how appropriate self-management is as a sole means of therapeutic offer for people with quite complex needs.

138. Professor Kay Cooper, Clinical Professor of Allied Health Professions at Robert Gordon University and NHS Grampian, who is undertaking research with Professor Duncan concurred and added that more research and evaluation needs to be done on identifying those people for whom self-management is most appropriate and those people whose needs require more complex multidisciplinary or professionally led rehabilitation services.

139. Professor Duncan also suggested it would be valuable to undertake further research on the effectiveness of the breadth of delivery of self-management services and whether it meets patients' needs and whether there are other needs that are not being met. [100]

140. A number of health boards highlighted the use of self-management services. For example, NHS Greater Glasgow and Clyde (NHSGGC) explained it has adopted a person-centred approach in order to provide a comprehensive interdisciplinary approach to Long COVID services saying its approach primarily focuses on self-management and supported self-management pathways. [101]

141. NHS Highland highlighted its Clinical Resource Group recommendation that a tiered approach of screening, self-management and multi-disciplinary support to be established. The Board already has an operational Long COVID pathway, including occupational therapy and physiotherapy staffing to support assessment, goal setting, rehabilitation and coordination for people with Long COVID. The pathway will signpost to self-management resources as a first option and can be stepped up to supported self-management including one to one or group support. [102]

142. In its latest letter to the Committee, the Scottish Government informed the Committee that funding had been made available to support ten initiatives being led by third sector organisations up until the end of the financial year 2022-23. It stated [103] —

> Funding for these third sector initiatives has been made possible as a result of the projected underspend by territorial Boards. It is intended that these activities will complement the work already underway by NHS Boards and ensure that we are offering a wide range of support to people living with Long COVID.

143. The initiatives include funding for CHSS, Let's Get on With it Together (LGOWIT) Self-Management Programme and the expansion of the Thistle Health and Wellbeing National Self-Management and Rehabilitation programme.

144. When asked exactly when the organisations were awarded the funding and whether it has to be spent by the end of the financial year (2022-23), the then Cabinet Secretary could not confirm these details and committed to providing them. In supplementary evidence, the Scottish Government confirmed that officials engaged with third sector organisations in late December 2022 and early January 2023 to invite proposals for initiatives that they could undertake by the end of the financial year 2022-23. Organisations were then informed of the outcome of their proposals between 18th January and 27th January 2023, and payments were processed to organisations on receipt of signed grant offer letters and appropriate paperwork. The Scottish Government confirmed that the funding was to be used for activity which will be delivered by the end of March 2023. [104]

145. The Committee welcomes the work being done by health boards and the third sector on self-management services for Long COVID but notes that it is not working in the integrated way the third sector considers it should be. The Committee welcomes the Scottish Government's funding for these initiatives and notes that this funding was to be used by the end of March 2023. The Committee however acknowledges that self-management services are not suitable for all patients and this recent funding does not address the need for better treatment and services in the NHS.

Consistency of services and coordinated approach

146. In order to improve the consistency of services and a coordinated approach across territorial health boards, the National Strategic Network has recommended that additional resources should be prioritised to allow more time to be spent on the holistic assessment and support of people with long-term effects of COVID-19. The Scottish Government said [88] —

> NHS Boards are using the resource to develop pathways which aim to support early intervention and improved co-ordination of support and services for people with Long COVID. For example, many Boards are introducing a single point of access for assessment and coordinated support from services including physiotherapy, occupational therapy and psychology, depending on what is most appropriate for a person's needs.

147. The Committee sought witnesses' views on the work being done by the National Strategic Network set up by the Scottish Government to support the coordination of health and social care services for people with Long COVID. Many respondents to the call for views spoke of a lack of consistency and coordination in the services offered by health boards. This was echoed by Jane Ormerod who told the Committee [105] —

> What the Government says is happening and the reality for people with lived and living experience do not match up. I agree that different things are happening in different health boards and that consistency is an issue. I know that everywhere is different and that the geography is different, but there needs to be overall consistency and shared principles of what that should look like in each health board, and that message is not getting through.

148. She spoke of the need to coordinate health services for people with Long COVID. She commented— [106]

> Co-ordinating care for Long COVID— whether it is done through a one-stop shop or something else—would surely be a better use of resource than sending people here, there and everywhere to different specialties. In the current climate, that takes a long time. Unless it is an emergency, getting a referral—even for respiratory issues—could take quite a long time.

149. CHSS argued for a coordinated approach to be adopted with access to multiple specialisms for treatment and diagnostics including integrated referrals to third sector self-management and support. On the lack of coordinated care, CHSS said [107] __

> 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.

150. When asked if there were any plans to issue standardised guidance across all health boards on accessing and coordinating services, Janis Heaney said [108] —

> I guess that that will develop as the network develops. The key guidance document that will be used is a NICE guideline, which is a living document on standard clinical guidance in the area. As we develop the network and work with the subject matter experts and service planners, we may look to develop further guidance for specific pathways if it becomes clear that there is a need for that. However, the main document is the NICE clinical guidance in that area.

151. Claire Jones, Advanced Clinical Practitioner and Long COVID Therapy Lead at Betsi Cadwaladr University Health Board made the point that Long COVID does not sit under a single specialism with symptoms covering a range of specialist areas such as cardiac, respiratory, neurological and gastric. The result being patients reported feeling abandoned or passed from pillar to post, with referrals to multiple specialisms and long waiting times. She argued co-ordination of care and case management is therefore fundamental when treating the condition. [109]

152. The then Cabinet Secretary acknowledged the lack of consistency across health boards saying [110] —

> It is clear that they [health boards] are looking at where such an approach is working well—NHS Lanarkshire provides a good model in that respect—and are trying to get that level of consistency, but Jane Ormerod is not wrong: there is a lack of consistency and a difficulty in accessing pathways.

153. He explained the importance of having national consistency in access to pathways however, that does not necessarily mean adopting a 'one-model-fits-all approach' and spoke of NHS Highland as a good example of where a virtual model has been developed to meet the needs of the geography and population of the area. [110]

154. On the role of the National Strategic Network in developing and consistency of services across health boards, Christopher Doyle, Senior Policy Manager of the Clinical Priorities Unit at the Scottish Government said it was key in supporting improvement and consistency at a national level and evaluating service provision across health boards. He said [111] —

> I would add that the network has a clinical and subject matter expert group that is collating information on current pathways of care for people who have Long COVID, and the group has indicated that it will support the development of standardised guidance in addition to that work, if appropriate.

155. The then Cabinet Secretary explained that the National Strategic Network brings together clinical experts, those who are delivering local services, and those with lived and living experience to look at service improvements. He said [111] —

> A load of key actions has come out of the National Strategic Network, with more actions to come, but its value lies in bringing those three key partners together to improve services for those who have Long COVID.

156. The Committee welcomes the establishment of the National Strategic Network to help support the development of Long COVID services across Scotland particularly in light of the pressures facing the NHS. However it is not clear what actions it has taken to address consistency of access to services across Scotland and evaluate service provision across health boards.

157. Moreover, while the Committee welcomes the establishment of the National Strategic Network, the Committee notes that information on the Network and its ongoing work is extremely scant, with no website or contact details available online. In the interest of transparency and accountability, the Committee recommends that the Scottish Government takes a more proactive role in overseeing the work of the National Strategic Network including raising the visibility of its meetings, priorities, and outputs. The Committee also requests that the Scottish Government provides an update to the Committee on actions taken to date by the National Strategic Network to improve coordination and consistency of access to services across Scotland over the next six months.

Access to clinical pathways

158. In its letter to the Committee, the Scottish Government explained that the National Strategic Network has established a clinical and subject matter expert group, bringing together professionals from different disciplines with expertise in the management of symptoms associated with Long COVID. It said [112] —

> the group is currently collating information on existing pathways of care for the management of symptoms associated with Long COVID, and will support the development of standardised guidance as required where variation in practice is identified.

159. NSS highlighted that its future plans included "scoping and development of clinical pathways" and the publication of a Self-Management Workbook developed by NHS Lanarkshire that can be shared with patients to support clinical pathways. [113]

160. The lack of clear Long COVID clinical pathways and associated support systems was raised by many respondents to the call for views. For example, Lynsay Gracie's point was typical [114] —

> 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.

161. Stuart McIver spoke of the services in NHS Lothian [115] —

> The pathways are not working. People are going to see their GP and the consistent feedback we get is that their GP looks at them and says that there is nothing available— that is not a slight against GPs, but there is a need for clinics for diagnostics.

162. He explained further by saying that although individual symptoms are treated [116] —

> ...in addressing individual symptoms people are just having little bits of their illness treated; nobody is actually looking at the complete picture of their illness or at the underlying pathology of it. A little bit of their illness is treated, but other things are being missed.

163. Lorraine Crothers representing RCOT spoke of the need for rehabilitation services and for patients to be able to access a range of multidisciplinary team members and developing clear pathways and support for them. She highlighted NHS Lanarkshire as a good example where occupational therapists are working in primary care settings working alongside GPs. [117]

164. Dr Shackles highlighted the NHS Lothian RefHelp guide is a good example which gives GPs a single point of access to which they can refer and called for clearer pathways so that GPs and patients know how they can access the system and what is available. He explained it was the responsibility of the health boards to put these pathways in place commenting [118] —

> There needs to be better direction to the pathways, which need to be smoother and simpler and to give easier access to all the modalities in specialist care, if that is required, whether we are talking about cardiology or respiratory care or whatever, to the rehabilitation pathways and to the third sector.

165. Jane-Claire Judson agreed it was the responsibility of health boards to put clear pathways in place but she said the implementation should also be co-ordinated nationally across all boards. [119] This point was echoed by Dr Claire Taylor who expressed concern regarding the number of rejected referrals to specialist services.

120

166. Both Manira Ahmad and Heather Cameron stated there were clinical pathways however Heather Cameron acknowledged that some were "arguably more robust than others." She said— [121]

> When there are very clear medical or symptomatic presentations as opposed to people having a less medically targetable presentation, some of those clinical pathways are more robust. For example, we know that chronic fatigue and brain fog are significant issues, but there is not a single profession or clinical specialty that owns them.

167. Linda Currie acknowledged shortcomings in the communication of clinical pathways and highlighted the time required to develop expertise saying [108] —

> We could definitely be doing more on communication of the pathways as they are being established. We also need to recognise that our clinicians are new in post and that they have to really be given time to develop their own expertise. There is an expectation that, once postholders come into post and the pathway is set up, there is an expert team.

168. Dr Janet Scott, Consultant in Infectious Disease (NHS Highlands) and Affiliate Senior Clinical Lecturer, MRC-University of Glasgow Centre for Virus Research also called for clear and well-publicised pathways. She said— [122]

> We have people sitting at home needing care and we do not have the pathways to deal with it, so we need to ensure that those pathways exist. We need to ensure that, if a patient needs self care, face-to-face physiotherapy or occupational therapy, a secondary care advocate or a general physician, they can access those facilities. Then, we need to publicise it.

169. Professor Duncan spoke of his research which included four case studies which looked at various health boards and settings. He commented that in the two health boards that have had the promotion of accessible pathways for people to access that care had been useful and involved active publicising to GPs and patients of how to access the services. He said [123] —

> Where that happens, we see a massive influx of people coming for care. Where it does not happen, including where such services are not available, the numbers of people who come through to secondary services—to the rehabilitation professionals who are delivering integrated Long COVID rehab—are very small. The difference is quite stark.

170. As previously stated, at present, six health boards have Long COVID pathways up and running. When asked when clear clinical pathways will be available across all health boards, the then Cabinet Secretary highlighted that some do at present with NHS Highland having 100 referrals and in NHS Lanarkshire, there have been over 500 referrals made. He said [124] —

> I have every faith that more and more health boards will develop those services much more consistently. Some are already doing that. Some are using the funding and giving us timescales for when the pathways will be more fully developed...That is the number 1 issue that comes up from Long COVID sufferers time and again. They say that it all sounds good, but they ask whether the approach is consistently working across the country. The answer to that is not yet. That is what we are working on.

171. The then Cabinet Secretary confirmed he was aware of people being unable to access the correct support from their GPs and highlighted the NICE guideline and the Implementation Support Note which are there to provide GPs with details of available pathways. He commented that was why the Scottish Government had worked with the National Strategic Network on educational tools for GPs. He went on to say [125] —

> We have the implementation support note and an education strategy to raise awareness of Long COVID. NHS Education for Scotland also has its learning platform, and I suspect that members will know that it contains a video and webinar content on Long COVID. There is a lot in that space, and we are working closely with our primary care and GP colleagues to make sure that they know about the pathways that are available.

172. Mr Yousaf did however acknowledge that accessing and navigating support services for people with Long COVID can be challenging saying [32] —

> There is certainly room for improvement—there will be no challenge to that premise from me.

173. The Committee notes the evidence on the need for Long COVID clinical pathways across all health boards and is disappointed to hear that, to date, only six health boards have these in place and two more were aiming to have them in place by the end of March 2023. The Committee recommends that the Scottish Government works with National Strategic Network on implementing Long COVID pathways across all territorial health boards in Scotland and the development of standardised guidance. The Committee requests that the Scottish Government provides the Committee with indicative timescales for implementing these priorities.

Single point of contact

174. When seeking treatment for Long COVID, being passed 'from pillar to post' was a point raised by a number of respondents to the call for views. [126]

175. The Committee considered the issue of a single point of contact for access to Long COVID services within health boards, an issue raised by witnesses and highlighted by the Scottish Government as something which many health boards are introducing.

176. Dr Strain noted that people with lived and living experience said providing a single

point of contact for every patient who had been referred was absolutely essential. He explained that patients are often referred to multiple different specialists and can find it difficult to navigate the various health service teams, a point made in written submissions. He said [127] —

> The most important and best feedback that we received was that every single patient going through the system should have a named individual as a core point of contact to act almost as their liaison between the different specialities.

177. He also made the point that a single point of contact was essential for people with learning disabilities and those who might be differentially advantaged due to their socioeconomic status. He explained that those people may not be computer literate and, therefore, might not have the ability to do video consultations. He said [127] —

> A key component of the service has been the use of simple phone calls, which would always be from a person who the patient would be able to recognise and whose voice they would know. One of the difficulties has been establishing boundaries, which we have managed to achieve really effectively; that appears to be the way that we have addressed some of those issues.

178. During the informal evidence sessions, the Committee heard about the levels of potential unmet need in Scotland and inequalities in accessing services. It is estimated that 175,000 people in Scotland have self-reported symptoms of Long COVID. Claire Jones said a single point of contact would provide support for marginalised patient groups. [128]

179. The then Cabinet Secretary agreed that a single point of contact would be important in helping patients access a number of services and that the Scottish Government funding is intended to address this. He said [57] —

> I have heard far too often from Long COVID sufferers that, when they go to primary care or their GP, they are passed from pillar to post and there is no single point of access. I think that I can safely say that the majority of the health boards—or a significant number of them—are using the funding that we have given to them to create a single point of access so that an individual is not passed from pillar to post.

180. The Committee considers a single point of contact for patients to access services and coordinated support would be helpful. The Committee recommends that the Scottish Government and the National Strategic Network works with health boards to introduce a single point of contact for each Long COVID patient across all territorial health boards in Scotland.

Workforce and capacity

181. The Committee was informed that a key challenge for health boards setting up Long COVID services related to workforce and capacity issues and funding underspends. Staffing capacity issues within the NHS and the challenges this brings in developing effective Long COVID services was highlighted both in written and oral evidence. Dr

Shackles highlighted the ever-increasing pressure on GPs. He commented [129] —

> Over the past three years, there has been a very small rise in the head-count number of general practitioners, but there has been a drop of 3 per cent in the whole-time equivalent number of general practitioners.

182. Ian Mullen highlighted that there are an estimated 10,000 NHS staff in the UK who are now off work long term with COVID-related symptoms. [130] Dr Small and Lorraine Crothers also highlighted the reduced capacity within the NHS as a result staff sickness due to Long COVID. [131]

183. Dr Heightman highlighted that 10 per cent of her patients are NHS staff, a figure which is replicated in the national registry across many services in England. [132] Dr Strain highlighted a BMA survey of doctors which suggested that across the UK, approximately 7.2 per cent of doctors are suffering on-going symptoms of Long COVID, and 5.3 per cent have had Long COVID but have managed to make a sufficient recovery and have returned to work on their normal hours. [133]

184. The Scottish Government confirmed that for the week ending 21 March 2023, a daily average of 528 NHS staff were absent due to COVID-related illness. This represents 0.29% of the total workforce, or 39% of the absence recorded as related to COVID-19. [134]

185. A number of the health board responses also highlighted the difficulties in recruiting specialist staff for their Long COVID services. For example, NHS Fife said it had no spend in this year against the Scottish Government available funding saying [135] —

> The primary reason for this is that we have had recruitment challenges into our specified posts (Rehabilitation Co-ordinator, Occupational Therapist and Physiotherapist).

186. It went on to outline the challenges around the non-recurring nature of the funding saying—

> ..when advertised, these posts are temporary in nature with the offer of a 21-month fixed term contract. Given the significant challenge we have in recruitment across these professions for permanent posts, the temporary nature of these makes them less attractive to prospective applicants.

187. NHS Borders highlighted 'Whole system pressures' had prevented clinicians and service leads from dedicating time to Long COVID service development over the winter of 2022/23. [136] NHS Tayside also spoke of recruitment challenges saying [137] —

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

188. NHS Forth Valley too spoke of recruitment difficulties saying [138] —

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

189. Judy Thomson, Director of Training for Psychology Services at NHS Education for Scotland, agreed that retention and recruitment were issues affecting the development of services and pathways. She referred to temporary funding commenting [139] —

> Quite a lot of the funding has been provided on a temporary basis, so it is quite difficult to make those posts attractive enough to get specialists from AHPs and other disciplines into them. That is a significant issue that has come through in the submissions from a number of our health boards and which has an impact on how effective the pathways that have been set up can be.

190. Claire Jones, Dr Heightman and Dr Strain all spoke for difficulties in England and Wales regarding recruitment and non-recurrent funding. Claire Jones commented there has been a commitment to recurrent funding from the Welsh Government. She said [140] —

> We were not able to spend the money because we were not able to recruit to temporary positions. It was a challenge. That has led to longer waiting times than we would like or are acceptable, so we hope that the recurrent funding will mitigate that. We have certainly had more interest in posts that we have advertised as permanent, so I am confident that recruitment will be successful.

191. When asked how health boards could be supported to recruit for Long COVID posts, and to what extent would recurrent funding address the recruitment issues that health boards had highlighted, the then Cabinet Secretary argued that the Scottish Government has made it clear that the £10 million funding will be available over the next few years. He said [47] —

> We know that there are some issues with recruitment, but we are working—and will continue to work—with the boards to see what more we can do about those challenges.

192. Mr Yousaf also acknowledged that the recruitment challenges were one of the reasons that the full £3 million was not being spent this year by health boards and therefore the Scottish Government approached third sector organisations and allocated funds to them. **[11]** When asked exactly when the organisations were awarded the funding and whether it has to be spend by the end of the financial year, the then Cabinet Secretary could not confirm these details and committed to providing them.

193. In supplementary evidence, the Scottish Government confirmed that officials engaged with third sector organisations in late December 2022 and early January 2023 to invite proposals for initiatives that they could undertake by the close of the financial year 2022-23. Organisations were then informed of the outcome of their proposals between 18th January and 27th January 2023, and payments were

processed to organisations on receipt of signed grant offer letters and appropriate paperwork. The Scottish Government confirmed that the funding was to be used for activity which will be delivered by the end of March 2023. [104]

194. The Committee notes the workforce and capacity pressures faced by health boards across Scotland and the impact this is having on Long COVID service development. The Committee further notes the recruitment difficulties faced by health boards due to the non-recurring nature of funded posts and other pressures is resulting in health boards not using all of the budget allocated to them. Whilst reallocating the underspend in health board funding will assist with self-management of some patients where appropriate, it is really symptomatic of the current funding arrangement for Long COVID clinical services being not sustainable. The Committee urges the Scottish Government to work with health boards to rethink its approach to funding Long COVID services as a matter of urgency.

Long COVID clinics

195. The Scottish Government's position on Long COVID clinics is that it is for each NHS Board to develop and deliver the best models of care tailored to the needs of their local population and said that this may involve strengthening the co-ordination of existing services, or establishing dedicated services where appropriate. It stated [90] —

> While none of the services being delivered by NHS Scotland Boards are termed 'Long COVID clinics', initiatives being supported by the funding include key elements of care that are also offered by post COVID assessment clinics elsewhere in the UK, including pathways providing assessment and co-ordinated access to relevant support and services in line with individual patient needs.

196. The Committee heard mixed views on the use of Long COVID clinics. The call for written 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.

197. 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.

198. NHS 24 said that it was is aware from its staff who talk and listen to people with lived and living experience of Long COVID that many of them say that they would welcome the use of Long COVID assessment clinics. [141]

199. Both Michelle Powell Gonzalez and Ian Mullen said they were in favour of Long COVID clinics where a joined up approach could be adopted. [66] Rob Gowans commented [21] —

> The people whom we have spoken to who are living with Long COVID have been supportive of the idea of clinics. I do not know whether those would necessarily be a magic bullet, but they would provide an opportunity to bring specialisms together and might allow for earlier diagnosis, which has been a particular issue.

200. He went on to say that the key thing was to provide holistic support, whatever the route. [142]

201. However, most of the substantial submissions provided details of what types of Long COVID assessment and diagnostic services they would like to see implemented, rather than focusing on how these services are delivered (such as through a Long COVID clinic, or in another way).

202. Many respondents to the call for views 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. [143]

203. 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 [144] —

> 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.

204. 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. [145]

205. The Long COVID Rehabilitation in Scotland Study Team highlighted its study of Long COVID Rehabilitation (LOCO-RISE), 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 [146] —

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

206. A lower number of respondents were not in favour of clinics said 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.

207. RCGP Scotland argued that Long COVID patients should be managed within general practice. It 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. [147]

208. There were also mixed views on the use of Long COVID clinics from Stirling University's research study, COv-VOICES, undertaken by a team of researchers from the Universities of Stirling, Aberdeen and Oxford. 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. [148]

209. 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. [149]

210. NHS Fife, RCGP and the Royal College of Physicians of Edinburgh (RCPE) all called for an evaluation of the clinics set up in England. RCPE said [150] —

> 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.

211. Claire Jones questioned the use of clinics in terms of the cost and staffing issues saying, in Wales [109] —

> We do not have an abundance of consultants from a variety of specialties who are available to run clinics for Long COVID. More importantly, our argument is that that model is not always necessary.

212. The then Cabinet Secretary reiterated the Scottish Government's position on Long

COVID clinics saying he had never been opposed to them in principle but wants to support health boards to design services that meet their local needs. He said he strongly agreed with the views of the RCGP who said the GP is best placed to provide a holistic approach due to the risk that a patient may present with Long COVID symptoms but may in fact have another condition. For this reason, the RCGP argued that patients should undergo a GP assessment and investigation rather than being sent to a clinic designed to specialise in one condition. Mr Yousaf said [151] —

> In effect, they try to cut out the middle person. We have GPs and, if they have the appropriate referral pathways through the implementation support note that take people directly to a Covid rehabilitation service in, for example, Lanarkshire—that is the example that I keep using—that is a better model than a GP having to refer someone to a Long COVID clinic that would then have to refer them on to another pathway.

213. The Committee notes the differing views on the use of Long COVID clinics and can see both advantages and disadvantages to that approach. The Committee notes the then Cabinet Secretary's comments that he had never been opposed to Long COVID clinics in principle but wants to support health boards to design services that meet their local needs. The Committee invites the Scottish Government, working with the National Strategic Network, to take a leadership role in reviewing the best practice of Long COVID clinics and evaluate whether they may be an appropriate development here. The Committee considers it essential that, whatever approach is adopted by health boards, it must be a holistic approach to Long COVID services, supported by a clear referral pathway that includes access to multidisciplinary teams of specialists.

Paediatric services / transitions to adult services

214. The ONS estimates that 23,000 2- to 11-year-olds have Long COVID in the UK and 39,000 12- to 16-year-olds 12 are estimated to have Long COVID. NHS England has established a specialist Long COVID service for children and young people through 15 paediatric hubs. [152]

215. The Committee heard that Long Covid Kids supports around 12,000 families worldwide. Roughly 50-60% of those 12,000 are UK based with over 200 families who reside in Scotland. Participants in the informal discussions said it is expected that the number of families affected by Long COVID is much higher. [153]

216. The issues discussed throughout this report are, of course, relevant to children and young people with Long COVID, however the Committee wanted to look specifically at the services available for children and young people as concerns were raised during informal discussions and in written evidence regarding this. Parents spoke of feeling very let down by the medical profession and the Scottish Government regarding the lack of help and support in diagnosing children with Long COVID and providing appropriate treatment and support. [153]

217. Long Covid Kids highlighted in its written submission a lack of awareness of the need for paediatric services stating [154] —

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

218. The Committee also heard of examples of where children have had problems accessing both paediatric and adult services for Long COVID. RCOT highlighted a lack of support services for children and young people experiencing symptoms of Long COVID. It stated that members 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. [155]

219. On the impact of Long COVID on children and young people, Stirling University [156] highlighted research findings which showed the importance of education 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.

220. In its submission NHS Education for Scotland (NES) highlighted its work with children and young people saying [157] —

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

221. Janis Heaney confirmed during evidence that the National Strategic Network is establishing a children and young person workstream which will have lived and living experience representation. [158]

222. On service provision, the then Cabinet Secretary confirmed that assessment and initial investigation are still provided by the primary care team for children and young people with symptoms of Long COVID. He pointed out that primary care clinicians can then refer them to occupational health or physiotherapy for further advice or support. He highlighted that the Implementation Support Note has information on the referral pathways and the other support that exists for children and young people and that this was developed in consultation with the Royal College of Paediatrics and Child Health. He went on to say [159] —

> It sets out that, where self-management, for example, is not effective, and there is a significant impact on the young person or child's education or quality of life, they should be referred to general paediatric services for investigation.

223. He pointed out that the Long COVID Support Fund is intended to strengthen services for young people with Long COVID and cited NHS Greater Glasgow and Clyde's recruitment of additional paediatric occupational therapist support for young people, children and their families as an example of health boards using funding in this way.

224. He also highlighted work of the National Strategic Network where it is progressing a dedicated workstream that brings together clinical experts and people with lived experience to identify needs and priority actions that are specifically for children and young people. He explained that this would include looking at the transition of children and adolescents into adult services to ensure no gaps exist. He also said [160] __

> As you would imagine, that issue presents itself in many other parts of the health and social care system, but it has not been raised with me specifically in relation to Long COVID. However, I am happy to take that issue up with Long Covid Scotland and Long Covid Kids.

225. The Committee notes the Implementation Support Note contains information on the referral pathways and the other support that exists for children and young people. The Committee is also somewhat reassured regarding the work being done by the National Strategic Network on identifying priority actions that are specifically for children and young people. However, evidence to this Committee suggests that currently not enough is being done to help support and treat children and young people with Long COVID including transitions to adult services therefore this work needs to be progressed.

226. The Committee recommends that the Scottish Government works with National Strategic Network to progress the workstream on children and young people as a matter of urgency and involves Long Covid Scotland and Long Covid Kids in this work, which should include milestones and timescales for action. The Committee also requests to be kept updated on this work.

Approaches to referrals across the UK

227. As a comparison with developments in Scotland, the Committee was interested in the development of Long COVID services across the rest of UK. The NICE/SIGN guideline on managing the long-term effects of COVID-19 applies across the UK. However, there has been some variation in how services for Long COVID have been organised. In England the NHS has established around 90 post COVID assessment services clinics. These are intended to provide access to specialist diagnosis, treatment and rehabilitation.

228. In July 2022, NHS England, published National commissioning guidance for post

COVID services. [161] This sets out post COVID service requirements, referral routes and criteria for post COVID services, pathways of care and the role of primary care, multidisciplinary rehabilitation, children and young people – including the children and young people (CYP) patient pathway, workforce, data management and information and key service outcomes. This was published alongside the NHS plan for improving Long COVID services. [162] A similar approach has been taken in Northern Ireland.

229. In Wales, as in Scotland, support is provided within the wider NHS services through local health boards. The Welsh Government published the All Wales Community Pathway for Long-COVID in June 2021. [163] The NHS Wales Respiratory Health Group has developed a Long COVID Recovery App as part of the wider support available for people experiencing the longer-term effects of COVID-19.

230. Dr Melissa Heightman spoke of the expansion of clinics in England from initially, in 2020, acting as assessment clinics to the current situation where the clinics offer a holistic assessment and treatment pathway and are designed to bring in multi-disciplinary teams. She highlighted that these were referral clinics where patients were referred to by their GPs or a hospital specialist. She said [164] —

> In short, the services have evolved into integrated networks within each integrated care system and are trying to drive proactive treatment of Long COVID as a multisystem condition.

231. She highlighted commissioning guidance which aims to provide consistency of services across England however this will not always be the case given the complicated nature of the services, NHS constraints and workforce shortages.

232. Claire Jones, told the Committee what happened in Wales. She explained that the All-Wales community pathway for Long COVID has been used to inform local pathways and ensure a consistent approach across Wales but recognises that the services might be organised differently according to local needs and circumstances, therefore there is some variation across the seven health boards in Wales. She also said that the composition of the multidisciplinary teams can vary due to recruitment challenges and service design issues. She highlighted that GPs and health professionals can refer patients multidisciplinary recovery services in North Wales but that patients can also self-refer. She said [165] —

> The pathways ensure that patients can get personalised assessment and treatment for their needs and that care is provided as close to home as possible. As a result, we have more of a community model in Wales, with the aim of treating the symptoms that can be treated, promoting and supporting self-management and value-based care that can be accessed in the community and agreeing with the individual care that is tailored to their specific needs.

233. She said the service consists of a GP with a specialist interest in Long COVID, other allied professionals and a psychology team which allows them to manage symptoms from within that service, rather than having to refer to all the different specialties or Long COVID clinics. She said [109] —

> We think that our model works because our service is staffed with the correct skill set and the correct mix of MDT professionals.

234. On self-referral, she explained that this approach was a direct result of collaboration with people with lived and living experience of Long COVID and their desire for ease of access which has proved to be successful with no more inappropriate referrals than would be the case with healthcare professional-only referrals. [165]

235. Dr Heightman explained the decision was taken against self-referral in England because of the uncertain medical risk within the patient group where other conditions could be causing symptoms but added it was not necessarily a bad thing. [166] Dr Strain also highlighted they have referral to their services through GPs, saying an initial primary care assessment is absolutely central in order that those core investigations are done to ascertain whether there are other medical causes resulting in the patients' symptoms. [166]

236. He explained in Devon they operate Long COVID assessment and triage-based service using a hub-and-spoke model. He said that referrals are assessed by a multidisciplinary team, and they are then referred out to an appropriate team locally depending on what their needs are. He said [167] —

> Rather than moving to a pure Long COVID service, we are now looking far more at a multidisciplinary assessment followed by the utilisation of existing services. That is driven partly by geography, and partly by staff shortages; there are simply not the additional staff with the appropriate expertise to run a pure Long COVID service without taking anything away from other essential services in our health service.

237. When discussing the different approaches taken across the UK, Dr Heightman commented the concept of a Long COVID service 'is one that sits at the interface between primary, community and secondary care and can draw in all the elements that the individuals need' which will vary depending on geography. She said [168] —

> As we try to transition to a more business-as-usual model in England, we are starting to think about what elements have been very successful and what we must keep going forward after this year of funded services.

238. On the involvement of people with lived and living experience in the development of services in England and Wales, Dr Heightman confirmed that they had been a key part of the national programme in NHS England and co-designed the commissioning guidance and the plan for improving services. She made the point that it was important to have a strong lived-experience voice at the regional level, 'because you need to look at the granularity of what you are offering' which can be challenging for people who have severe fatigue, 'but it is something that we will really encourage as we move to that business-as-usual model'. [168] Dr Strain also confirmed the involvement of people with lived and living experience in Devon's service development and that this has been a major part of their recent redesign of the service. [168]

239. The Committee notes the evidence it received on what is working well across the UK and the differing approaches to self-referral. The Committee recommends that the Scottish Government and National Strategic Network review the evidence heard by this Committee to identify areas of best practice and opportunities for shared learning and to ensure that clinical pathways and NHS services in Scotland reflects this.

Study and research

Research commissioned by the Scottish Government

240. In October 2020, the Chief Scientist Office (CSO), part of the Scottish Government's Health Directorates, launched a funding call, seeking applications for research to investigate the longer-term effects of COVID-19. Following an independent expert review process, nine projects were funded with a total funding commitment of around £2.466 million. [169] The funding outcome was announced in December 2020 and included projects to better understand the symptoms of, and factors associated with, Long COVID, to examine effects on cognitive function, and to evaluate rehabilitation approaches. [170]

241. The following nine projects are currently at the mid-point stage, with some publishing initial findings—

- Amplifying the voices of people with lived experience to improve understanding, support, treatment and education. Share-to-improve: Long COVID experience (COvVOICES) Study University of Stirling Professor Kate Hunt £299,883.
- Defining and understanding the longer-term effects of COVID-19: A mixed methods study exploring the frequency, nature, and impact of 'Long COVID' in the Scottish population University of Glasgow Professor Jill Pell £299,562
- COVID-19: Tracking Persistent Symptoms in Scotland (TraPSS) University of the West of Scotland Professor Nicholas Sculthorpe £239,358
- Prevention and early treatment of COVID-19 long term effects: a randomised clinical trial of resistance exercise University of Glasgow Professor Colin Berry £286,660
- Developing and validating a risk prediction model for Long COVID-19 University of Edinburgh Professor Aziz Sheikh £189,659
- Clinical phenotyping to enable targeted treatment of persistent cognitive symptoms after COVID-19 University of Edinburgh Professor Alan Carson £290,941
- Longer term impact of COVID-19 infection people with diabetes University of Glasgow Dr Robert Lindsay £295,201
- Evaluating emerging models of community rehabilitation for people experiencing the effects of long-COVID to inform responsive service delivery across Scotland Robert Gordon University University of Stirling Professor Kay Cooper (RGU) Dr Edward Duncan (UoS) £296,545
- Lived experience of long term COVID-19 on NHS workers in health care settings in Scotland: a longitudinal mixed methods study Robert Gordon

University Dr Nicola Torrance Dr Aileen Grant £294,605

242. Professor Dame Anna Dominiczak, Chief Scientist and Regius Chair of Medicine at the University of Glasgow made the point that under normal circumstances, the CSO would not necessarily commission research rather, it has two research committees which contain expert scientific advisers who advise on the best projects to fund.

243. She also pointed out that the majority of health, clinical, and public health research in Scotland is not funded locally through Scottish funding but through other sources. She informed the Committee that the CSO proactively informs all stakeholders across Scotland about opportunities with UK Research and Innovation, the Medical Research Council and the National Institute for Health and Care Research. She said— [171]

> We do everything that we can to ensure that Scottish clinicians, scientists and public health researchers get optimal access to funding for Long COVID research and everything else, but we do not normally give priorities in relation to what they should be applying for.

244. On the Scottish Government's use of research, Dr Harden highlighted it incorporated in practice through the SIGN, NICE and the RCGP guideline. [172] He pointed out that published research is constantly reviewed and incorporated into updates to the guideline. He said as the CSO funded research projects are published, SIGN, NICE and the RCGP will review the evidence and update the guideline. [31]

UK wide funded research

245. In 2020, two long-COVID specific calls were launched in 2020 from—

1. (National Institute for Health and Care Research (NIHR) / UK Research and Innovation (UKRI)

2. National Institute for Health Research (NIHR)

246. The NIHR/UKRI call announced in February 2021 that 4 projects totalling £18.5m had been funded. The NIHR call announced in July 2021 that 15 projects totalling £19.6m had been funded. Two of these 15 projects were Scottish led—

1. Activity tracking and just-in-time messaging to improve adaptive pacing: a pragmatic randomised control trial – Professor Nicholas Sculthorpe – University of the West of Scotland

2. ReDIRECT – Remote diet intervention to reduce Long-COVID symptoms trial - Dr Emilie Combet and Dr David Blane – University of Glasgow [173]

247. Dr Janet Scott made the point that participating in UK wide funded research and clinical trials, such as the LOCOMOTION study and drug trials platforms run through Long COVID clinics in England, can be difficult due to the virtual nature of

the services and lack of Long COVID clinics in Scotland. [174]

248. When asked what oversight of UK wide funded research exists, Professor Dame Anna Dominiczak confirmed that CSO works closely with colleagues across the four nations involving oversight groups such as the office for strategic co-ordination of health research—OSCHR—where funders of clinical and public health research come together. She said [175] —

> We discuss things bilaterally with UKRI, including the Medical Research Council, and major charities, including the Wellcome Trust. However, as we said before, like the CSO, all those bodies, including the National Institute for Health and Care Research, have their own expert committees.

Priorities for research

Understanding the causes of Long COVID

249. Many individual respondents to the call for views called for more research into the causes of Long COVID and for biomedical research into diagnosis and possible treatments. For example, Sarah McDonald said identifying potential treatment targets and testing therapies should be priorities for research and study. She said [176] —

> 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.

250. This was echoed by Professor Dame Anna Dominiczak who said there was a need to understand the mechanism of Long COVID saying [177] —

> We need to find the biomarkers that would allow us to stratify patients and, through precision medicine, provide treatments that truly address the underpinning mechanism, which might be different in different groups of patients. There is still a lot to do, but it will be done through international effort rather than our local effort. It has to be part of international work.

251. Dr Scott also agreed that more research is needed into the cause and treatment of Long COVID [174] —

> ...we have to develop experts in Long COVID, which means seeing the patients so that we can come up with the right studies and the right questions to move things from characterising—which is what we did in 2020—on to, as Professor Dominiczak says, understanding the underlying aetiology and then providing proper management strategies and treatments.

252. Dr Strain highlighted in evidence that a major barrier to providing Long COVID services was a lack of knowledge where the natural history of the disease is unknown. He said [178] —

> There has been a dearth of research into the most similar disease to it, myalgic encephalomyelitis, so we do not yet have an understanding of that similar condition.

253. This was 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/ Post-Viral Fatigue Syndrome (PVFS) / Mast Cell Activation Syndrome (MCAS).

254. Dr Heightman spoke of the lack of understanding of the epidemiology and treatment of the condition and highlighted that only one trial of treatments is currently running in England on repurposed medicines. She said [179] —

> The void in the understanding about mechanisms and treatments is putting patients at risk, as they are seeking so-called miracle cures by travelling abroad to foreign clinics that are claiming benefits from certain treatments. We have not seen evidence of that, but we are all very concerned about it.

255. The then Cabinet Secretary acknowledged that more work has to be done on the causes and treatments for Long COVID saying that the science is still in its early stages and the lack of effective treatments can add to patients' stress [32] —

> That science is still in its early stages, and proven, safe, evidence-based treatments are still in their infancy. Scotland is contributing to that worldwide research effort and, in the meantime, we are taking steps to test new ways to support people.

Clinical trials and treatments

256. 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. Jane Omerod also called for Scottish research projects to be linked to British and international research. [180]

257. Dr Scott suggested further study and research into developing diagnostic techniques and imaging e.g., Xenon Gas MRI and ImmunoPET and into treatment strategies. She also called for treatment strategies with swift, prioritised national

trials to rule in and rule out treatment options. She said that Stimulate_CP has been set up for this 'but is struggling with prioritisation and recruitment'. [181]

258. 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.

Children and young people

259. In written responses to the call for views, there were a number of calls for further research into the impact of Long COVID on children and young people. The University of Stirling suggested this could include a comparison of experiences by age, gender, social class and ethnicity to identify where interventions could be focused [182] .

260. NHS Fife, COSLA and Social Work Scotland (SWS) 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.’ [183]

Health inequalities

261. During evidence the Committee heard of the inequalities that exist in relation to people accessing support and treatment for Long COVID, particularly in relation to women, people with disabilities and those from deprived areas. This was also raised by some respondents to the call for views.

262. 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 [184] —

> 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.

263. 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 [185] —

> 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.

264. The University of Stirling 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.

265. Dr Aileen Grant and Dr Nicola Torrance called for further research into the impact of health inequalities and deprivation on people affected by Long COVID. They said [186] __

> 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.

266. The Committee commends the Scottish Government for funding the nine projects in Scotland and considers the results will be valuable in increasing understanding of the condition. The Committee notes that this funding was made available due to the exceptional nature of the pandemic and that the majority of health, clinical, and public health research in Scotland is not funded by the Scottish Government.

267. The Committee also notes the numerous suggestions for priorities for future research particularly in relation to—

- Understanding the causes
- Clinical trials and treatments
- Children and young people
- Health inequalities

268. Given the importance of ongoing research into Long COVID on service development and treatment of the condition, the Committee encourages the CSO to continue its work in ensuring that Scottish clinicians, scientists and public health researchers get optimal access to UK funding for Long COVID research. In addition, the Committee recommends that the Scottish Government considers funding further research through CSO on areas outlined in this report.

Data

269. The Scottish Government highlighted that the Strategic Network is undertaking a work stream to facilitate a consistent national approach to the collection of data relating to Long COVID, that allows for comparative analysis across Scotland. It

said [112] —

> A workshop has been held with key stakeholders to identify data collection needs and further activity is planned to determine and agree recording and reporting mechanisms required at local and national levels.

270. In its Long COVID service [187] , the Scottish Government said that accurate data was vital and it had worked with RCGP Scotland to support primary care teams in the recording of long-term effects of COVID-19 within clinical information systems.

271. Dr Strain spoke of research he has been involved in which has access to 25 million patient primary care records in England. The research looked at the coding in patient records across different areas and found as Long COVID services were set up in a particular area, the number of patient records with Long COVID coding in that area increased. He commented that although Long COVID was being recognised by GPs, they may not have been using the appropriate coding and tools in patient records.

272. The issue of how data is deployed in developing services was raised by a number of witnesses including Jane-Claire Judson who said there was enough data and evidence which could be used in designing services. She explained further [188] —

> Data is great, but what really counts is what you do with it, and getting that in place internally in the NHS is really important.

273. Dr Shackles agreed that there was enough evidence on Long COVID to design services however he argued that data collected from GPs needs to be improved such as coding. This issue was considered in more detail by the Committee in relation to the data on prevalence below. [189]

274. Manira Ahmad commented that PHS are developing whole systems modelling. She said the PHS has the opportunity to make that data translatable and digestible by reaching into local and regional systems and getting them to use it in their strategic planning and operational service delivery. [190]

275. The then Cabinet Secretary agreed that data and research into Long COVID was important and cited the usefulness of the EAVE II surveillance study. He informed the Committee that the Scottish Government intends to 'have such discussions on a four-nations basis—to look at the international data and research that exist'. He went on to highlight the work of the National Strategic Network's dedicated workstream which will 'agree outcomes, indicators, monitoring and evaluation to accelerate progress on capturing data' which will inform planning of our health service provision for people suffering from Long COVID. [31]

276. The Committee notes the importance of data and how this is used to plan future Long COVID services and welcomes the confirmation that the Scottish Government reviews published evidence and updates the guideline on an ongoing basis. However, the Committee notes that despite Scotland being a leader in collecting data, it considers that not enough is being done to deploy the data into clinical practice.

277. The Committee welcomes the work done by National Strategic Network to facilitate a consistent national approach to the collection of data relating to Long COVID, however the Committee considers that progress in this area needs to be accelerated. The Committee requests that the Scottish Government works with the National Strategic Network to progress this work on agreeing data collection outcomes, indicators, monitoring and evaluation both locally and nationally and keeps the Committee updated on this work.

Prevalence

278. Many respondents to the call for views spoke of the lack of data on the prevalence of Long COVID across Scotland, including COSLA and SWS. The University of Stirling 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 [191] —

> …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).

279. A number of respondents commented on the usefulness of ONS data, including CHSS, NHS 24 and NHS Fife, as it captures people who are not presenting to primary care may include people from lower socio-economic backgrounds and black and minority ethnic communities. The Chartered Institute of Personnel and Development (CIPD) noted its limitations, explaining [192] —

> 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.

280. Dr Heightman also said it was difficult to know the exact prevalence of Long COVID but said that the ONS COVID Infection Survey, in which people self-report a Long COVID illness, has been the best source of information. She made the point that the proportion of those people who need to access NHS care is unknown but is estimated to be about a fifth. She went on to explain that in England, clinics submit data returns at patient level every two weeks providing a national registry of all the patients who have been seen. Dr Heightman explained that this can be a useful learning resource however this information must be joined up with coding data from GP practices to get a better understanding equity of access and health inequality issues. [193]

281. Dr Scott highlighted the Long COVIDa study led by Jill Pell, "Defining and understanding the longer-term effects of COVID-19: A mixed methods study exploring the frequency, nature, and impact of ‘Long COVID’ in the Scottish population", of which she is the co-investigator. This research is gathering data on

prevalence of Long COVID in Scotland and patients with lived experience of COVID-19 symptoms and members of a steering group providing advice during the project. [174]

282. Claire Jones suggested a national registry for patients be established, which could potentially provide support and help to record services and prevalence, as well as support diagnoses. Ms Jones said, however, that this could potentially exacerbate the risk of diagnostic overshadowing where new symptoms are not investigated as it is assumed they are related to the Long COVID diagnosis. [193]

Coding

283. In March 2021, the Chief Medical Officer outlined the codes that should be used to record the long-term effects of COVID-19. He stated 'As you will appreciate, accurate recording of information within clinical systems is necessary in order to provide an accurate picture of activity in relation to this new condition.' [194] In October 2021, PHS also published COVID19: ICD-10 Analytical Guidance. [195]

284. However, concerns were raised regarding GPs not coding patients with Long COVID correctly and therefore affecting the accuracy of prevalence data. 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 [196] . Concern around the lack of appropriate coding by GPs of Long COVID cases was echoed by many individual respondents to the call for views and by witnesses. Stuart McIver said— [197]

> If the illness is not being properly coded and we do not know the scale of the problem, how can we solve it? Analytical work must be undertaken to address that, and that could be done.

285. 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 [198] .

286. Dr Aileen Grant and Dr Nicola Torrance called for awareness of the need for coding in electronic health records [199] . This point was also raised by Michelle Powell Gonzalez who argued that GPs were unaware of the diagnostic code for Long COVID. She said [200] —

> In my group, we were circulating screenshots of the different diagnostic codes, because the NHS uses two different systems, and we were presenting them to our GPs and saying, “Hey, this is a diagnostic code for Long COVID. Please put that in my records. I want that to be in my records to show that I have Long COVID.” A lot of the time, GPs could not find the codes, so, in essence, the burden was put on us to try to get that information into our records so that you guys and the Government would have that information and be able to do something. It is quite absurd to have that information circulating in the group and for us to have more information than GPs.

287. This point was also echoed by Professor Robertson who found during the EAVE II study on electronic health records, the Long COVID code was not used very often,

with GPs frequently using the free text option to note patients' conditions instead. [201]

288. The Committee notes the calls for more data on the prevalence of Long COVID and the impact that incorrect coding of Long COVID can have on the accuracy of prevalence data. The Committee recommends that the Scottish Government works with the National Strategic Network and health boards on improving accurate coding of Long COVID by GPs and explores possible simplifications to the process of coding. The Committee requests that it is kept updated on this work.

Data sharing

289. The Scottish Government published its Health and Social Care: Data Strategy in February 2023. This acknowledged that information systems do not offer universal accessibility to make it easier to share information and that the strategy seeks to illustrate how current systems can maximise information-sharing to support practice as it considers future innovations to meet this need. The Strategy also explains that the protection and sharing of data is managed by information governance and cyber security processes and procedures which is governed by data protection legislation. [202]

290. Dr Strain said the BMA plans to use healthcare records to improve healthcare planning and services however concerns remain regarding who has access to these records and ensuring this has no effect on the trust between a patient and doctor. [203]

291. When asked does Scotland have an information technology system that allows for the proper deployment and sharing of data across the whole system, Professor Chris Robertson, Professor of Public Health Epidemiology at the University of Strathclyde said 'The answer is yes and no.' [204] He highlighted the EAVE II which has data from 5.1 million health records and GPs from everyone in Scotland however, the ethical and governance permissions meant that researchers were not allowed to interrogate the GP data itself. He explained [204] —

> We had to pre-specify clinical risk groups that would be important, as well as vaccination data. Having pre-specified that amount of data, we were then able to extract it and move it into Public Health Scotland for surveillance and studies on vaccine effect during the pandemic. A copy of the data also went into the electronic data research and innovation service—eDRIS—platform for other researchers to access.

292. He said that once the GP information was obtained and having community health index numbers in Scotland, meant that the project could link that to all the other data that is available providing 'a phenomenal resource not just for research but for management and surveillance of COVID and almost any other disease in Scotland.' [204]

293. This lack of data sharing was confirmed by Heather Cameron who said the information system is not fit for purpose as it does not provide an overall picture across primary care, secondary care, specialist services as 'different health boards have different services, so if someone happens to move across different health boards, their information is not always easily shared'. [205] This point was also echoed by Linda Currie who also highlighted the opportunities for data collection presented by C19-YRS app which is currently going through a national procurement process. [190]

294. The then Cabinet Secretary acknowledged the challenges associated with sharing data saying [206] —

> So many of the challenges that we have faced across health and social care have happened because we simply have not dismantled the barriers to sharing data effectively.

295. He went on to say that through the health and social care data strategy, rather than having one IT system across the NHS, the Scottish Government is considering whether it is possible to use the cloud infrastructure to ensure that 'anyone in either system who has to access data can do so through a cloud-based system'. He highlighted that this was one of the data strategy's eight priorities for action. [206]

296. The Committee notes the importance of data sharing across NHS IT systems in planning services and the barriers faced regarding data protection issues. The Committee requests that the Scottish Government keeps the Committee updated on its work in this area and on the delivery of its priorities of the Health and Social Care: Data Strategy.

Annexe A

Extracts from the minutes of the COVID-19 Recovery Committee, public engagement sessions and associated written and supplementary evidence

28th Meeting, Thursday, 15 December 2022

4. Long COVID: The Committee agreed its approach to the inquiry.

3rd Meeting, Thursday, 9 February 2023

1. Long COVID: The Committee took evidence from—

- Rob Gowans, Policy and Public Affairs Manager, Health and Social Care Alliance Scotland (the ALLIANCE);
- Jane Ormerod, Chair and Stuart McIver, Long Covid Scotland ;
- Michelle Powell Gonzalez, Long COVID Support Group: Scotland ;
- Ian Mullen, Covid Action Scotland;
- Sammie Mcfarland, CEO and Founder, Long Covid Kids.

2. Consideration of evidence (private): The Committee considered the evidence heard earlier in the meeting.

Written evidence:

The Alliance

Covid Action Scotland

Long Covid Kids

Long Covid Support Group: Scotland

4th Meeting, Thursday, 23 February 2023

1. **Long COVID:** The Committee took evidence from—

- Dr David Shackles, Joint Chair, Royal College of General Practitioners Scotland;
- Jane-Claire Judson, Chief Executive Officer and Dr Amy Small, Clinical Advisor, Chest Heart & Stroke Scotland;
- Lorraine Crothers, Board member, Royal College of Occupational Therapists;
- Dr Claire Taylor, Tayside Complete Health Ltd and Expert Advisor on Long COVID to

the World Health Network;

and then from—

- Manira Ahmad, Chief Officer, Public Health Scotland;
- Janis Heaney, Associate Director – National Strategic Networks, National Specialist and Screening Services Directorate (NSD), NHS National Services Scotland;
- Linda Currie, Associate AHP Director, NHS Highland;
- Heather Cameron, Director of Allied Health Professions, NHS Lothian;
- Judy Thomson, Director of Training for Psychology Services and Professor Lindsay Donaldson, Deputy Medical Director, NHS Education for Scotland .

Murdo Fraser indicated that he is registered with Dr Shackles' practice.

2. Consideration of evidence (private): The Committee considered the evidence heard earlier in the meeting.

Written evidence:

Chest Heart & Stroke Scotland

NHS Education for Scotland

Royal College of General Practitioners Scotland

Royal College of Occupational Therapists

5th Meeting, Thursday, 2 March 2023

1. **Long COVID:** The Committee took evidence from—

- Claire Jones, Advanced Clinical Practitioner and Long COVID Therapy Lead, Betsi Cadwaladr University Health Board;
- Dr Melissa Heightman, Clinical Lead, Post Covid Service, University College London Hospitals and North Central London Respiratory Network, National Specialty Advisor, Long COVID Program, NHS England;
- Dr David Strain, Senior Clinical Lecturer, University of Exeter Medical School, Lead on Long-Covid, British Medical Association, Member of the NHS Long-COVID Taskforce.

Stuart McMillan was invited to declare any relevant interests. He indicated that he had no interests to declare.

2. Consideration of evidence (private): The Committee considered the evidence heard earlier in the meeting.

6th Meeting, Thursday, 9 March 2023

1. **Long COVID:** The Committee took evidence from—

- Euan Dick, Head and Professor Dame Anna Dominiczak, Chief Scientist (Health),

Chief Scientist Office;

- Professor Chris Robertson, Professor of Public Health Epidemiology, University of Strathclyde;
- Professor Kay Cooper, Clinical Professor of Allied Health Professions, Robert Gordon University and NHS Grampian;
- Professor Edward Duncan, Nursing Midwifery and Allied Health Professions Research Unit, University of Stirling;
- Dr Janet Scott, Consultant in Infectious Disease (NHS Highlands) and Affiliate Senior Clinical Lecturer, MRC-University of Glasgow Centre for Virus Research.

1. **Consideration of evidence (private):** The Committee considered the evidence heard earlier in the meeting.

Written evidence:

Chief Scientist Office

Dr Janet Scott

7th Meeting, Thursday, 23 March 2023

1. **Long COVID:** The Committee took evidence from—

- Humza Yousaf, Cabinet Secretary for Health and Social Care,
- John Harden, Deputy National Clinical Director,
- Ashleigh Simpson, Team Leader - Planning and Quality Division and
- Christopher Doyle, Senior Policy Manager – Clinical Priorities Unit, Scottish Government.

1. **Consideration of evidence (private):** The Committee considered the evidence heard earlier in the meeting.

9th Meeting, Thursday, 20 April 2023

Long COVID (In Private): The Committee considered a draft report. Various changes were agreed to, and the report was agreed for publication.

Written submissions:

The Committee received a significant number of written submissions from organisations and individuals to the call for views which have been published online—

Published responses

Summary of responses

Supplementary Evidence

Public Health Scotland

Professor Kay Cooper and Professor Edward Duncan

Long Covid Scotland Action group board feedback survey

LOCOMOTION Long-COVID Study Lay Summary provided by NHS Highland

Long Covid Scotland Hearing our Voices

Long Covid Scotland Employment Survey Report

Correspondence

At the outset of the inquiry, the Committee wrote to the Cabinet Secretary for Health and Social Care on 25 November 2022. The Cabinet Secretary responded on 20 December 2022.

Letter to the Scottish Government

Scottish Government's response

On 22 March 2023, the then Cabinet Secretary for Health and Social Care wrote to the Committee with an update regarding the funding made available through the Long COVID Support Fund.

Letter from the Cabinet Secretary for Health and Social Care - Long COVID Support Fund

The Committee also wrote to all the health boards, NHS National Services Scotland and the Thistle Foundation at the outset of the inquiry on their current Long COVID services. The responses are listed below.

NHS Ayrshire and Arran

NHS Borders Long COVID inquiry response

NHS Dumfries and Galloway

NHS Education for Scotland

NHS Fife

NHS Forth Valley

NHS Grampian

NHS Greater Glasgow and Clyde

NHS Highland

NHS Lanarkshire

NHS Lothian

NHS National Services Scotland

NHS Orkney

NHS Shetland

NHS Tayside

NHS Western Isles

Thistle Foundation

Informal engagement sessions

On Thursday, 12 January 2023 the Committee spoke with participants, who were contacted through Long Covid Scotland as part of the launch of its inquiry into Long COVID.

Note of discussion

The Committee hosted an informal, online meeting on Thursday, 2nd February 2023. The Committee spoke with participants, who were contacted through Long Covid Kids as part of the inquiry into Long COVID.

Note of discussion

[1] SIGN Guidance - Managing the long-term effects of COVID-19, November 2021 update. (n.d.) Retrieved from https://www.sign.ac.uk/our-guidelines/managing-the-long-term-effects-of-covid-19/ [accessed 6 April 2023]

[2] ONS. Coronavirus (COVID-19) latest insights: Infections. (n.d.) Retrieved from https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/coronaviruscovid19latestinsights/infections [accessed 4 April 2023]

[3] Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK. (n.d.) Retrieved from https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/30march2023 [accessed 5 April 2023]

[4] Long COVID: where are we now?. (n.d.) Retrieved from https://spice-spotlight.scot/2023/02/08/long-covid-where-are-we-now/ [accessed 7 March 2023]

[5] Scottish Government news release. Long COVID Support Fund. (2021, September 9). Retrieved from https://www.gov.scot/news/long-covid-support-fund/ [accessed 8 2023]

[6] Scottish Government Press Release - £3 million awarded to long COVID projects. (2022, May 19). Retrieved from https://www.gov.scot/news/gbp-3-million-awarded-to-long-covid-projects/ [accessed 5 April 2023]

[7] Scottish Government. Scotland's Long Covid service. (2021, September 30). Retrieved from https://www.gov.scot/publications/scotlands-long-covid-service/ [accessed 7 March 2023]

[8] Letter to Cabinet Secretary for Health and Social Care, 25 November 2022. (n.d.) Retrieved from https://www.parliament.scot/-/media/files/committees/covid19-recovery-committee/correspondence/2022/letter-to-cabinet-secretary-for-health-and-social-care--long-covid-inquiry.pdf [accessed 7 March 2023]

[9] Letter from the Cabinet Secretary for Health and Social Care 20 December 2022. (n.d.) Retrieved from https://www.parliament.scot/-/media/files/committees/covid19-recovery-committee/correspondence/2022/letter-from-cabinet-secretary-for-health-and-social-care--long-covid.pdf [accessed 7 March 2023]

[10] Letter from the Cabinet Secretary for Health and Social Care 21 March 2023. (2023, March 21). Retrieved from https://www.parliament.scot/-/media/files/committees/covid19-recovery-committee/correspondence/2023/cabinet-secretary-for-health-and-social-care-long-covid-support-fund.pdf [accessed 28 March 2023]

[11] COVID-19 Recovery Committee. Official Report, 23 March 2023, Col 11. (n.d.) Retrieved from http://archive2021.parliament.scot/parliamentarybusiness/report.aspx?r=15228&mode=pdf [accessed 29 March 2023]

[12] Sample letter to health boards 17 January 2023. (n.d.) Retrieved from https://www.parliament.scot/-/media/files/committees/covid19-recovery-committee/correspondence/2023/long-covid-sample-letter-to-health-boards.pdf [accessed 7 March 2023]

[13] No title (n.d.) Retrieved from https://www.parliament.scot/chamber-and-committees/committees/current-and-previous-committees/session-6-covid19-recovery-committee/business-items/long-covid [accessed 8 March 2023]

[14] SPICe paper - Therapy and rehabilitiaiton. Annexe. (n.d.) Retrieved from https://www.parliament.scot/~/media/committ/5291 [accessed 15 March 2023]

[15] Long COVID inquiry. Call for views - summary of responses. (n.d.) Retrieved from https://www.parliament.scot/-/media/files/committees/covid19-recovery-committee/long-covid-call-for-views-summary-of-responses.pdf [accessed 6 March 2023]

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