OFFICIAL REPORT
AITHISG OIFIGEIL

COVID-19 Recovery Committee

Thursday 9 February 2023

Session 6

The Scottish Parliament
Pàrlamaid na h-Alba

Thursday 9 February 2023

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COVID-19 RECOVERY COMMITTEE

3rd Meeting 2023, Session 6

CONVENER

*Siobhian Brown (Ayr) (SNP)

DEPUTY CONVENER

*Murdo Fraser (Mid Scotland and Fife) (Con)

COMMITTEE MEMBERS

*Jim Fairlie (Perthshire South and Kinross-shire) (SNP)
*John Mason (Glasgow Shettleston) (SNP)
*Alex Rowley (Mid Scotland and Fife) (Lab)
*Brian Whittle (South Scotland) (Con)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Rob Gowans (Health and Social Care Alliance Scotland)
Sammie Mcfarland (Long Covid Kids)
Stuart McIver (Long Covid Scotland)
Ian Mullen (Covid Action Scotland)
Jane Ormerod (Long Covid Scotland)
Michelle Powell Gonzalez (Long Covid Support Group: Scotland)

CLERK TO THE COMMITTEE

Sigrid Robinson

LOCATION

The David Livingstone Room (CR6)

Scottish Parliament

COVID-19 Recovery Committee

Thursday 9 February 2023

[The Convener opened the meeting at 09:44]

Long Covid Inquiry

The Convener (Siobhian Brown): Good morning, and welcome to the third meeting in 2023 of the COVID-19 Recovery Committee.

This morning, we will take evidence as part of our inquiry into long Covid. I welcome Rob Gowans, policy and public affairs manager at the Health and Social Care Alliance Scotland; Ian Mullen, from Covid Action Scotland; Sammie Mcfarland, who is chief executive officer and founder of Long Covid Kids, who joins us online; Jane Ormerod, who is the chair of Long Covid Scotland; Stuart McIver, from Long Covid Scotland; and Michelle Powell Gonzalez, from the Long Covid Support Group: Scotland, who also joins us online. We have received apologies from Donna Convery of Long Covid Support Group: Scotland.

I thank the witnesses for giving us their time and for their written submissions. We estimate that the session will run until about 11 o'clock, and each member should have about 10 minutes to speak to the panel and ask their questions.

For witnesses who are attending remotely, if you would like to respond to any issue that is being discussed, please type R in the chat function, and we will try to bring you in. I am keen to ensure that everybody gets an opportunity to speak, so I apologise in advance for the fact that, if time runs on a bit too much, I might have to interrupt members or witnesses in the interests of brevity.

I invite the witnesses to introduce themselves briefly, starting with the witnesses who are joining us online.

Sammie Mcfarland (Long Covid Kids): Good morning. I am the CEO and founder of Long Covid Kids. We have a Scottish branch as well; Helen Goss was unable to be here today, so I am filling in for her. My daughter and I both got Covid in March 2020 and still have long Covid.

Michelle Powell Gonzalez (Long Covid Support Group: Scotland): Hi, everybody. I am the founder of Long Covid Support Group: Scotland, which is an online support group that I started in October 2020. I got Covid in April 2020 and have never recovered.

Rob Gowans (Health and Social Care Alliance Scotland): I am the policy and public affairs manager for the Health and Social Care Alliance Scotland. We have done quite a bit of policy and lived experience engagement work on long Covid, which I hope to tell you about this morning.

Ian Mullen (Covid Action Scotland): Good morning. I have been a member of Covid Action Scotland for approximately two and a half years, and I am also a Unison trade union representative with the City of Edinburgh Council. I have done a number of presentations to various campaign groups.

Jane Ormerod (Long Covid Scotland): Hello. I am chair of Long Covid Scotland, which is an advocacy and action group for people with long Covid that was established in 2020. I have long Covid; I have had Covid twice and, unfortunately, am still suffering the after-effects.

Stuart McIver (Long Covid Scotland): I am also from Long Covid Scotland—I am a trustee and a member of the steering group. Unfortunately, I, too, have long Covid.

The Convener: Thank you. We turn to questions, and I will begin with the theme of public awareness of long Covid. The Scottish Government has committed to delivering a targeted long Covid awareness campaign, in conjunction with community pharmacies, but a lot of the submissions that we have received so far in our inquiry have highlighted that there is a low level of awareness of long Covid. What more could or should be done to raise public awareness and recognition of long Covid? Stuart, do you want to go first?

Stuart McIver: Certainly. I think that education—at an occupational level and through public health messaging—is key to that. There should be mandatory Chartered Institute of Personnel and Development training for health professionals, public sector human resources units and, where possible, in private businesses. On-going health messaging is also really key.

Public information material, such as television and radio ads, can reach out across the community and make people aware of the risks of catching Covid. There is limited recognition of the effects that long Covid has on people or of the risk to people's health of multiple infections if they do not take any precautions. 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.

The Convener: Thank you, Stuart. Does anybody else want to come in on what the Scottish

Government could be doing to raise awareness further?

Ian Mullen: I fully support what my colleague has just said. Employers have to do more; I do not think that the understanding exists in workplaces around reasonable adjustments and the long-term health surveillance plans that require to be put in place. In my experience, I have not come across any really good examples of that.

I would like to see a lot of the employers—the Government, especially—leading by example by signing up to the Independent SAGE Covid safety pledge. There are a number of supporters of that in big companies and in the voluntary sector; my own union branch has recently signed up to it. The pledge makes employees, service users and third parties aware that we take Covid seriously and that it has not gone away, as much as the United Kingdom Government would like to just sweep it under the carpet. The Scottish Government and the Scottish Parliament should lead by example.

Rob Gowans: I echo those points. It is incredibly important that more is done to raise public awareness. It is disappointing that people who live with long Covid still describe not being believed. There is a lot more scope for awareness among healthcare professionals, employers and state agencies, such as the Department for Work and Pensions, Social Security Scotland and local authorities, around things such as social security payments, self-directed support and social care.

There is scope for more awareness in wider society, too, because long Covid is outwardly invisible; the impact of people being told, “I don’t believe you,” or “There’s nothing wrong with you,” is devastating. Encountering that attitude from healthcare professionals and employers, in particular, has negative effects. Targeted and wider public awareness raising work needs to happen.

The Convener: Michelle, would you like to come in?

Michelle Powell Gonzalez: Yes, please. I would like to make the point that the Scottish Government and the UK Government have made very little effort to do any awareness raising of the effects and dangers of long Covid, throughout the pandemic and now—essentially, we are still in the pandemic. We are now living through a time when mitigation measures have been completely scrapped, which is atrocious, because lots of people with long Covid feel further alienated from society.

Really simple things, such as wearing masks indoors in public spaces that are heaving with people, as well as better air filtration systems in schools to protect our community members, could easily be implemented. We feel completely let down by the Government. It is almost as if Covid does not exist any more—we do not hear anything about Covid at all, let alone long Covid.

Doctors do not know anything about Covid, either—when I talk to them, general practitioners tell me that I am the long Covid expert, which leaves me feeling quite unnerved. Many of the members in my group feel exactly the same way. Many doctors say that long Covid does not even exist. A lot more briefing and educating needs to happen, and pathways need to be created in the NHS for us to be able to get proper testing and treatments and so on.

The Convener: Thank you, Michelle—that was helpful.

I turn to Jane Ormerod. Do you consider that enough is being done to encourage people with long Covid to seek help?

Jane Ormerod: No, I do not. Many of them do not need encouragement—they need a system in which they can speak openly about what is going on for them. With regard to access to healthcare professionals, and GPs in particular, the experience is very mixed. It is not consistent, and many people are discouraged by that.

People—me, for example—are getting lost in the system and falling off the edge, down the cracks or whatever. I have had long Covid for three years now, and it is very challenging to try to be acknowledged as somebody with a more chronic disease and to get effective treatment and care for that.

Yes, people need encouragement, but I do not need encouragement—I need somebody to offer me a consistent approach to managing what has become a chronic illness. We all need that.

The Convener: You need a clear pathway.

I bring in Sammie Mcfarland.

Sammie Mcfarland: We desperately need an awareness campaign for the general public to ensure that families can identify long Covid in their children and can seek support, and we need clear guidance on the pathway and what that support looks like.

Further, we need education for clinicians and allied health professionals so that they can identify long Covid and the associated conditions, and apply treatment protocols. Many conditions that sit under the umbrella of long Covid can be treated, but they are currently not being treated. That area could be expedited in order to improve people’s quality of life.

It would be nice to see a way for policy makers to have a full and comprehensive understanding of the obstacles and challenges that families face. It would be helpful to build policy around lived experience and to have lived experience input in the design from the very beginning, rather than as an afterthought, with people being invited to comment on something that has already been created.

Importantly, we need prevention: we need to turn off the tap of long Covid. We have been campaigning for clean air since 2020, and for better health and learning outcomes. That is about not just reducing Covid, but improving health outcomes across the board. It is well documented that the benefits of clean air will help in many scenarios, not only for asthma but for a lot of other conditions. We have a specific interest in educational settings, all the way through to higher education.

The Convener: Thank you, Sammie. We move to questions from Murdo Fraser.

Murdo Fraser (Mid Scotland and Fife) (Con): Good morning to you all. I will pursue a similar line of questioning, but I will look at the specific question of training on long Covid, which Stuart McIver mentioned.

As a committee, we have already picked up anecdotally that a lot of medical professionals simply do not have an understanding of long Covid. As you can imagine, GPs are very busy dealing with many other things, and when people present with long Covid, they do not understand the condition.

There are some obvious questions. What specific training would be helpful? Are you aware of any examples of good practice that already exist around training, not just for medical professionals but for employers in the public sector and elsewhere?

Jane, do you want to start?

Jane Ormerod: There is a range of resources out there; you do not have to look very far. For instance, there are accredited professional resources, including from the Royal College of General Practitioners, and the SIGN—Scottish intercollegiate guidelines network—guidelines. We have a plethora of information; the issue is how that gets to professionals.

I think that it is well known that healthcare professionals tend to listen only to other healthcare professionals. Listening to lived experience in terms of education is a bit further down the list. However, it is vital that lived experience is incorporated into the whole process.

10:00

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

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

There are plenty of online resources, but there are also plenty of people with lived 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.

There are online resources to learn from, including on how things are done in other places, predominantly England, but I do not think that people there are in a better position than we are, in that respect.

Michelle Powell Gonzalez: From what I am seeing in my group, a lot of people are going private. There is one doctor in Dundee, Claire Taylor, who has long Covid, and she is helping other people with long Covid, as 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.

I really feel that we need long Covid clinics that use a joined-up approach. At the moment, we are seeing loads of specialists who look at things from a tiny little perspective, and they do not talk to one another. We are not getting any answers.

I have had X-rays and ultrasounds and all kinds of different tests that show absolutely nothing, but we know that something is going on. The tests that I am sent for at the moment are not really doing anything. The doctors do not know what to do, and they send people for routine tests but, to my mind, that is a huge waste of money. There are tests that could be done that actually target long Covid, and if the healthcare professionals were trained properly, they could look into that. Patient-informed long Covid clinics with joined-up resources and specialities to address what is a multisystem illness that affects the whole body would be amazing.

Ian Mullen: I fully agree that long Covid clinics are absolutely critical. The sooner they are introduced, the better. There is an inconsistent approach at the moment. We were having a discussion before we came up here this morning, and we were saying that you could ask two different GPs or medical practitioners for their interpretation of long Covid symptoms and they will come up with different answers. One colleague mentioned good-quality air. I have been campaigning for almost two and a half years for the introduction of high-efficiency particulate air—HEPA—filtration units in public buildings and workplaces, given the long-term benefits to health that the introduction of HEPA units brings.

That is especially relevant for schools. A huge number of children nowadays have bronchitis, asthma and other respiratory problems. If that can be caught at an early age, through the school system, there is a long-term health benefit. There is also an opportunity for older folk—I include myself in that group—who have respiratory issues.

I have seen the guidance that the Scottish Government produced on HEPA units, and I am not at all impressed. We spoke about that before coming to the meeting. During my campaign to get HEPA units in workplaces, which is still going on, managers have consistently copied and pasted the Scottish Government guidance. They cannot be bothered to write to me and give their personal opinion on HEPA. They copy and paste what the Scottish Government says, which is that HEPA units are not effective. They are effective. They have been used in clinical areas for at least the past 20 years.

My union branch set up two Teams meetings last year with a HEPA unit manufacturer that was an adviser to Sir Patrick Vallance. We invited managers, other trade unions and other campaign groups, but no more than 12 people turned up to those two meetings. I firmly believe that the Scottish Government is responsible for the lack of interest in producing good-quality air. We heard questions about what happens if a child touches a HEPA unit in a school, or who is going to change the filter.

There seems to be a perception that HEPA units are all small and mobile. They are not. They can be mounted on walls or fitted into air-conditioning units. I would like to see them in all new public buildings, and they could be retrospectively fitted into air-conditioning units to produce better quality air that would bring health benefits for workers and service users.

Murdo Fraser: Rob Gowans, to go back to my original question, are you aware of examples of good practice in training? A number of people have also mentioned long Covid clinics. Do you have a view on whether those would be a good thing?

Rob Gowans: There are some examples of good practice. The situation is inconsistent and comes down to individual employers or healthcare professionals. As other witnesses have said, there are plenty of resources out there, including from people with lived experience—Long Covid Kids has produced some excellent resources—but there is difficulty in getting those into the hands of healthcare professionals and in raising awareness in general.

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. People have waited for a long time or have been passed around without meeting someone with a specialism in or particular knowledge of long Covid.

The Convener: Alex Rowley has some questions.

Alex Rowley (Mid Scotland and Fife) (Lab): I want to look at the issue of stigma. Our papers refer to a recent study that said that 95 per cent of people with long Covid reported experiencing stigma related to their condition. Have you experienced or been told about discrimination as a result of long Covid? I will start with Sammie.

Sammie Mcfarland: 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. The negative media coverage and the minimising language that is used around long Covid feed into those issues, which make the obstacles and challenges facing families and children and young people 10 times harder.

Alex Rowley: If stigma is an issue, as the evidence suggests, what can be done, Stuart?

Stuart McIver: We have not really learned anything from myalgic encephalomyelitis—ME. 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.

As Jane Ormerod has intimated, there is an issue, too, about people falling out of the system due to stigma. Some progress has been made around self-management of treatment, but people have fallen out of the system. The stigma is that if you have long Covid and are getting nowhere, you will not go anywhere anyway. There is resistance from some GPs around getting treatment to individuals, who then become stigmatised by that experience and fall out of the health system—they are not getting anywhere so they just disappear from the system, which obviously affects the metrics about what is happening.

It is a very gendered issue, too. Women tend to be dismissed, which is an on-going issue with a lot of chronic illnesses, and men are underrepresented—I speak to my own bias here. Anxiety is regularly cited as an issue. The need for education and awareness ties into all chronic illness. We are not doing enough to tackle the problem at societal level. Employers are not doing enough, and more could be mandated in the public sector, too. Long Covid is not going away; we need to deal with the situation now so that we do not save up those problems for the future.

Alex Rowley: ME has a lot of similarities with long Covid. ME sufferers have talked for years about stigma—being dismissed as lazy and so on. Have we learned anything fae ME that we can bring to the table here, Rob?

Rob Gowans: As you have said, people have described similar experiences. It is disappointing and concerning that stigma and discrimination continue—that shows that we probably have not learned enough. We could use the experiences of long Covid and ME sufferers to inform treatment of ME. Sufferers could learn from each other—people who live with ME have had a long battle with similar issues, such as to be believed and recognised as having a long-term condition. With regard to how we progress, we have not learned enough as a society.

10:15

Alex Rowley: Jane Ormerod, are we seeing stigma with regard to the response of professional services?

Jane Ormerod: I would echo everything that everybody has said so far. There is no doubt that stigma influences the way that people with long Covid are viewed and treated and can access services. If there is an opportunity in this—there has been an opportunity for a long time with ME, I guess—it is to realise that, if things are not addressed, it just compounds the longer-term public health issues and the consequent burden on the health service and society. 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.

Alex Rowley: Ian Mullen, what about the workplace and employers? Is there stigma there as well?

Ian Mullen: I will add to what Jane Ormerod just said. It is bad enough when individuals have long Covid. I have a family member who developed long Covid after catching Covid in a school—they were one of 14 cases in a week. There is stigma attached to that, but there is also stigma attached to those who are immunosuppressed. 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. She actually left her job so that there would not be a conflict of interests—so that she could write articles about the guidance from the Scottish Government in relation to the workforce.

Again, we were talking about that before the meeting. There are individuals who just do not believe that Covid exists, and it is completely unacceptable that they preach that to staff or make silly comments to service users, such as “Oh, it’s just flu or a bad cold”. That should not be happening in any workplace.

On the situation in the national health service, I read an article last week by a campaign group called Keep Our NHS Public. There are an estimated 10,000 NHS staff in the UK who are now off work long term with Covid-related symptoms. Think about what 10,000 members of staff back working in the NHS could do right now, given the circumstances in the NHS. That would be a massive benefit to an already stretched workforce. There is a major issue with recruitment and retention in many workplaces.

Sammie Mcfarland: I will go back to the point about stigma. Following that false early narrative that children did not get affected by Covid, we see the attitude that they could not have caught Covid in the first place and that, therefore, any on-going symptoms could not possibly be long Covid. That is still happening—that goes back to the earlier comments about the lack of public awareness.

Children are usually screened for health issues at school, and because children with long Covid are often not in school, they are missed for screening. When their parents or caregivers try to take them to see healthcare professionals, they are told, “This is anxiety,” or, “It’s not possible for your child to have long Covid because children don’t get it.” Those caregivers eventually stop trying to go back for support because it is so crushing, demoralising and emotional. The detrimental emotional effect on the child and the caregiver outweighs any benefit that they would get from the help that they are seeking. That is really alarming and something that needs consideration.

John Mason (Glasgow Shettleston) (SNP): I recently met some GPs in my constituency who are working in some of the neediest areas in Glasgow—they are probably some of the neediest areas in Scotland. Among other topics, I discussed the following with them and they made some comments. I am interested to know the witnesses' reaction.

The GPs were pretty sceptical about long Covid clinics. That was partly because of cost, and because they would divert money and people away from existing NHS services. The rest of the NHS—GPs and the rest—is under a lot of pressure, and they felt that long Covid clinics would, effectively, put the rest of the NHS under even more pressure.

Another point that the GPs made was that most of the people whom they treat who have long Covid have multiple other long-standing issues as well, so to divert people away for long Covid would make the service even less joined up. At least at the moment a GP can deal with all their issues—including long Covid.

The other point that they made was that the main symptom they hear about in relation to long Covid is respiratory issues, and they are able to refer people to those with respiratory expertise, which seems to be working well. They feel that the present system is working reasonably well.

Would anyone like to comment?

Stuart McIver: I am quite surprised by that, because that is not represented in the comments and feedback on our website.

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

The illness is being treated as illnesses were pre-pandemic when a person would go and see their GP if they had an illness, but the correct level of diagnostics is not being carried out.

That is further borne out by people who have paid for medical care and interventions. The only improvements that I have made to my long Covid have been because I have paid to see specialists who have offered me treatment.

What John Mason said speaks to health inequalities—

John Mason: Can I just press you on one point? You said that if somebody goes to their GP they do not get referred, so are you saying that if somebody went to their GP with serious respiratory problems they would not be referred anywhere?

Stuart McIver: I can quote my GP, who said that there is no pathway.

John Mason: Did they say that there is no pathway for respiratory problems?

Stuart McIver: Well, there is a pathway for respiratory problems, but the overall pathology of the illness is not being addressed, and that is part of the issue.

John Mason: Symptoms are being addressed.

Stuart McIver: Yes, symptoms are, but 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.

John Mason: For some people, respiratory issues are the main problem, so that means that it is not only a little bit of their illness being treated.

Stuart McIver: Well, if respiratory symptoms are the main part of a person's long Covid, absolutely—treating them is great. However, that is not the feedback that we have got from other people who have been affected by the illness. I am sure that Jane Ormerod and the rest of the panel will say the same. Treating an illness in part is not treating the whole illness, and again, the feedback that we have had is that people are not getting any treatment because there is nothing to refer them to.

Health boards are starting to take action, but I have been very active in asking about what is going on because I would like to get treated, and I do not want to have to pay for private medical treatment. Treating individual symptoms does not address the underlying issues with the pathology, and other issues, properly, which could be—

John Mason: Okay. I will have to bring somebody else in. Jane Ormerod, do you want to come in?

Jane Ormerod: Like Stuart, I think that the message that you got from the GPs does not match up with what people with long Covid are saying. 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. The same applies to other specialties.

John Mason: The Government told us that it has a strategic network that is joining everything up. Are you aware of that?

Jane Ormerod: I am indeed.

John Mason: Do you think that it joins things up?

Jane Ormerod: What the Government says is happening and the reality for people with lived 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.

Some health boards have nothing in place and some have a little bit in place. The situation across Scotland is mixed. You might say that we are further on than we were two years ago, but that does not match up with what the Government says is happening. If it is happening, why is the experience of people with long Covid still so abysmal? That is the feedback that we get from our people. The two do not match up.

Ian Mullen: I will come in briefly. I agree with what Jane Ormerod and Stuart McIver said. It is not only about respiratory issues; long Covid also affects the internal organs. The mental health aspect of long Covid—and of catching Covid in the first place—is even more of an issue.

I have said this for the best part of a year and a half or two years: we could be heading towards a mental health pandemic, but that is not being addressed. I am not aware that any advice or guidance for long Covid sufferers and their mental health issues is being seriously considered.

John Mason: Do you think that long Covid sufferers need special treatment that is separate from that for everyone else who has mental health issues?

Ian Mullen: There could be joined-up working on that. Aspects of mental health services could be incorporated into long Covid clinics, so that it could be looked at as a complete illness.

It has to be recognised that we have a problem in this country, because the Health and Safety Executive did not recognise Covid as a virus of concern in the first instance, but many people became ill and ultimately died from it. We need to address that problem now. Well, it is too late—we cannae address it now. We have been through three years of this, and it has not been addressed. In the long term, if we do not address the overall illness, including respiratory issues and the effects on internal organs and mental health, we will be on a rocky road.

Rob Gowans: As I mentioned, as part of our engagement, we found that the majority of people living with long Covid supported the idea of clinics. People had different views on what the clinics should look like, but they thought that clinics could address the lack of a holistic approach.

John Mason: Is the argument that resources might be diverted away from existing NHS services a problem?

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

10:30

John Mason: Is that my time up, convener?

The Convener: No. We have a little bit of time. I think that Michelle Powell Gonzalez wants to come in.

John Mason: Jane Ormerod wants to come back in, too.

Michelle Powell Gonzalez: I want to address a couple of other things. First, in the vaccine campaign, people with long Covid are not on the list for getting boosters. 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.

Secondly, I would like to address the fact that long Covid is not a respiratory illness. I run the biggest support group in Scotland for long Covid, and I guarantee you that 99 per cent of the people in my group have at least three or four symptoms at the same time, which are ever-changing. Usually, there are a couple of base symptoms, but different things pop up—gastrointestinal, blood and cardiovascular issues, as well as mental health issues and other things.

We need a joined-up approach. We are desperate to get better, but what is happening now with our GPs is not working. The long Covid—what do you call them? I am sorry—brain fog. The places where you go to get diagnosed, the long Covid spaces—

John Mason: Assessment centres, maybe.

Michelle Powell Gonzalez: Yes—assessment centres. Thank you. Those places are not working; they are not helping us. All the people in my group are going to those places and not getting the help that they need. 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.

John Mason: Okay. I think that we are listening.

Ms Mcfarland wants to come in.

Sammie Mcfarland: I echo the point that Michelle Powell Gonzalez has just made. Long Covid is not a respiratory disease. Evidence is emerging that it is a vascular condition and, as such, any system in the body can be affected.

I have somewhat forgotten what I originally wanted to say, but I want to let you know that we have recently done a survey relating to healthcare services, which we are publishing in collaboration with the University of Derby, in which 72 per cent of people highlighted that their experience had not met their expectations. Those are preliminary findings; we are currently working on the deeper analysis. We will be able to provide specifics from the Scottish respondents—about 400 people—in our survey.

John Mason: That is great. If the witnesses have other points, they can bring them in later.

Brian Whittle (South Scotland) (Con): Good morning. I thank the witnesses for giving us their time.

I was going to look at current long Covid services and ask about your experience of accessing specialist care but, from the responses that we have had today, I conclude that we still have some way to go.

I want to put a couple of things on the table. First, are we collecting and utilising data? Secondly, we need to understand from the people who have gone through this journey what specialist care and assessments would look like. What do we need to build?

Stuart McIver: In England, some specialist clinics are working. We often refer to the clinics that do not work, but attention is not drawn to other models that do. Your colleague Dr Gulhane has cited the Hertfordshire model many times. The clinic at University College London hospital deals with post-Covid follow-up, neurology, anosmia and services for children. There are services out there.

Statistics from the Office for National Statistics are often quoted and derided for being self-reported. We are now three years into the pandemic, but we still do not know the scale of the long Covid issue. It is often said that Scotland has great data sets, but we are not using those. I do not know what the funding that has been allocated for long Covid services is based on, but the need will obviously grow as more people fall sick. We have heard from GPs and from people in the Long Covid Scotland group that GPs are not actually coding illnesses as being long Covid.

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

Jane Ormerod: Sammie Mcfarland talked about research. There is a reasonable amount of good-quality research looking at what long Covid is, suggesting approaches to assessment and looking at some work on tentative treatments.

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

We have done well in what some people might think is a short time to move things along, but we need things to happen more quickly. We need more focus, and people with long Covid should be more significantly involved in the process. That links to the data that you are asking about and that Stuart McIver talked about. We would have better and clearer data on a range of issues, as well as examples of good practice that could be shared.

Ian Mullen: I agree with what Jane Ormerod said. In each of our groups, there are medical people and scientists with huge amounts of experience in their fields. There should be a joined-up approach, whether that comes from the Government or from Independent SAGE. We are hearing absolutely nothing from the Government's SAGE.

There is a major issue with collating data. The Scottish Government issued guidance that there was no need to report or record cases, which was a fundamental error. The Scottish Government is responsible for not allowing workplaces in the public, private and voluntary sectors to collate the necessary data. We cannot rectify a problem unless we know that it exists.

I can talk about the example of schools. I received infection rate statistics first thing each morning for every school in Edinburgh, and I got statistics again at half past 6, or a bit later, each night, which gave me an understanding of where the spikes were. From 1 January to 31 March that year, there were 18,500 Covid cases in Edinburgh schools and early years settings—pupils and staff—which had a massive impact on the education system. There are 31 other local authorities, so imagine how many schools were impacted directly. However, with regard to that number, there is no information about how many staff or pupils have become long Covid sufferers, which is a major issue. It is the same with all the essential workers who worked all the way through the pandemic. There is no data available—I certainly have not seen any—that identifies how many essential workers have suffered through attending work.

Michelle Powell Gonzalez: I will speak about my personal experience and that of the group. We noticed that, for a year or two, there was no diagnostic code for long Covid and, when there was one, GPs did not know about it. 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.

Ian Mullen: In relation to Scottish local authorities and workplaces, I think that you would be amazed at how many reporting of injuries, diseases and dangerous occurrences regulations reports have been submitted to the Health and Safety Executive relating to long-term absences and absences of more than seven days as a result of work-related Covid cases. I have yet to come across one Scottish local authority that has actually submitted a RIDDOR report. Again, that is a result of the UK and Scottish Governments' guidance. It was part of the answers that I was given—which were copied and pasted—in response to the questions that I raised. Not one RIDDOR report to the HSE has been submitted in Edinburgh in relation to Covid infections.

Brian Whittle: What I am hearing is the suggestion that, "If we don't look, there won't be a problem."

I want to tie up the issues that were raised in response to questions from my colleague John Mason with what Stuart McIver said about assessments and the ability to diagnose long Covid. You described how, after going private, a long Covid diagnosis was reached by a process of elimination, using ECGs, MRIs and blood tests. The issue is that that is an intensive process for NHS staff to carry out. As my colleague John Mason said, that would be a huge amount of resource to allocate and potentially take away from other areas of the NHS. How do we deal with that?

10:45

Jane Ormerod: The diagnosis of long Covid is no different from the diagnosis of any other complex healthcare condition. It is a diagnosis of exclusion. Every process that a GP or doctor has to go through with a patient takes time. To put long Covid in a separate little box and treat it as so much more difficult and more complex than other complex diseases—or, indeed, any disease that requires a diagnosis and assessment—is not useful. Putting long Covid in the "more difficult" box stigmatises it for everybody, including for GPs and other healthcare workers.

John Mason was speaking about referral to specialist services. We have had members, and still have members, who were referred to specialist services, but the staff at those services refused to see them, because they had long Covid and the staff knew nothing about long Covid.

Brian Whittle: The health service is under such stress at the moment. We are aware of the waiting time for an MRI scan, for example. A long Covid sufferer might join that waiting list, and they might then join the waiting list for an ECG and for something else. The reality is that getting an early diagnosis of long Covid will be extraordinarily difficult under the circumstances that the NHS currently finds itself in. I am just putting that out there.

Jane Ormerod: I think that we understand that. We are all not immune from realising what is going on in the health service, as I think I pointed out earlier. However, if there was a consistent process for assessment that led, at some point, to diagnosis, that would be a vast improvement.

Brian Whittle: That is the point that I was trying to tease out.

Stuart McIver: It is about diagnostics. Tests are done, but they are not necessarily the tests that would help. If there was a baseline of set tests that would inform delivery, that would be more useful. We are talking about the strain on the NHS at the moment. By the same token, people are not getting any, or they are getting a minimal amount of, long Covid care, as we have fed back. Those people are taxpayers, too—I am a taxpayer, and I am entitled to long Covid care just as anyone else is.

Jim Fairlie (Perthshire South and Kinross-shire) (SNP): I thank you all for your patience and your determination to be here, which I know is causing some of you some difficulty.

I will try to do the mop-up bit at the end. The other committee members will have heard me talk about this before. I was interested to hear you talking about having complex issues. We know that women going through the menopause have exactly the same problem: they cannot get individual treatment. Whether it is menopause, ME or long Covid, there seems to be an issue in the health service around the need to treat things holistically. I have no idea how we solve that, but I hope that this inquiry will bring the health service and practitioners to the Parliament so that we can have a conversation about how we can improve the situation. We do not have the answers; we ask the questions so that people can come up with the answers.

How do we co-ordinate the support for folk who are suffering from long Covid? How do we bring things together so that we have comfort that what you have been dealing with is being dealt with? I am hearing that none of you feels as though what you are dealing with is being taken seriously.

Jane Ormerod: That is still an issue—I cannot deny that. I think that all of us here would say that it is a matter of not being taken seriously. I go back to what Brian Whittle said: it is almost like long Covid is being put in the “too difficult” box, and is yet another burden that the health service has to bear. It is complex and, as we know from any complex disease, it is too much for people to get their heads around. A lot of psychologising goes on around it; there is a lot of dismissing and gaslighting. That has gone on for many years with some of the diseases and conditions that have been mentioned.

Both for people who have the disease and for healthcare professionals, it is challenging to see beyond that and for the professionals to accept that sufferers need assistance and to be listened to. Even if they were to say, “I hear what you say, but I can’t solve it for you,” that would be better. We are not so naive as to think that a magic wand could be waved, but if the message that came back was, “We hear you,” it would help. That goes for the Government as well. I ask it not to pretend that something is happening when it is not.

Jim Fairlie: Let me push you on that point. In our evidence sessions, we have heard that long Covid has around 200 different symptoms and that someone could have one, 10 or 50 of them. Have you ever thought, “That is what has happened; there is nothing that I can do to change it”? Have you considered that?

Jane Ormerod: No one is going to make 200 symptoms go away. Not all of us have 200 symptoms, though. Last year we did a piece of research—a small survey—that came up with a whole range of symptoms, as you have described. However, there is a top six that the majority of people with long Covid suffer from.

If I were a healthcare professional facing someone who came in with a myriad of symptoms and I were to do a bit of research on PubMed or whatever, I would quickly see that those could be distilled down. I would ask where that patient sat within that range. It is not difficult to do that. If someone is faced with that and thinks, “Gosh, I don’t know what this is all about”, literature is available to help them. It could be that when people who are short of time are faced with such situations, they put them into the “too difficult” box.

Jim Fairlie: Sorry, Jane. I am going to stick with you, because I am on a thread here. The rest of you can come in in a bit. If the range of symptoms can be distilled down, which areas need to be prioritised in co-ordinating care and help for long Covid sufferers?

Jane Ormerod: We have talked about assessment being crucial. The first port of call has to be primary care.

Jim Fairlie: Would acceptance of the existence of the disease not come before the assessment? Earlier, Ian Mullen said that people dismiss the idea that it exists in the form that it does.

Jane Ormerod: Well, I do not think that that is a process—it is something else entirely. I am not sure that we can influence that. We have discussed measures such as publicity, better messaging and education. A patient cannot go through that process in a GP practice, whereas they can have access to a healthcare professional who can do a comprehensive assessment of their condition, make recommendations and filter that patient through accordingly. There is a gatekeeper function whereby they say, “Okay, we have done this assessment. This is what we’ve found, and this where we think this person ought to go next.” That might be happening in some instances, but I do not think that it is happening consistently. The process has to start, or be based in, primary care, simply because of the way in which the healthcare system in Scotland and the UK is set up.

Jim Fairlie: Okay—thank you. Does anyone else want to come in?

Stuart McIver: I was just thinking about Brian Whittle’s comment about support for long Covid sufferers. A suite of conditions falls under the category of chronic illness. For example, ME, the symptoms of which overlap with those of long Covid, is being discussed in the Parliament just now. Perhaps that presents an opportunity to look at chronic illness and try to deliver support across that whole suite of issues, including chronic fatigue syndrome and ME.

There is an overlap of symptoms and it might be a more effective use of resources to address overlaps and similarities in terms of symptoms, to look at chronic illness as a whole and to meet that need collectively. That would be more efficient than reinventing the wheel.

However, we are not saying that we should reinvent the wheel for ME or for long Covid. The problem with ME has come back to the Parliament after 20 years, but there are overlaps with long Covid that could lead us to address some of the fragmentary issues, such as mental health support—which, as we have said, is non-existent—employability and so on. That is a useful channel that could be developed to benefit people's lives.

It is also important to impart the crushing misery of the illness and how people are suffering. We are talking about systems, but people desperately need help. It is not about being a little bit tired; it is about taking five hours to get out of bed.

Jim Fairlie: Yes, the systems are important in terms of allowing people to deal with the illness.

Let me just clarify that you are not necessarily talking about long Covid clinics but about chronic illness clinics, for want of a better description.

Stuart McIver: That would be a start. It would certainly take some of the strain out of addressing such things. Long Covid might have its own pathology but virtually nothing is being addressed at the moment. Only very small elements of it are being addressed, so that would be an improvement on where we are just now.

Ian Mullen: I want to go back to the point that we have all discussed about the pressures that the NHS is under. I do not want to politicise this, but putting this into a quango is not going to make it any better. There is no quick fix for the NHS unless we reinvest the £600 million from the proposal in the National Care Service (Scotland) Bill into a properly run, resourced and funded care service. It should be properly run by the NHS; we should not be setting up a quango that does not address the needs of clinically ill individuals.

We have also not discussed the lack of information from the Scottish Government about high-risk categories. In the early part of the pandemic in particular, we heard about how the black and minority ethnic community was at five times higher risk than any other individuals. That then became a wider issue and other characteristics were added. I had to ask a member of the Scottish Parliament to ask a question in Parliament about guidance specifically for the BAME community. We are a multicultural nation but we have not addressed that issue.

Jim Fairlie: I am going to challenge that, Ian, because we have had numerous committee meetings at which the BAME community, disabled communities and others have all been taken into consideration. Time and again, we have talked about messaging. We had Jason Leitch before us specifically to talk about how to target that messaging. I challenge the point that you are making.

Ian Mullen: I am going back to when the pandemic and lockdown started. I registered for the UK's daily briefings, and we were going through anything from 30 to 50 a day. It took a few months, but references were made to the BAME community being at higher risk, and that messaging did not seem to come from the Scottish Government until quite a bit later. I accept that there were further discussions about that at a later date.

Jim Fairlie: Sammie, would you like to come in?

11:00

Sammie Mcfarland: Thank you. What I hear is that there seems to be this blinkered approach that, if someone has long Covid, they will need a certain set of assessments and services that somebody else does not need. However, due to the high number of infections, it is really likely that people who use NHS services have long Covid. We should start any medical assessment now by asking people, “Tell me about your Covid experience.”

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

I want to highlight the siloed aspect of the discussion about people with long Covid needing something above and beyond, or different from, what other people need. In truth, Covid has touched the entire population, including people with cancer, arthritis or other conditions and diseases. This is not about pulling resources away from those populations, but about supporting all populations better.

Michelle Powell Gonzalez: On the point that was made about diagnostics for long Covid—I do not remember when it was made; I am having a hard time remembering everything—in my limited knowledge of medical things, the main symptoms of people with long Covid tend to fall into four or five categories, three of which can be easily treated in GP surgeries. The first is postural tachycardia syndrome—PoTS—which can be easily diagnosed with a test, because GPs have everything that they need for it in their surgery. The second is mast cell activation syndrome—MCAS—which can easily be treated with certain antihistamines. I cannot remember the third one for the life of me—I have been trying to remember, but I cannot.

Those things can be easily treated as long as the GP does the research or is briefed and knows that we have these things. Instead, we are constantly going to the GP and saying, “Oh, look, I found this online and this is what could be happening.” I feel like I am a guinea pig at the moment—I am always going to my GP, who says “Maybe.” Why is my GP not looking into those things? Why are GPs not interested in investigating? Although we are talking about care, we also want results and investigations into why our bodies are having this issue.

The numbers in my support group are just going up. I started it in 2020; we had a big influx around the end of 2020, and the numbers keep growing exponentially every year. I added more than 100 people to the group just in January. The highest influx was last year in June, when I added nearly 200 people in one month. This is a growing problem and it is not going away. People are having to leave work; people in my group cannot afford to pay their bills any longer because their employer has sacked them—there is no way for them to work in a meaningful way because they would just make themselves sicker.

It is hard to navigate the benefit system as well, to be honest—a lot of us really struggle with that.

Thank you. I am kind of all over the place.

Jim Fairlie: No, thank you very much, Michelle. We will look at the last couple of issues that you have raised as we go through the process.

The Convener: We have gone slightly over time.

This has been a very informative and engaging start to our inquiry. I thank all the witnesses for their time and evidence. We will continue to take evidence in February and March before we hear from the Cabinet Secretary for Health and Social Care at our 16 March meeting. If the witnesses would like to give any further evidence to the committee, they can do so in writing. The clerks will be happy to liaise with them about how to do that.

The committee’s next meeting will be on 23 February, when we will continue our inquiry by looking at therapy and rehabilitation.

11:05

Meeting continued in private until 11:19.

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