OFFICIAL REPORT
AITHISG OIFIGEIL

COVID-19 Recovery Committee

Thursday 23 February 2023

Session 6

The Scottish Parliament
Pàrlamaid na h-Alba

Thursday 23 February 2023

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COVID-19 RECOVERY COMMITTEE
4th 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

COMMITTEE SUBSTITUTES

Jackie Baillie (Dumbarton) (Lab)
Sandesh Gulhane (Glasgow) (Con)
Stuart McMillan (Greenock and Inverclyde) (SNP)

THE FOLLOWING ALSO PARTICIPATED:

Manira Ahmad (Public Health Scotland)
Heather Cameron (NHS Lothian)
Lorraine Crothers (Royal College of Occupational Therapists)
Linda Currie (NHS Highland)
Professor Lindsay Donaldson (NHS Education for Scotland)
Janis Heaney (NHS National Services Scotland)
Jane-Claire Judson (Chest Heart & Stroke Scotland)
Dr David Shackles (Royal College of General Practitioners Scotland)
Dr Amy Small (Chest Heart & Stroke Scotland)
Dr Claire Taylor (Tayside Complete Health Ltd)
Judy Thomson (NHS Education for Scotland)

CLERK TO THE COMMITTEE

Sigrid Robinson

LOCATION

The David Livingstone Room (CR6)

Scottish Parliament

COVID-19 Recovery Committee

Thursday 23 February 2023

[The Convener opened the meeting at 09:13]

Long Covid Inquiry

The Convener (Siobhian Brown): Good morning, and welcome to the fourth meeting in 2023 of the COVID-19 Recovery Committee. We continue our inquiry into long Covid. I welcome Jane-Claire Judson, chief executive officer of Chest Heart & Stroke Scotland; Dr Amy Small, clinical adviser to Chest Heart & Stroke Scotland, who joins us online; Dr David Shackles, joint chair of the Royal College of General Practitioners Scotland; Lorraine Crothers, board member of the Royal College of Occupational Therapists, who joins us online; and Dr Claire Taylor, from Tayside Complete Health Ltd and expert adviser on long Covid to the World Health Network, who will be joining us online shortly.

Thank you for giving us your time and for your written submissions. We estimate that the session will run up to about 10 past 10. Each member will have about 10 minutes to speak to the witnesses and ask their questions.

If a witness who is attending remotely would like to respond to an issue being discussed, I ask them to type "R" in the chat box, please, and I will bring them in. I am keen to ensure that everyone gets an opportunity to speak. I apologise in advance because, if time runs on too much, I might have to interrupt members or witnesses in the interests of brevity.

I invite the witnesses to briefly introduce themselves.

Dr David Shackles (Royal College of General Practitioners Scotland): Good morning, everybody. I am a general practitioner in Perth and Scone. Along with Dr Chris Williams, I am one of the joint chairs of the Royal College of General Practitioners Scotland.

09:15

Jane-Claire Judson (Chest Heart & Stroke Scotland): Good morning, everyone. Thank you for having us. I am the chief executive of Chest Heart & Stroke Scotland. We have been working on long Covid since late 2020.

Dr Amy Small (Chest Heart & Stroke Scotland): I am clinical adviser to Chest Heart & Stroke Scotland. I am a practising GP and am also living with long Covid.

Lorraine Crothers (Royal College of Occupational Therapists): [*Inaudible*.]—currently offering a long Covid service in Glasgow.

Dr Claire Taylor (Tayside Complete Health Ltd): I am a GP in Tayside, and I run a private long Covid clinic in Dundee. I also work with the World Health Network as an adviser on long Covid.

The Convener: Thank you. I will ask the first question. Dr Taylor, based on your experience as a GP running a private practice that specialises in treating long Covid, how do you think the national health service could improve long Covid treatment and services?

Dr Taylor: As the doctor, I am the main person who sees patients at my clinic. When I see a patient, I assess them by looking at any tests that they might or might not have had, the pathophysiology of long Covid and what underpins it. From that, I can work out what is likely to be wrong with that particular person and can give them treatment and stabilise them. I can treat them for conditions such as postural orthostatic tachycardia syndrome and mast cell activation syndrome, which does not really happen on the NHS. I co-ordinate their care as a whole. Once a patient is stable, they can start to rehabilitate.

People are not really getting co-ordinated care in the NHS, and they do not have one doctor in the one place who is dedicated to their care. The NHS could improve the situation by having a long Covid clinic in each health board area, with a doctor to oversee each patient's journey and direct their care.

The Convener: That is helpful. What training on long Covid is available for healthcare professionals? How can healthcare professionals, including GPs, be encouraged to undertake training on long Covid?

David Shackles: The Royal College of GPs has produced some information and resources about long Covid. There are online modules and we have run some webinars on long Covid, which we encourage GPs to access themselves.

One difficulty that we have had in Scotland is that, even before the pandemic, 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. We hope to be able to restart that initiative in the next few months by working with partners in the British Medical Association and the Scottish Government. However, that has been the situation throughout the pandemic, which has held back some areas of education.

It is important to be able to access good, digestible and practical information about long Covid. That is where the RCGP initiatives came in, but there can be a paucity of other, locally available, information for GPs to let them see what is available in their own areas.

The Convener: We have heard from previous witnesses that there is a lack of awareness among local GPs. However, when I went to my GP last week, there were signs up all over the place asking people to talk to a doctor if they have long Covid. I think that the position varies from place to place.

We move to questions from Murdo Fraser.

Murdo Fraser (Mid Scotland and Fife) (Con): Good morning. In case of any conflict of interests, I should say that I am registered as a patient with Dr Shackles's practice. By the grace of God, I have not troubled him or his colleagues very much so far.

I want to ask about the level of demand for long Covid treatment. We believe that there are 175,000 long Covid sufferers in Scotland, and I am interested in exploring whether there is enough capacity in the system for that level of demand. Clearly, some people will not come forward to look for support, but is there capacity in the system to support them if they do?

Is there a specific issue with inequalities? Are particular groups more likely to be affected—for example, women rather than men, or people who have disabilities—and do they therefore require additional support?

Dr Shackles: Those are all very good questions. That is a vast area to explore.

Before this committee meeting, we cast out to our membership to ask what their experience was of people coming forward with long Covid. We did not find that GPs were overwhelmed with such cases. We are aware—through self-reporting and the surveys to which you alluded—that there seem to be more people out there who feel that they have long Covid, but they do not seem to be reporting that to us. That is a problem, because we need to see and hear from people if they have a condition that we can potentially help with.

On the question about disadvantaged populations, we are aware that health inequalities exist. When we asked some of our deep-end practices, which cover areas of greater deprivation, they reported seeing and hearing less from people who potentially have long Covid, so there is an issue with that. We are aware that more women might have the condition, and we are not hearing from some of our patients with disabilities, particularly learning disabilities. We are not sure why that is the case and whether we are getting good access to, and help for, them.

Dr Small: Murdo Fraser asked about the numbers. I think that 85 per cent of people living with long Covid are of working age. We need to remember that some of those people have caring responsibilities—for both the young and the old—and up-front investment in their care will lead to long-term support so that they can return to being functioning members of the community who are able to work in society.

People are not presenting because they have repeatedly been told that there is nothing on offer for them. They are at home dealing with the condition on their own because, to date, nothing has been available for them.

As a person living with long Covid, I signed up to a lot of surveys and qualitative research initially. I received survey after survey every month, and it is very tiresome to keep filling out forms when one is not feeling well. It is also tiring to fill out a form every month for nearly three years to say that you are still not feeling well. I confess that I have not filled out one of the surveys for more than two years, because it did not feel as though that was getting me, or anyone else, anywhere.

Although there is a perception that people are getting better, I think that a lot of people are just not presenting to tell us that they are still unwell. We need to be aware of that.

Dr Taylor: I am completely and utterly overwhelmed. I see hundreds of patients. I will give a little bit of background. A couple of years ago, I started this work, online, for a charity. Long Covid patients started to come forward at the start of 2021, but the charity went bust during the pandemic, at the start of 2022. At that point, I worked with local health boards to see whether I could set up an NHS clinic. Unfortunately, there was not enough money to provide a doctor, so I had to either do nothing at all or provide something privately. Obviously, there is inequality if people have to pay for treatment, but it was either that or nothing.

The majority of my patients are female. They are usually of working age and have usually previously been fit and well and on no medication. They are plunged into an utter nightmare from the start. They go on a wild goose chase trying to go to various specialties. At the moment, they do not get much co-ordination in their care.

People often find their way to me because patients talk online and have support groups. I am utterly overwhelmed; I am booked up for months. I am overwhelmed by all the stories of their journeys and how difficult they have found it to access care.

I provide virtual consultations, in which I see patients who are bed bound. A lot of the time, they cannot speak to me—I speak to their parents or carers because even talking for 10 minutes exhausts them to the point that they cannot function. Those people often cannot access healthcare—they cannot make it to NHS clinics, and they cannot go to a rehab clinic to do physio—because they are bed bound. Although that is not the biggest part of long Covid, it is one that means that people cannot access healthcare and are unable to even speak a lot of the time.

It is eye opening to provide virtual consultations as well as face-to-face ones. Anyone in the United Kingdom with long Covid, myalgic encephalomyelitis or any other such condition can access my clinic. I cannot even count how many people I have seen since the start of the pandemic.

Murdo Fraser: Thank you, Dr Taylor. I know that Lorraine Crothers wants to come in, but I want to follow up on one—quite relevant—point. You have obviously developed a specialism in that particular field. Are you the only person in Scotland who has that level of specialism or are there others?

Dr Taylor: Well, I have had hundreds of hours of meetings with various groups that work on long Covid around the world, and I have read every paper that there is to read on the condition. Some integrative medicine doctors possibly do a bit of long Covid work, but I am not aware of anyone else who has my level of interest or knowledge or has seen as many patients as I have. As I said, this work led on from working in an ME charity; naturally, patients found their way there thinking that it could help.

I do not think that anyone else is doing work on postural orthostatic tachycardia syndrome—POTS—which about 50 per cent of long Covid patients have. Basically, their heart rate goes up when they stand up—the rate can double and even go up to 200 beats per minute while they are washing the dishes. As far as I know, no POTS service exists in Scotland, so I have taken that on, too, and become an expert in managing POTS. I find it really interesting and really want to help the patients. I am not sure that being able to manage all that is generally a GP thing; it has to be a special interest—you have to work at it, keep up to date and be interested.

Murdo Fraser: Thank you. I think that Lorraine wants to come in.

Lorraine Crothers: I want to add to some of the points that have already been raised this morning. I currently work for a health board that employs 38,000 staff members. Of those, we have had referrals for 676 patients between July 2021 and February 2023, and we suspect that some staff have yet to be referred.

You asked about demographics. Predominantly, the people who we see are female and very much of working age—obviously, because we are an employer. They present with, on average, 12 symptoms, the most overriding of which are cognitive and physical fatigue.

The Royal College of Occupational Therapists is interested in the medical management of patients with long Covid, but we are also keen to express the need for rehab services and for sufferers of long Covid to be able to access a range of multidisciplinary team members. Medics are one part of it, but we also need occupational therapists, physiotherapists and other allied health professionals to offer support to clients to manage all the normal activities and routines in which they really need to engage in order to be active members of society. They must be supported to engage in the things that are important to them.

In response to questions about where people are going, there are some small, dedicated services, but we are aware from our members that there are other services that are absorbing some referrals. We had information from our occupational therapy colleagues in Edinburgh who work in children and young people’s services that children are being referred to rheumatology services, in particular. Those colleagues are struggling with onward referral for those young people; with the question of how the young people access mainstream education and so on again; and with finding pathways and support for them.

We have a really good example from our colleagues in NHS Lanarkshire, where occupational therapists are working in primary care settings and, in particular, through GP practices. They are able to work alongside GPs in those practices and support some patients with long Covid back to their normal routines and activities. Occupational therapists are key in that process—they are one part of it and the medical aspect is another. It is really about reinforcing the multidisciplinary aspect of patients’ needs.

Thank you for the opportunity to give evidence.

09:30

Murdo Fraser: Did you want to come back in briefly, Dr Taylor?

Dr Taylor: Obviously, we are very grateful to OTs, physiotherapists and so on for everything that they do, but I just wanted to say something about the pathophysiology of long Covid and rehabilitation.

I am not sure that most people know what long Covid is—they think that they do, but they do not.

It is a vasculitis—that is, an inflammation of the blood vessels. Every part of your body has a blood supply; indeed, that is why this is a multisystem disease. The immune system does not work properly—it is overactive. It is a bit like what happens to people who have autoimmune disease; when they try to do things, their immune system activates and they feel, for example, as if they have flu.

Something that we know about Covid, because there are thousands of research papers on it, relates to the fact that, when you have a vasculitis—there are other forms of it—you are usually, as the OT has just been saying, under a whole team of people in the form of an MDT. However, you would never try to rehab someone with a vasculitis without giving them treatment. That is what is missing here.

We always have to go back to the pathophysiology to look at the condition itself. There is a spectrum from mild to severe disease, but the pathophysiology and the fact that this is a vasculitis are poorly understood by most people. It is worth doing further reading on what a vasculitis is. Studies are on-going—in England, there is the symptoms, trajectory, inequalities and management: understanding long Covid to address and transform existing integrated care pathways, or STIMULATE-ICP, project—but the fact is that, once we target that area, we will be able to properly treat and rehab people.

I just wanted to remind you that this is not a psychological disorder or a case of people thinking themselves better or having positive thoughts; it is a medical condition with roots in the blood vessels. People with long Covid are what we might call canaries in the coalmine, because their risk of having a myocardial infarction is 50 per cent higher for 18 months afterwards. That is a stunning statistic. The canaries in the coalmine are getting long Covid symptoms, while the rest are just having the heart attack, but with the same pathology underlying it.

We know all this because there are hundreds of studies. Again, I am grateful for everybody in the MDTs—I wish that I had one here with me now, but I do not—and for being able to say a little bit about the pathophysiology and the fact that we do not usually rehab people who have these sorts of diseases untreated.

Murdo Fraser: If we have time, I would like to bring in Jane-Claire Judson.

Jane-Claire Judson: I will be very brief.

I totally agree with the rest of the panel on this issue, but I want to focus on the health inequalities aspect. We know that Covid affected disadvantaged groups more, so obviously that, too, will come through as far as long Covid is concerned.

I also wanted to pick up on the issue of women presenting. Women who present with certain symptoms might be judged in certain ways; if they talk about, say, feeling anxious or having palpitations, that is often put down to a mental health or psychological issue, and we have to be really careful of that when it comes to long Covid. There is certainly a general feeling that women feel dismissed—indeed, that is why we have a women's health plan—and we need to take that into account in the design of services to ensure that those biases, which we all have and on which we have to challenge ourselves, are tackled. After all, the majority of people presenting with long Covid are women, and of course a lot of women were on the front line with Covid, because they were in those kinds of caring positions. As I have said, we need to take that into account when designing services.

Alex Rowley (Mid Scotland and Fife) (Lab): Good morning. I want to start by asking about capacity in the NHS. It is fine for us to listen to the experts, telling us what needs to be put together, but the capacity to do that needs to be there. For example, the Royal College of General Practitioners Scotland has said:

> “Increased and long-term investment in access to therapies based in the community, such as physiotherapy, occupational therapy and specialist rehabilitation”

services, is “important”, while the Royal College of Occupational Therapists talks about

> “a lack of awareness of how occupational therapy and rehabilitation services can support individuals”.

What I am finding day to day, though, is that those services in the community, which people need just now, are lacking. NHS Fife, for example, has talked about shortages and not being able to recruit OTs and, indeed, a whole range of medical professionals.

What is the capacity in the NHS, right now, to deal with all the other pressures? Is there enough capacity, and is there a joined-up disciplinary approach to tackling long Covid? If someone goes to their GP, will they be referred here, there and wherever?

Dr Shackles: Even pre-pandemic, capacity in the health service was poor. We have been making that point for many years. Certainly, in general practice, our capacity was poor pre-pandemic, and it is poor now.

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. That is not good enough. It means an increase in workload because, over that period, the population of Scotland went up by 2 per cent. We have a dropping workforce for a rising workload, which involves not just the new and emerging condition of long Covid but all other conditions, as well.

We are in a very difficult part of our remobilisation, trying to get through the backlog of multiple other conditions. We in general practice are struggling. Over the past year, acute Covid has not gone away, and there are increasing burdens of long Covid. We have had influenza and we have had streptococcus A infections. All those things have sapped the strength of general practice, given that our workforce is smaller.

As Amy Small has said, a great number of the health workforce has itself been affected by Covid, including long Covid, and that has had an effect. We have a reduced workforce because of illness. That includes other areas—such as OTs, physios, pharmacists and other colleagues—in which we still do not have a good enough workforce.

We are therefore trying to create capacity, which is difficult, because all the other conditions still need treating. We are very well aware of that. The chief medical officers of all four nations put out letters of concern indicating the potential rise of heart disease, once again, because we have not been focusing on secondary prevention during the pandemic. We are trying to mitigate many such risks, but with too small a workforce.

Dr Small: We might need to turn the question on its head. Yes, we know that there is no capacity, but we cannot single out long Covid as an individual illness to pick on and question whether we are going to manage it because there is no capacity. We cannot pit one condition against another.

We have good multidisciplinary care for diabetes, for example. Every patient with diabetes will have an ophthalmologist, a podiatrist, a GP and a specialist nurse. That is what we need for long Covid. We cannot single it out as just another thing, because those people are not going away. The condition is not going away. It will continue to develop. In the past couple of months, I have seen people who are developing long Covid, having had Covid recently, and we know that Covid is still rife in our community. Today, I am working in a general practice that has several staff members who are off because of Covid.

We in the third sector have capacity. Chest Heart & Stroke Scotland's advice line has been doing amazing work in helping people with breathlessness, fatigue management and pacing advice. Pacing is absolutely key. Claire Taylor will back me up on that. Whatever stage of long Covid someone is in, pacing can be really helpful to conserving their energy.

The third sector has capacity, but we have to free up the ability of health boards and general practice to refer into us so that we can take some of the workload off the NHS. 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.

I will say a little about the fact that so many NHS workers are affected by long Covid. The BMA has run a survey, the results of which we await. More than 570 doctors in the UK who have long Covid filled out that survey. If I had been diagnosed with my POTS earlier in my journey, I never would have lost my job. If I had seen the right people early in my journey, I would have been able to continue as a GP partner in East Lothian. That is the big difference. The earlier that we get in there with treatment and management, the earlier we get back to work and can continue to look after the people who need us most.

Lorraine Crothers: I will keep my answer brief and echo comments that have been made by other panel members.

We surveyed our members, who told us that they are having to absorb the extra referrals that are caused by long Covid. We already have issues with capacity, yet we are trying to get staff to see and treat people with long Covid on top of that. I am currently working for a health board on occupational health, and I am very aware of the number of members of staff who are off sick with Covid. I am also talking to staff who are transitioning back to work. They find themselves working in an environment that is quite worrying because of the number of staff who are off sick. We do not have capacity in the system to deal with that.

We are really interested in increased investment in services that already exist. Putting more investment into current community and rehabilitation services or getting more investment into primary care services so that we pick people up much more quickly and at an earlier stage would prevent the longer-term impacts that the condition has on people's health and wellbeing and on their economic productivity.

Jane-Claire Judson: There is an issue with capacity and with what that means. I totally agree with what has been said: we all know that the NHS is under pressure, but we could work better and smarter with the capacity that we have.

That is where multidisciplinary teams come in. At the moment, people are ping-ponging without much co-ordination between services and specialisms. That does not help the capacity issue, but there is a sense that we could sort that now.

It is difficult to hark back to the past when we want to look to the future, but Chest Heart & Stroke Scotland flagged that issue two and a half years ago. We said that there was a need to increase training and awareness, to look at the capacity issue and to plan for that. At that point, we did not realise that there would be 175,000 people with long Covid; at that point, we thought that there might be 30,000 or 40,000. However, even then, we were saying that we would have to look at capacity. For some reason, that message has not got through in the past two and a half years. The lesson to learn now is that we cannot wait for another two and a half years to get it right—goodness knows what the situation will look like then. That would be terrible for people such as Amy Small who are going through that journey.

We want all our clinical colleagues to operate at the top of their licence. There are things that we at Chest Heart & Stroke Scotland can do to support self-management and to support people with that part of the journey. We do not want clinicians to spend the 10 minutes that they might have with a patient trying to solve all of that at once. As Amy Small has said, we can spend much more time with individuals than clinicians can, and we can do that at different times. We are not as constrained in having to tell people that they must come at, for example, a certain time on a Monday. We can be flexible and can support people with their condition where they are. We have made that key offer throughout this whole discussion, and we would like the offer to be taken up.

I would love Chest Heart & Stroke Scotland to be overwhelmed by people with long Covid. At the moment, we are not overwhelmed, because of the referral process. People might be signposted to us if they are lucky. We need an integrated service. 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. I would love to come back in a year's time and say, "Oh my goodness, we were overwhelmed, but we have sorted a lot of the issues." That would be a much better place in which to be.

Alex Rowley: I have a brief question to ask before I bring in Claire Taylor. Who at NHS level needs to take responsibility for ensuring that there is a far more joined-up approach? GPs are run off their feet. I get a huge amount of correspondence every week from people who are complaining about issues. Given that GPs are totally run off their feet, who should take responsibility for ensuring that services are working together and joined up, and that there are clear pathways? Is that a task for the NHS board or for someone within the board? Who should do that?

Dr Shackles: I absolutely agree with everything that Jane said. We must think about capacity planning, and GPs need space to be able to do that. The royal college has been pressing for a better interface between primary and secondary care so that we can discuss those pathways and have them better signposted in local areas. That is not happening at the moment.

09:45

There are some honourable mentions to be made. The NHS Lothian RefHelp guide is useful in giving GPs a single point of access to which they can refer. However, that is not uniform across Scotland. We need clearer pathways so that GPs and patients know how they can access the system and what is available. What happens is that services sometimes change, morph and, I hope, improve over time, so when patients ask what will happen to them, a lot of the time, the GP will not know, which is dispiriting for patients. If a health professional does not know what is going to happen to a patient, it does not give them great confidence. 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.

Alex Rowley: Who can make that happen? Who should be leading on that? Should it be the chief executive of the board who says that that needs to be put in place?

Dr Shackles: I think it probably has to be the chief executive of the board. We are working in a situation in which we have 14 territorial boards, for better or worse, with each board setting up a service in their own area. There might be some discussions about or sensibilities around having a super-regional service for the most severe cases, but patients are best treated in their own area and close to home, and the boards need to make sure that the system is sorted out.

Alex Rowley: Jane?

Jane-Claire Judson: I am just going to mention that my full name is Jane-Claire and, when people call me Jane, it makes me think it is my mum and it stresses me out. [*Laughter*.]

Alex Rowley: Sorry, Jane-Claire.

Jane-Claire Judson: On the point about who should take responsibility for co-ordination, David

Shackles is right that health board chief executives have to take responsibility and accountability for that. We have seen the diversity that is happening at health board level.

However, I would also argue that there needs to be national steering. I know that the committee is going to hear from others who will talk about that. From our perspective, the challenge that we have had is that there have been three versions of national steering and none of them has come to fruition in the way that we would have expected. I have no doubt that the two cabinet secretaries with whom we have worked have been committed to and believe in long Covid—they have not argued that it is not a condition or that it does not exist—but when we have agreed plans and a course of action, they just sort of disappear and we do not see them being implemented or action being taken for people who have long Covid. I am sure that lots of work is being done behind the scenes somewhere—I really hope that it is—but we do not see it on the ground. The real challenge is implementation.

The implementation also needs to be nationally co-ordinated, to share good practice and to ensure that health boards can tackle the issues that they face on the ground.

Alex Rowley: What is your view, Claire Taylor?

Dr Taylor: [*Inaudible*.]—the fact that a lot of people are still getting long Covid. I think that reinfection is going to be an issue, because people are being re-infected, sometimes within a few months, and some people are now on their fourth or fifth infection.

On capacity, as I have patients from all over Scotland, I have a good overview of Scotland and I think that there is no longer an issue with people seeing their GP. Patients are seeing their GP and, from what I gather, with some exceptions, they are getting good support, on the whole, and GPs are trying hard to work out what to do with them. They often seem quite happy to take on whatever I suggest, because it means that someone is getting some input.

The problems seem to come about with referrals to different specialties. Somebody with long Covid might need a cardiology referral for chest pain, a respiratory referral for shortness of breath, a neurology referral for pins and needles in their hands and feet, an occupational therapy referral, a physio referral, and so on. The waiting times in each service vary and who a patient gets to see at the end of that varies, too. They might well go to cardiology with their chest pain, but their referral can be refused; lots of referrals are. Somebody with chest pain is not usually rejected from cardiology, but if the words "long Covid" are attached to the referral, it seems to make it easier for whoever is sifting through referrals to say, "Sorry—we're not seeing them."

This is a true story. A couple of years ago, as a GP, I referred somebody to cardiology for POTS, and the referral was rejected. The letter said, "Sorry, we have no expertise in POTS. Get them to visit the POTS UK website." The POTS UK website tells patients all about the medications that they could have, if somebody prescribed them.

At that point, I became very determined that I would be someone who would be able to do that, but that was a rejected referral, and there are rejected referrals throughout the system. I totally understand that there are massive pressures on the system, but GPs are having their referrals rejected and are having to write back again and again to ask that their patient be seen, and people are having to wait a year for each service because the services do not interact—that is just the way that the system is.

I agree that there needs to be a national model. Perhaps there could be some individual changes across health boards, but there needs to be a national agreed model whereby, for example, as Dr Shackles said, there is access for GPs to get such tests. Perhaps there could be a referral pathway where you could go straight to test. With some education, GPs could direct who needs to have an exercise tolerance test and who needs to have a cardiac MRI. You might want a cardiologist to go through the referrals, but they might not need to see the patients.

At the moment, it is taking too long, and there are too many rejected referrals. I have to say that sometimes at the end of the process, when they get to see someone, I hear a lot of trauma from patients. That is a lot to take on as one person. It is nothing compared with what patients have gone through, but I hear the same story over and over again about patients eventually getting to see someone and being told that long Covid is not real, or that they are just overweight or are—

The Convener: Thank you, Dr Taylor. I am sorry, but I must interrupt. I am conscious of time, and we still have three members to get through.

John Mason (Glasgow Shettleston) (SNP): I will start with Dr Shackles. In its submission, Chest Heart & Stroke Scotland said:

> "While most GPs have heard of Long Covid",

which suggests that some GPs have not heard of long Covid. It also said:

> "Most concerningly, there remain clinicians who dispute that Long Covid exists".

What is your reaction to those statements?

Dr Shackles: I would certainly be very surprised if GPs had not heard of long Covid. I do not have any survey or research evidence that tells me how many GPs believe in the condition. In all the information that we put out, it is important to make sure that we believe our patients and listen to them. That is one of the critical parts of our job.

On an individual GP basis, I do not know, so I cannot comment. I have not had any feedback that what you put to me is the case.

John Mason: Chest Heart & Stroke Scotland, do you stand by the statement that some GPs have not heard of long Covid?

Jane-Claire Judson: We certainly stand by the fact that patients have reported to us that they have been in appointments in which GPs have said, "I don't know what this is, and I don't understand what this is." We stand by the patient experience, because people with long Covid are the experts on it at the moment. They have lived with the condition and engaged with the service, and they have insight into the journey, such as it is.

That thread runs through the submissions that the committee has received from people with long Covid. There is a sense that people do not believe in it, have not heard of it and do not understand it. As Dr Shackles says, it is not all GPs, but there are enough for people to report that to us and for that thread to come through in the submissions.

John Mason: If I broke my arm or had cancer, I would not be the expert; the GP or the specialist would be the expert. Why is that different with long Covid?

Jane-Claire Judson: The difference with long Covid is that people with long Covid termed it long Covid, and started to identify what was happening with the condition way back in August or September 2020.

We talk about expert patients because they live with the condition. They are not specialists who can diagnose, but they understand what it means to them and how it affects their life. As a third sector organisation, we stand by saying that if someone presents to you and says that that is their journey, as Dr Shackles says, you should believe them. We do not believe that people are going to their GP, lying about long Covid and making it up. From that perspective, I would say that patients are the experts.

Uniquely, this condition was not discovered by the medical community and then used to diagnose people or to find people with the condition. That is something that we should have been doing and have been doing in partnership to a great extent, but it is people with long Covid who have pushed and campaigned for that.

John Mason: Dr Small wants to come in.

Dr Small: I go back to what Jane-Claire Judson said earlier about a lot of women being affected by this and the bias that continues to run through a lot of society with regard to female-related problems or women who are suffering from these issues.

The other day, I spoke to a leading cardiologist in Scotland who works for a large health board. He told me that the vast majority of his cardiological consultants do not believe in POTS and that he is the only one in the whole of that health board who believes in it—he admitted that to me. We have to take that very seriously, because he said—he asked me to excuse the pun—that it is pot luck who patients with long Covid symptoms that mimic POTS or that are POTS-related issues get when they are referred to cardiology. We have to listen to our colleagues. Our colleagues are telling us that their colleagues do not believe in it, and we cannot ignore that.

I have been to so many meetings where I have heard that. I have heard it even from Government advisers. The Scottish Government put on a webinar for GP teaching in October 2021. There were three Government advisers—clinicians from health boards around Scotland—and one of them stated that it was predominantly women who were overweight, had anxiety and stared at their Fitbits too much who were suffering from long Covid. That is what is coming through at the top level. This is happening and we cannot deny that.

John Mason: Thank you. Dr Shackles, in your submission, you say that

> "Most people gradually recover, but a small percentage continue to have long term symptoms."

Is that based on data and studies?

Dr Shackles: Yes, that is based on the information that I have received from the reading and learning that I have done. I believe that long Covid is common, to start off with. Many people will have mild symptoms that they will recover from, but some people have severe symptoms that are on-going. I have patients whose symptoms are on-going after two years, but they are the minority. What we do not know is whether—if this is a relapsing and remitting condition—symptoms will recur, even if those symptoms are mild.

John Mason: An issue that has come up quite a lot is whether we should have dedicated long Covid clinics. In your paper, you say:

> "Patients need a GP assessment and investigation, rather than being funnelled inappropriately into a clinic that is designed for one condition".

I assume that that refers to the fact that people can have multiple issues, one of which might be long Covid, but that, if they go straight to a long

Covid clinic, a lot of other stuff might be missed. You also go on to say:

> "We note that the English clinics have been hugely expensive for the number of patients treated".

Therefore, is it your argument that we should stick to the GP model and not go down the route of a long Covid clinic model?

Dr Shackles: We need to look at the evidence that is coming out of those clinics and how cost-effective and effective for treating the patients they are. We are not particularly wedded to one model or another. At the moment, it is that question of resource and what a long Covid clinic looks like. As has been said before by colleagues, you have to have the secondary care specialists who are interested and expert in the various areas that we are talking about, whether it is POTS, mast cell activation or whatever. First, we have to find those specialists, potentially across each health board area, and then we have to ensure that we have the resource within cardiology or respiratory medicine to put such clinics together. At the moment, in my area, I am not seeing that being available.

Certainly, that is what is needed in order to be able to refer people to long Covid clinics that would offer appropriate medical advice, from people with an interest—that is okay; I approve of that—and also very much from the rehabilitation system, where there are experts who understand what needs to be done for the rehabilitation of patients, including occupational therapy, physiotherapy and dietetics.

Dr Taylor: I want to read something out from the Scottish study—our very own study in Scotland by Hastie et al:

> "Between 6 and 18 months following symptomatic SARS-CoV-2 infection, almost half of those infected reported no, or incomplete, recovery. Whilst recovery status remained constant over follow-up for most, 13% reported improvement over time and 11% deterioration."

From that study, which was a large study in Scotland, we can see that, no, people are not recovering within a year. I read that out to show that there is some evidence for those numbers. That is probably why the numbers are not particularly going down.

10:00

Dr Small: If we can get the model of care right for long Covid, we can get it right for so many other chronic diseases. I would love to see an integrated approach, because there are many other diseases, such as ME and rheumatoid arthritis, with which people suffer over the long term. If we can get the model right, which will involve taking a multidisciplinary team approach, we can make things better for a huge number of patients across Scotland, not just those who live with long Covid.

Hertfordshire has a very good model. A GP with a special interest in long Covid is based there—she is employed by the local clinical commissioning group. She has access to physiotherapists and all the other allied health professionals, but she also has direct access to tests, which Dr Taylor talked about. The process does not have to involve lots of consultants sitting around the table, but it needs someone who has direct access to those people for further advice. There are models in England that work well—I agree with Dr Shackles that there are some that do not work so well, but I do not think that we can tar all of them with the same brush.

John Mason: I see that Ms Judson wants to come in. I was going to come back to you anyway, Ms Judson. You can say something else if you want, but my final question is about the fact that your paper is critical of the committee for not meeting enough sufferers of long Covid. How many do you think that we should meet? Should we meet 100? Should we meet 1,000? How many should we meet?

Jane-Claire Judson: I will take that question first. We fed back openly to the committee on how we felt about the consultation process. That was based on the feedback from our long Covid peer support group and people with long Covid.

It is not necessarily a case of hearing from 100 or 1,000 sufferers. It is about the multiple ways in which you could engage with people who have long Covid. For example, we know that the condition can involve brain fog and tiredness, and that the engagement with various processes can be challenging. It is a question of looking at how you engage across multiple channels and giving people an opportunity over a period of time. That is really important.

In addition, it is a question of how you continue to engage with people with long Covid over the course of the inquiry, and continue to keep those voices front and centre of the inquiry. It is great that Chest Heart & Stroke Scotland is getting the privilege of putting that voice forward, but being able to bring people with long Covid to the committee, which you did last week—

John Mason: I am afraid that I have run out of my 10 minutes.

Jane-Claire Judson: Oh—sorry.

John Mason: I will have to draw that bit to a halt. Thank you.

The Convener: I am conscious of the time. We were meant to finish at 10 past the hour. I suggest that we extend to 20 past, if that is all right with the witnesses. I call Brian Whittle.

Brian Whittle (South Scotland) (Con): Good morning to the witnesses. I have been listening with great interest to what they have said.

I have a big beef about how we collect and utilise health data and how we deploy that in an information technology system that is not fit for purpose. I used to say that long before the arrival of long Covid. It worries me that, in the NHS system, which is under great pressure—it was under pressure before Covid and is under greater pressure now—access to health services varies greatly across the country. That being the case, how can we be sure that the data that we gather reflects what is really happening in the system? If people cannot see a GP or get to secondary services, or if the GP cannot find a way to refer, how can we be sure that the data that we collect around Covid—and, therefore, how we treat Covid—is accurate? I come first to Jane-Claire Judson.

Jane-Claire Judson: The Office for National Statistics data is widely accepted as solid and capable of being used to help us design services and look at what long Covid is and how it should be dealt with in the NHS, so we have data and our clinical colleagues might come in to say that there is not necessarily a lack of data to help us design services; I believe that we could be doing that right now.

You absolutely have a point about the use of data as it comes into the NHS—about who gets to see it and share it. There is a coding issue at GP primary care practice level. We have argued for more than two and a half years about getting that sorted. I do not believe that GPs find it easy to find the long Covid code, mainly because it is not called "long Covid"—despite the fact that, daily, that is what people call the condition. Using that data to create actions is therefore going to be difficult.

There is also a major issue with referrals. Certainly, we as an organisation suffer from that. Currently, in order to be able to receive referrals from the NHS, we have to go to each of the 14 health boards and fill out a 40-page form. That is 560 pages that we as a third sector organisation have to navigate. That makes it challenging for us to get access to that data and usage.

We were told for many years before Covid came along that there was going to be a national solution to the issue and that it was being sorted. However, that solution has not transpired for long Covid or for the other conditions that we work with, which has been hugely disappointing. As Amy Small has said, we had a real chance to solve this and sort it out, and we do not entirely understand why that has not happened.

There is an element of people saying, "We need to wait for the data to understand what's happening," but our clinical colleagues have shown this morning that we have plenty of evidence and data that we can use to design services. 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.

Brian Whittle: Dr Shackles, can you broaden that out from a GP perspective? As a member of the Health and Sport Committee in the last parliamentary session, I remember that nearly everyone who came before us said, "We need our GPs to learn about this condition," or "Education is needed on that condition." It seems to me that long Covid is just being added to the list of things that we are asking our GPs to learn about, and you have already alluded to the fact that, at the moment, learning time is not being given to them for that.

I have to say that I take issue with the suggestion that the committee has not taken evidence from long Covid sufferers; I think that we have done so, and a consistent message that has come out is that a lot of long Covid sufferers have had to pay for private treatment, because they have been unable to access NHS services in order to get a long Covid diagnosis. How can your members gather this data if, first and foremost, they are struggling to access the education that would allow them to make such a diagnosis?

Dr Shackles: I agree—we have issues with data collection in general practice, and it disappoints me to say so. The committee might well be aware that, previously, we had the quality and outcomes framework, under which we would code conditions and develop disease registers. I think that we were very good at that in general practice; we had some quite advanced systems for doing that and for looking at the data. However, that stopped some years ago with the new contract. Unfortunately, with the pandemic intervening, we have not developed newer coding systems that are effective and efficient.

I agree with you about the computer systems in general practice not being fit for purpose. In my practice, we have just migrated to the new hosted solution, which is better, because it is much faster and is now usable; however, a lot of other things such as finding the coding or having the ability to input data are not much better.

Early in March 2021, Chris Williams and I were invited by Gregor Smith to write a joint letter, encouraging GPs to do coding. However, a lot of other issues with, for example, vaccination were going on at the time, and the letter and the information about coding were probably lost in that noise. We can probably do more to encourage GPs with regard to coding, but I absolutely agree with Jane-Claire Judson that we have plenty of other evidence on long Covid. We should therefore rely not just on evidence from GPs; it would be useful in working out how we are managing things in general practice, but it is not absolutely essential in the design of services.

We believe that long Covid is a real condition and a big issue, and that is why we as GPs need to know about it. For many GPs, the Covid pandemic, both its acute stage and the fallout from it in the form of other diseases and excess deaths, will define their careers. It is a big thing, and we need to be able to take it on board and learn about it in all of its manifestations, but we also need the time and resources to do that. At the moment, we are not seeing that in general practice. In fact, funding has been withdrawn from general practice over the past year, and that is not good enough.

Brian Whittle: Finally, I want to expand this discussion with a question for Dr Taylor. You have gathered data and information from around the world, Dr Taylor, but it concerns me that you, personally, have taken it upon yourself to do that. Is there even a system in the NHS that can share data across health boards, let alone gather data from around the world? Interestingly enough, I read in an article that Australia is having exactly the same problems as we are with data not being shared enough. What is the solution?

Dr Taylor: I do not think that there is sharing of data across health boards, although everyone feeds data into the Government, as far as I can work out. I would be happy to work with the Scottish Government to try and sort that out, having run a clinic single-handedly and set it up from scratch to try and fix the problems.

On the issue of coding, as somebody with a vested interest in long Covid, I could not find the codes. I had to go and find the code that we type in—the letters and numbers. For example, if I had to put a heart attack into the coding system for GPs, I would type in “myocardial” and “infarction” would then come up—easy. However, if I started trying to put in “long Covid” or “post Covid”, about one hundred Covid codes, including polymerase chain reaction tests and whatnot, would come up. That is easily fixed. Somebody who knows about computers could go in and sort that so that if someone types in “long”, the word “Covid” comes up. That would sort out the coding issue.

People are getting diagnosed. I do not see an issue with GPs not diagnosing people, on the whole, but they are having to rule out other things first, which is natural for conditions of this sort, because we have to ensure that a person does not have lung cancer hiding behind long Covid. However, after diagnosing people, we are not counting how many of them there are. We know that 5 per cent to 10 per cent of people get long Covid, so we can work out what we should expect, and the ONS survey is generally pretty good at picking up who has symptoms, but it does not quite tell us who has long Covid. It tells us who is self-reporting symptoms, and it is pretty sensitive, but more work could be done in Scotland, rather than in the UK as a whole. There has to be a co-ordinated approach that is done centrally, so that all the information can be put together to allow us to work out what the need is.

We know that those figures of 5 per cent to 10 per cent of the population having long Covid are the same across the world. There are people who are more vulnerable to long Covid because of genetics or other factors. However, on the whole, those figures are what we are looking at and they do not seem to be going down. I think that it was NHS Lanarkshire that said in its submission that it expected a bell-shaped curve with deferrals, but that it has not seen that, and instead the number is constant. It would help to put all of the data together centrally.

I have not done any work with the Scottish Government. I have been on my own and I have taken on a huge task. I had no idea what it would be like when I started this. I thought that it might be like any other service and that some people might want to come and spend a bit longer with a doctor, but I had no idea that I would be all that is there for them.

Jim Fairlie (Perthshire South and Kinross-shire) (SNP): I understand that Dr Amy Small wanted to respond to Brian Whittle. Do you want to do that before I come on to my questions?

Dr Small: Thank you. I will make it quick.

The various long Covid clinics in England are working in networks to share education and learning. 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. If we had long Covid clinics and networks, we would learn from each other and improve our treatment and management of patients.

Jim Fairlie: Dr Shackles, I will come to you first. There has been a lot of talk about workforce pressures. What impact have they had on establishing and delivering the services that people with long Covid need, and what action can be taken to assist NHS boards to fill the specific posts that are required to deal with long Covid?

Dr Shackles: That is a really difficult question. In our own workforce, it is about retaining people in jobs. As has been said before, that is because a lot of people are feeling burnt out by the pressures of acute Covid and the secondary work from remobilisation and other conditions. Some thought about how we can help people to manage that, and how we can help with workforce wellbeing and put that front and centre, is important.

We should ensure that, for the workforce, work on long Covid is not stigmatised and that working on long Covid is not seen as being put into a silo that is not, necessarily, valued. We might have to change the messaging about that to say that the work is important and valuable and not just an afterthought.

10:15

Jim Fairlie: I am curious about some of the evidence that I have heard today. At the start, you said that your members are not being inundated with people presenting with long Covid. I think that it was Amy Small who said that that was because people have stopped coming because they are not being listened to.

Jane-Claire Judson is saying that she wants her organisation to be inundated with people who have long Covid. GPs are being inundated generally. Why is the situation not being co-ordinated better? Is it because her organisation is in the third sector? Does the NHS not work closely with her third sector organisation? Clearly, we have a huge problem. Is it because GPs are under so much pressure? Are you not getting the time to think about how to do things differently?

Dr Shackles: Absolutely. We do not have time to think. We are inundated with lots of other conditions and people coming in. The story that went round that general practice was closed was a false narrative. We have been open right the way through for face-to-face and remote consultations. Our members report that they have never been busier. The spike of activity pre-Christmas was unprecedented.

Lots of people are presenting but, as you say, we are not getting time to think about how to do things better. We need to be able to do that. We need to think about how we can integrate and interface with secondary care, the third sector and the care sector.

Jim Fairlie: Do we need—[*Interruption*.] Claire Taylor has indicated that she wants to intervene. She might have the answer before I come back to you, Dr Shackles.

Dr Taylor: I agree with David Shackles that general practice has never been so busy. It is absolutely inundated. GPs have 10 minutes and patients have more and more complicated problems that have built up or developed due to Covid.

Even though I am a GP, I do not think that long Covid is a fully GP-manageable condition. To put that on to GPs is too much because you would not expect a GP to fully manage rheumatoid arthritis. You would expect that they would know the right pathway, be able to support their patients, know how to suspect it and what tests to do to refer patients on and then there would be continuing contact between secondary and primary care.

Jim Fairlie: Can I interrupt you for a second, Claire? I am very short of time.

I go back to my question for Dr Shackles. Do we need somebody else who is not on the front line day to day to come in, look at what you are dealing with and think about how to manage it better?

Dr Shackles: I do not know whether I can answer that question.

Jim Fairlie: The purpose is to find solutions to what is clearly a problem. How do we sort the problem? The problem is that people have long Covid. It has been diagnosed and given that name by patients. Would it help if the medical profession said that it was going to rename the condition and start again? We are also hearing that some medical practitioners do not recognise long Covid. I do not understand why there is so much disinformation.

The system is fragmented and not working. Does someone else need to come in and say, “This is a national problem. These guys are trying to deal with everything else that is happening on the front line,” and ask how we can help to solve that problem?

Dr Shackles: One of the key points, as Amy Small mentioned, is to examine what works in other areas. If networks work well, let us consider that approach. Let us look at the gold standard somewhere else rather than just trying to dream up something out of the blue. We have to look more widely at what works to make sure that we get it right.

As GPs, we need the evidence about what works at our fingertips. The guideline from the Scottish intercollegiate guidelines network, the National Institute for Health and Care Excellence and the RCGP is good. It needs to be a living guideline that is updated to tell us what to do when. That is really important.

It is probably sensible to consider what has worked for other clinics, networks and even countries rather than completely reinventing how we do things. We have to listen to our patients. We cannot just call the condition something else because we have decided that things are not working. Let us listen to our patients and use the language that they are using. That is important.

Jane-Claire Judson: In Scotland, we have an integrated model for long Covid in Lothian. We just need to embrace a model and get on with that work.

We have been waiting on a national clinical lead. Apparently, the recruitment exercise finished in August last year, but we still do not know who that person is and when they will start. We could have someone co-ordinating the work nationally.

My final point relates to the referral process. Signposting to the third sector is not that effective. It needs to be integrated into the system. We built our service to work in partnership with the NHS. I do not believe that the NHS does not want to work with the third sector; I just do not think that it is being enabled to happen.

I have one extra point to make because it is not fair to leave it hanging. On the committee's engagement with people with long Covid, I take the points that were made. We fed back to the clerking team our views on that and an extension was granted to the consultation process for written submissions. We are happy to work with the committee on those issues but, if I get feedback from people with long Covid, I will put it to the committee and offer to help you on that.

Jim Fairlie: Thank you.

Lorraine Crothers, would you like to come in?

The Convener: I am sorry, Mr Fairlie, but we are at 20 past 10, so I will have to stop the questioning there.

I apologise that we have run over time. I thank the witnesses for their evidence and giving us their time. If they would like to raise any further points with the committee, they can do so in writing to the clerks. We will be happy to liaise with the witnesses about how to do that.

I will briefly suspend the meeting to allow for a changeover of witnesses.

10:20

Meeting suspended.

10:24

On resuming—

The Convener: We will now continue to take evidence in the long Covid inquiry. I welcome our second panel of witnesses to the meeting. Judy Thomson, director of training for psychology services, and Professor Lindsay Donaldson, deputy medical director, are from NHS Education for Scotland; Linda Currie is associate allied health professions director of NHS Highland; Heather Cameron is director of allied health professions at NHS Lothian; Janis Heaney, who is joining us online, is associate director of national strategic networks, national specialist and screening services directorate at NHS National Services Scotland; and Manira Ahmad is chief officer at Public Health Scotland. I thank everybody for giving us their time this morning.

We estimate that this part of the meeting will run until about 25 past 11—I have added an extra 10 minutes—and each member will have approximately 10 minutes to speak to the witnesses and ask their questions. I am keen to ensure that everybody gets an opportunity to speak, so I apologise in advance if time runs on too much and I have to interrupt members or witnesses in the interests of brevity.

If Janis Heaney, who is joining us online, would like to respond to an issue that is being discussed, she should type "R" in the chat box, please, and we will bring her in.

I invite the witnesses to introduce themselves briefly.

Janis Heaney (NHS National Services Scotland): I am the associate director of national strategic networks in NHS National Services Scotland. The long Covid national strategic network sits within my remit.

Manira Ahmad (Public Health Scotland): Thank you for inviting me to the meeting. I am the chief officer of Public Health Scotland and the chair of the long Covid strategic network.

Heather Cameron (NHS Lothian): Good morning. I am director of allied health professions at NHS Lothian. My background is that I am a physiotherapist, and I co-led some of the work in NHS Lothian on long Covid.

Linda Currie (NHS Highland): I am the associate allied health professions director for NHS Highland and the board's clinical lead for long Covid.

Judy Thomson (NHS Education for Scotland): Good morning. I am the director of training for psychology services at NHS Education for Scotland, where I also have a broader corporate leadership role in mental health. I am a clinical psychologist by training.

Professor Lindsay Donaldson (NHS Education for Scotland): Good morning. I am deputy medical director of NHS Education for Scotland. My clinical background is in intensive care. NES is the statutory education and training body for health and social care in Scotland.

The Convener: I move straight to questions from Alex Rowley.

Alex Rowley: Good morning. I think that most of you were here for the earlier part of the meeting. Now that you are in front of us, this probably follows on well. One of the issues that we heard about was that there are differences between boards. I think that one witness talked about NHS Lothian having a good model.

What are the key enablers for and barriers to setting up specific services for people who are suffering from long Covid? One witness said that that might not be how we want to do it, because a lot of people report similar symptoms. What are the enablers for and barriers to putting joined-up and patient-centred services in place?

I had better get people’s names right this time. I will start with Professor Lindsay Donaldson.

Professor Donaldson: Many of the enablers sit with education, training and learning. There is an iterative process of learning as we hear from people with lived experience and as we learn as a profession and a multidisciplinary team. It will take some time. We know some things, but we do not know everything. We will keep learning.

Judy Thomson: I agree with my colleague that learning and education are a key enabler. If we are to make things work in Scotland, we need to be mindful of the different geographies and the social compositions of the populations across Scotland and take account of those in how we disseminate learning and in considering how services are constructed and how the networks can work together. There is no one solution that will work everywhere in Scotland. We need to be responsive to local need and what is already being done in clinical delivery and education in local services.

Linda Currie: We are seeing multidisciplinary teams coming into play and working closely with third sector colleagues. In Highland, we are working closely with the third sector Let’s Get On With It Together group, and we are thinking about joint groups. It is all about getting the tiered level of support right.

Alex Rowley: Good. Heather?

10:30

Heather Cameron: I am going to start with—or, I should say, stay focused on—some of the barriers. For me, one of the overarching barriers to delivering services for people with long Covid is still our understanding of what we mean by it. We have heard quite a robust debate about that this morning, and I know that the committee has heard from a number of witnesses on the issue.

Long Covid is, in effect, an overarching term that we use for a very broad range of symptoms. Some of the literature has suggested that there are up to 200, but obviously we know of a core five or six. We have therefore had to put an awful lot of things into one pot and say, “Right—let’s come up with a solution for managing this incredibly complex position.” That is why we, from an NHS Lothian perspective, have tried to take our learning from the management of other long-term conditions. It has, in that respect, become an enabler.

Long Covid is a long-term condition. There are some knowns around the pathologies, but there are also some unknowns. We know that, in common with a number of long-term conditions, there is not always a direct relationship between the severity of the disease and the severity of the symptoms that people are left with. We are therefore focusing from a symptom management perspective on being reactive and responsive to what people tell us that they are presenting with and, instead of trying to label everything from a long Covid perspective, we are being driven by a long-term conditions model. Under that model, if something can be managed medically and there is a medical target, we should be investigating and managing it; if not, we should be focusing on the symptoms and on how people are presenting and then giving them support through a rehabilitative approach from the NHS and then through our third sector partners, including Chest Heart & Stroke Scotland, from which you have heard this morning. As I have said, I guess—I hope—that we have turned that barrier into an enabler.

Alex Rowley: Does Manira Ahmad want to comment?

Manira Ahmad: My colleagues have made my job easier, so my update will be a short one.

One of the issues for me, and something that my colleagues started to lean in towards, is the amount of evidence and evidence-led decision making. A positive from our long Covid strategic network is the ability to bring groups of people together from local systems and use that knowledge for a once-for-Scotland approach.

One of our sub-groups is made up of service planners. I know that previous witnesses have raised questions about how we plan, bring in the right services and ensure that primary care, acute care and the voluntary and third sectors all work together. With the service planning group, we have an opportunity to support all of those aspects through evidence-led change, using some of what we already have from, say, the ONS, which has already been mentioned. We have, for example, the relative disease burden, and there is data coming, I hope, from EAVE II—the early pandemic evaluation and enhanced surveillance of Covid-19 project—in the months ahead. The issue is how we use those insights and make them digestible and translatable. Following on from what my colleague has said, I point out that we can also use lived experience.

All of that will help service planners to plan local systems through what is a multidisciplinary approach. I agree that that is happening, and we have learning to share. That is a massive enabler for us. Moreover, once more robust data starts to come in over the coming months—I will be happy to share that with the committee when it is available and ready—we will be able to use that to help service planners to bring together a multi-agency approach across different sectors.

Alex Rowley: Is it Janis Heaney who is online, convener?

The Convener: Yes.

Alex Rowley: Can you comment, Janis?

Janis Heaney: As Manira Ahmad has said, the network has brought together service planners across the NHS boards, and we have established peer support forums to enable those planners and people who work with those who have long Covid to come together and share best practice. One of the key enablers is allowing that sharing of learning and best practice across the NHS in Scotland to enable discussion to happen and to look at what is working and what can be taken back to health boards.

As has been mentioned, we will in future be establishing multidisciplinary team sessions to look at complex cases and see what has worked and what best practice can be taken from that. I therefore agree with my colleagues that the key enablers are the sharing of best practice and education and learning for those delivering services.

Alex Rowley: Thank you.

Murdo Fraser: Good morning to the panel. I want to ask about pathways for long Covid sufferers.

The committee previously took evidence from long Covid sufferers who expressed their concern that the pathways did not exist or, if they existed, they were not working. You may have seen that, in the previous evidence session, we heard from Jane-Claire Judson from Chest Heart & Stroke Scotland, which has assistance available. She said that it would love to be overwhelmed with patients, but it has not received them because of a lack of signposting. Amy Small said that she felt that those networks do not exist in Scotland and that we do not have long Covid clinics, which exist south of the border.

Do you accept that there is an issue with pathways not existing or not operating properly? What can be done to fix that?

Does Manira Ahmad want to kick off?

Manira Ahmad: That is a very big question, so I am sure that colleagues will come in on parts of it. I will address some elements of the question, if that is okay.

What we are learning and what colleagues from the long Covid strategic network and I are finding is that we cannot deploy a single practice across Scotland. Different things are happening in different areas. We have funding for supporting services and resources in different areas, but there is a challenge in being able to recruit in a timely manner. That is a recurring issue. All that is being worked through with sponsors, Government and colleagues in the network.

From hearing from colleagues in the previous evidence session, it is clear that pathways exist. We can galvanise the opportunity to mimic that for people who are not getting access to services or pathways. Although that is a challenge, there is also an opportunity in that.

Before I hand over to colleagues, as they may want to say more, the other issue is our lack of information. As I said, we have the ONS data, but we are reliant on people self-referring or understanding that they have long Covid. The data from the EAVE II study should give us enough more robust evidence to target the areas where we need to develop those pathways for people and populations.

We all need to consider that we are still in the challenge of recovery. Coming out of the pandemic, there are pressures across the entire system. We have an opportunity to work better in relation to all that, but we also need to be cognisant that, along with the burden of long Covid, there are lots of other symptoms that boards and local systems are grappling with. How do we make that sustainable and spread the learning from long Covid across the other pathways?

Murdo Fraser: Does anyone else want to come in?

Heather Cameron: I agree that there are pathways, but some are arguably more robust than others. 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.

Dr Shackles mentioned RefHelp in Lothian. We know that that is widely held up and well regarded. It is a clear source of information for GPs. We have some information on our long Covid offer in RefHelp, and we have a clinical reference group that has been working through what the demand is, where we hear about the additional need, and the challenges that our patients tell us about. We have an on-going patient reference group, and we have another two planned, so that we can make the information on RefHelp clearer for GPs and others to make those pathways.

There are pathways, but I accept that there are challenges. The situation is not perfect, but we are definitely working on it. We have made great strides, and there is more to come.

Murdo Fraser: Janis Heaney wants to come in.

Janis Heaney: Yes. Thank you.

To build on Heather Cameron's point, we have a lived experience network that sits alongside our strategic network. That is critical for us to get the voice of lived experience into the work that we do. We involve lived experience representatives in a number of the network's working groups. Some will consider children and young people workstreams, and some will consider pathways. We, as a network, are really committed to ensuring that we have lived experience representation and voice so that we can understand the experience of accessing those pathways.

Judy Thomson: There is an issue around retention and recruitment. As members are aware, some additional funding has been made available to health boards across Scotland. However, in common with our contacts in NES across the system, we are aware that it is quite difficult to attract people to temporary posts. 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.

Murdo Fraser: I think that one of my colleagues will ask about the workforce shortly. I go to Professor Donaldson.

Professor Donaldson: Thank you very much—and I thank my colleagues. NES has a role in training the health and social care workforce and accepting its inconsistencies. There may well be real reasons for differences in how health boards deliver, but NES has a role as a multidisciplinary team enabler. We look forward to working with those networks on the education of the entire team and delivering that work in perhaps different models. NES is looking at how we deliver health and social care, and a multidisciplinary team is key.

Murdo Fraser: I have a follow-up question for Janis Heaney. Are there plans to develop standardised guidance for use across all NHS boards in Scotland? If so, when is that likely to be in place?

Janis Heaney: 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.

Murdo Fraser: I am conscious that I did not let in Linda Currie. Do you want to come in?

Linda Currie: 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. The difficulty is that those clinicians have come from wide and varied backgrounds, and they need to be given the time to establish their own skills and to pick up on all the research that is out there.

A thing that has helped, which we have been developing more recently, is a multidisciplinary triage meeting. One of our secondary care respiratory consultants comes in to help us to guide our patients or primary care colleagues through the different clinical pathways. That has been really useful.

The Convener: I will cover the issue of long Covid in kids. The committee had an informal session with family members of children suffering from long Covid; some of those children have not been to school in years. It was quite harrowing to hear their stories. Family members felt that there was a lack of support and diagnosis for children suffering from long Covid.

Is there sufficient knowledge and understanding among health professionals in relation to long Covid in children? Does that impact on diagnosis of long Covid in children? Manira, would you like to come in?

Manira Ahmad: I will defer to my colleagues who are more clinically and medically trained, if that is okay, but I might come back in after that.

10:45

Linda Currie: From NHS Highland's point of view, as you can imagine, some of our teams are very small and integrated. We work closely with our colleagues who work with children and young people. We are not seeing a huge number of referrals coming through that service, but we would try to do what we have done in other areas, such as major trauma, by using the staff who have come into the long Covid-funded posts to support the children's clinicians. You almost need both skill sets. Certainly, children who are referred will be seen alongside other children within the services.

Heather Cameron: Similarly, in Lothian, from speaking to our clinicians, we are not seeing a massive increase in demand. We have taken a similar approach in children's services to the approach that we have taken in adult services, which is to embed the management according to the presentation. We have a number of teams that have significant skills in managing long-term conditions, so depending on the key initial presentation, that would be where children or young people would initially get their support, and then staff work across the teams if someone presents with multiple pathologies.

However, in relation to the data on the ground—I heard some of the earlier debate about data and I would add the caveat that it remains a significant challenge—we are not seeing significant numbers. Those who we are seeing are being managed within existing services, so we have not set up anything that is separate. However, as part of the work that we have been doing in scoping and looking at pathways, we will look at children's services as well.

Janis Heaney: With regard to the national strategic network, one of the workstreams that we are just establishing now is a children and young person workstream, so we will focus on that in the coming weeks and months. Again, we will have lived experience representation on that group to ensure that we capture everything that comes through. Colleagues are better able to answer from a clinical perspective, but from a network perspective, we will be focusing on that children and young people workstream, which I hope reassures the committee.

The Convener: Thank you, Janis. Manira Ahmad, this might be a good question for you. What support do children with long Covid have when they are transitioning into adult services? For example, if they developed long Covid when they were 15 and are now coming up to 18, how do they transition into adult services? Is there support for them?

Manira Ahmad: That is a pertinent question, but it is not one that I have the answer to to hand. However, I would like to make another related point. Public Health Scotland is doing a lot of wider work around children and young people. We are focusing increasingly on how we help that multidisciplinary team function and really getting it right in the early years, which means working with schools, nurseries and the wider system in the local and regional space. Part of that is to identify where support is needed—not specifically on long Covid—not just for the child or young person but for the family.

One example is that, through a public health approach, we are supporting the build of a new high school in Liberton. A public health approach means that it is not just about education but about the wider social determinants—health, care and the needs of the young people and their families. I hope that, by having those conversations and bringing a wider public health approach to building services, we will start to influence how resource is planned at a local level and where the focus should be for communities.

As my colleague was saying, we are still waiting for a better understanding. As the network is setting up a children and young people's sub-group, we will learn more and start to filter that in, through various guises, to all those places where our organisations have reach into.

Brian Whittle: Good morning. Thank you for being here—it is a really interesting evidence session. Those who have been here this morning will know that I have an interest in health data. We are actually very good at collecting data, but, funnily enough, we are not very good at deploying it.

I will speak to a point that Heather Cameron made at the start about the number of symptoms that can be involved in the diagnosis of long Covid. If a GP has to refer someone, they can refer them for an electrocardiogram for chest pain, or an MRI for abdominal pain. They can do blood tests for fatigue and brain fog. Without question, with something like Covid, there will be a mental health element to consider. I am interested to hear what you have to say about that, Ms Thomson. All that is just to get to a long Covid diagnosis as it is a condition of elimination as far as I can see.

We are putting a really resource-intensive request on to a system that is already under pressure. We heard from those with long Covid that they ended up having to go private to get their diagnosis. We also heard this morning about the pressure on the time of GPs and their capacity to learn and share their learning and experience.

That is a long-winded way of me getting back to the question of whether we have a data system or information technology system that is fit for purpose and that allows input from and output for our NHS professionals, and possible integration with the third sector. Having been on this issue for a long time, I do not think that we do, but I would be interested to hear whether that is the correct direction of travel to a long-term solution. I will go to Heather Cameron first.

Heather Cameron: There is a short answer to the question about whether the information system is fit for purpose and able to give us the overall picture across primary care, secondary care, specialist services and so on. The answer is no, not at the moment. We know that different health boards have different services, so if someone happens to move across different health boards, their information is not always easily shared.

We have come a long way on the health board side. People who work in acute hospitals do not have access to our GP systems, but we have been able to give our primary care colleagues better access. We have definitely moved on. There is no question that information-sharing is far superior now to what it would have been 10 to 20 years ago, but there are still gaps.

There is something around how the information that we get out is only as good as the information that we put in, so it is only as good as the question that we ask. If the question that we ask is about numbers, we are pretty good at counting numbers. If the question is about a complex diagnosis then, as you heard from colleagues earlier, people facing a selection of 20 codes who have one minute or two minutes to make a decision will pick a code quickly. Therefore, an aspect is how systems talk to each other, I guess, but the systems also need to be designed to answer the questions that we are all interested in asking. The systems that we have tend to be designed to answer questions about numbers rather than give out qualitative information.

Manira Ahmad: I think that I have met my match on passion for data. As colleagues and members round the table will be aware, Public Health Scotland is very much an evidence-led organisation. Some of the things that we are working on will, I hope, start to answer some of those questions. I am not saying that we will completely revolutionise everything, but that is where we are heading.

From the national perspective, Public Health Scotland clearly understands that change happens within local systems. Because of that, we have local analytical teams spread across Scotland, working to give our health and social care partnerships, local authorities and the third and voluntary sectors access to that joined-up data. Nationally, we collect what we have not got—we find where the gaps are in a local system and join that to our national holdings.

We are also developing whole-system modelling, and I can share some information on that if members are interested. We have a whole-system modelling platform that focuses on demand and need and how we can better utilise capacity in the system. The tool is particularly being used by NHS board chief executives to understand where the pressure is and how we can work at a regional and national level on resource allocation.

A lot is going on, and one of the opportunities that Public Health Scotland has is 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.

Linda Currie: I agree with Heather Cameron’s point about integrated systems. There is also an opportunity for Scotland to procure the C19-YRS app, which is based on the York rehabilitation scale. A couple of us in the health boards are already making use of the app, which is going through a national procurement process at the moment.

The app helps our patients. They self-assess and can do so regularly; there is a suite of outcome measures—we can ask for any formal, standardised outcome measures to go on to the system; and there is a huge wealth of education resources that patients can access. As we take forward the once-for-Scotland approach, we can develop data collection from that system, which will be very useful. In England, that is being done by individual clinics and services. The app will provide a huge amount of research and evidence for us.

Brian Whittle: I will come to you next, Ms Thomson.

Just to add to that, the concern is that, if we cannot go across an NHS border and transfer data from one NHS system to another during a global pandemic, which we have global data on, how can we expect to integrate internationally to help us to develop a strategy to tackle long Covid?

Judy Thomson: I agree with you that that is a significant issue, and it is not only an issue in relation to long Covid; it is a long-standing issue that applies across the whole health system. I am afraid that I do not really have any answers to that major challenge. A significant part of my organisation focuses on digital issues, including technology, but I do not claim to have any specific expertise on that issue. I could go back to colleagues and see if there is anything else that they would like to say about it.

Your question was not really about education, training and workforce development, was it? I think that your question was about clinical data.

Brian Whittle: I know that I am against the clock here, convener, but my question is about the challenge that GPs face. They want to know about long Covid, but they do not have the time to know about it and they do not have access to the information that they need. How can we join up the dots to ensure they use their time in the best way?

Linda Currie: There needs to be more investment in that. However, a system called care portal is being implemented in which clinicians can see letters and assessments on different systems, and we are using that in the background. That pulls quite a lot of clinical information together.

Brian Whittle: I will stop there.

John Mason: My questions probably follow on from Brian Whittle's, because I want to ask a bit about where we are with the education side of things. We had a paper from Chest Heart & Stroke Scotland—it gave evidence earlier—which said that

> "most GPs have heard of Long Covid".

That jumped out at me. I would be worried if some GPs had not heard of long Covid. Can you explain to us how GPs are educated on conditions, how their skills are kept up to date and that kind of thing?

Professor Donaldson: I will answer that question in two stages. NES employees are GP trainees. There are training programmes for our trainees, and there are regular training days on which we all come together, either virtually or in person. Last year, there was a trainee training day on long Covid.

We also have GPs who are on the register and no longer in training. The college puts out a module on long Covid—I suspect that it has been discussed many times—with the Scottish Intercollegiate Guidelines Network guidelines.

Although GPs hear about long Covid, they might not have seen a patient with it, so the number of long Covid patients presenting to GPs might explain some of the inconsistencies.

John Mason: Your paper talks about the general practice nursing education pathway. Is the main way into a GP practice not necessarily directly to the GP but maybe through the nurse?

11:00

Professor Donaldson: Again, I think that it is all through the MDT. It is key that general practices work very much in a multidisciplinary way, and the more angles and ways we can get learning and training into a practice, the more that helps.

John Mason: I probably should not make this confession, but I am an accountant, and we are meant to do continuing professional development. Let us say that some of us do it more than others, so there can be a bit of inconsistency. In general terms, would that also be true of GPs?

Professor Donaldson: Our General Medical Council good medical practice is very clear that, as clinicians, we must keep our CPD up to date, so we have guidance on that.

John Mason: I will turn to some of the more land-based regional health boards. How do you see that picture of educating GPs and other professionals?

Linda Currie: If you think about the geographical area that NHS Highland covers and all the different clinicians, that is a challenge. 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.

John Mason: In the case of NHS Lothian, we have had the good model of the pilot with Chest Heart & Stroke Scotland. I was at a separate seminar about that, which was very impressive. If individual GPs or other medical professionals really want to get into a subject such as long Covid, is it largely up to them or does the health board try and push things more?

Heather Cameron: There is a bit of both. As was rightly said, every registered healthcare practitioner has regulations around their CPD and they make declarations that they are maintaining their CPD. However, there is a wide breadth of what people can engage with. Obviously, if something within the board or primary care is prioritised, that will be pushed more but, to some extent, yes, of course, there are elements of self-choice or self-interest.

I think that there are opportunities for us to look at other ways in which we can support that learning. We talked about pathways earlier, and it is about being really clear and having really clear guidance. For us in NHS Lothian, that is RefHelp, and we know that GPs go to RefHelp to look for information to support them. That might not be formal learning, but they are learning through that process.

One other thing from an education perspective is that we also need to think about how we take the opportunities to look at the knowledge and skills that people already have in managing long-term conditions. We see a number of the issues that people with long Covid present with, such as fatigue, breathlessness and brain fog, in people with other long-term conditions. We know that our clinicians have expertise in managing those, so there is something around how we recognise long Covid as an entity but do not treat it as something that is completely stand-alone, unique and different from everything else, because there are commonalities. We need to empower some of our clinical staff to recognise the skills and knowledge that they have in managing those presentations.

John Mason: To take an example, I know that breathlessness is not the only major symptom of long Covid, but it is one of them and, when I had a meeting with a GP practice recently, the staff said that it was the main one that they were coming across. Are those patients referred to a respiratory specialist? Does that respiratory specialist need more education on anything to do with long Covid, or can they continue as normal, dealing with the respiratory condition?

Heather Cameron: I will give you the broad concept. If the specialist is an expert in respiratory conditions, they will investigate according to what their clinical pathways are. The honest answer is that I do not know at this stage whether they would need something extra on long Covid. They would have a breadth of skills that would allow them to manage the breathlessness that is associated with long Covid.

Professor Donaldson: Heather Cameron is absolutely right. Those clinicians are the ones who will be informing us of what they are seeing; they have the skills. What has been happening locally in health boards is that one or two clinicians have been the key link for the boards; they are developing that expertise and becoming the go-to person in that area. They will then inform us back, so it will be a circular thing.

John Mason: Are there good networks both inside and outside Scotland for those kinds of specialists?

Professor Donaldson: There are good informal networks. We were discussing that as part of the preparation for today with some of the key people who have been looking after both patients and colleagues with long Covid. There are informal networks that may, and hopefully will, formalise in time.

John Mason: Ms Heaney, I realise that you are not in the room. Do you want to add anything to that?

Janis Heaney: One of the key tenets of the national strategic network approach is a focus on education in the workforce. 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. The benefit of having the national network is that it enables us to give people the time and space to come together to have those conversations, to learn from peers and to look at what is, and is not, working. That will be an iterative process as we go through the network.

The strategy is there. As I have said, it is at a fairly high level, but we will develop it over time within the network to ensure that it is fit for purpose. Again, it is also about taking in the voice of lived experience to find out what people feel is important to them.

John Mason: That is great. Thank you.

Jim Fairlie: What work has been undertaken to ensure that international good practice and learning is integrated into long Covid services in Scotland? Professor Donaldson.

Professor Donaldson: Thank you very much. You come to me as I look along the panel. I am personally unaware of what we are doing internationally with long Covid; I do not know whether any of my colleagues has more experience.

Manira Ahmad: To give a bit more insight into what the long Covid strategic network has started to do, we are using our resource from Public Health Scotland to produce monthly bulletins in order to make concise information available and to spread it through the network and sub-groups for onward cascade.

I agree with what my colleague has just said. We are learning, and we are happy to share examples of that with you, convener, if that would be helpful for the committee.

That process will encompass what we are doing not just in Scotland or the UK but internationally. The information will be available in bite-sized amounts so that the communities and multidisciplinary teams can learn and pick up good practice in what is happening across the globe.

Linda Currie: The bulletin is very useful. It is so important to have the time to read and filter all the research that is out there, and the bulletin does that for us.

I want to mention the long Covid multidisciplinary team consortium optimising treatments and services across the NHS—LOCOMOTION—study, which is not international but UK-wide. It is a National Institute for Health and Care Research 10-site study that NHS Highland has just recently joined as the Scottish board, which links us directly into the national network and to the learning from nine English and one Welsh site. Places such as Leeds, Imperial College London and Oxford have had clinics for quite a while, and we can pick up all their learning.

Jim Fairlie: Okay. It seems to me that youse all need to learn how to work out what all the bloody terms mean. STIMULATE-ICP—does everybody know what that is? Anyway. I am sorry. Janis, I think that you wanted to come in.

Janis Heaney: I want to reinforce the point about the publication of that bulletin. It is great to hear from Linda Currie that she is finding that helpful. As Manira Ahmad said, that publication pulls together a raft of research and information, and that is led by colleagues in Public Health Scotland. Also, the network is linked in to the London long Covid allied health professionals network, so we are making those national links. Again, as the network develops and we start to work through the work plans for each of these working groups, we will look to make links internationally, too. We have done that successfully in other strategic networks, and we know that that model works, so we intend to look at that as the network develops.

Alex Rowley: I want to come back to an issue that was picked up in the earlier evidence session. There was a suggestion that there are third sector organisations, such as Chest, Heart & Stroke Scotland, that are geared up to be doing a lot more but that there is almost a push back on that from health boards. Is there a good working relationship, and do health boards see the third sector as having a role? If so, what would the issue be with Chest, Heart & Stroke Scotland doing more?

Linda Currie: We developed relationships very early on with a well-known third sector group in NHS Highland called Let's Get On With It Together, or LGOWIT. It already has modules on long Covid, which we purchased the licence for and which we are accessing. I think that some of our patients were able to access that from July 2021. We have stayed with that local service because it is involved with us in service planning, it has groups and peer networks and it does activities and because being based in Highland is really useful for that signposting and collaborative working. That is the way we have gone, but we did that very early on.

Alex Rowley: Therefore, there is a view that we are using all these different third sector organisations and bringing them together. Is that the general view, or could we be doing more?

Manira Ahmad: That is a great question. We can always do more in that space but, to reassure the committee, I note that a lot goes on that we do not get to see or hear about. For example, on primary care, I was surprised that community link workers were not mentioned in the previous evidence session. They are some of those unsung heroes who have those conversations, when the GP might not have the time; it allows the multidisciplinary team to look at more urgent cases.

Community link workers are part of the work that the ALLIANCE is doing. The ALLIANCE is part of our lived experience wider network. Good conversations are happening and referrals are being made. We can always improve on our data capture in order to showcase that, but a lot goes on in the third sector that just happens. We have an opportunity to capture that so that we can tell that story to the committee and others.

I will reiterate something that Janis Heaney touched on earlier: we have the ALLIANCE lived experience network, which is part of the long Covid strategic network, so we are really listening to the voices and to individuals and their experiences and building that into every level of our network and decision-making process.

The Convener: I thank the witnesses for their time this morning. If witnesses would like to raise any further evidence with the committee, they can do so in writing, and the clerks will be happy to liaise with them on how to do that.

The committee's next meeting will be on 2 March, when we will continue our long Covid inquiry by looking into comparative approaches.

That concludes the public part of our meeting. We will now move into private session.

11:13

Meeting continued in private until 11:24.

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