OFFICIAL REPORT
AITHISG OIFIGEIL

COVID-19 Recovery Committee

Thursday 9 March 2023

Session 6

The Scottish Parliament
Pàrlamaid na h-Alba

Thursday 9 March 2023

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COVID-19 RECOVERY COMMITTEE

6th Meeting 2023, Session 6

CONVENER

*Siobhian Brown (Ayr) (SNP)

DEPUTY CONVENER

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

COMMITTEE MEMBERS

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

*attended

THE FOLLOWING ALSO PARTICIPATED:

Professor Kay Cooper (Robert Gordon University and NHS Grampian)
Euan Dick (Scottish Government)
Professor Dame Anna Dominiczak (Scottish Government)
Professor Edward Duncan (University of Stirling)
Professor Chris Robertson (University of Strathclyde)
Dr Janet Scott (University of Glasgow and NHS Highland)

CLERK TO THE COMMITTEE

Sigrid Robinson

LOCATION

The David Livingstone Room (CR6)

Scottish Parliament

COVID-19 Recovery Committee

Thursday 9 March 2023

[The Convener opened the meeting at 09:40]

Long Covid Inquiry

The Convener (Siobhian Brown): Good morning, and welcome to the sixth meeting in 2023 of the COVID-19 Recovery Committee. This morning, we will continue our inquiry into long Covid.

I welcome to the meeting Euan Dick, head of the chief scientist office; Professor Dame Anna Dominiczak, chief scientist for health at the chief scientist office; Professor Chris Robertson, professor of public health epidemiology at the University of Strathclyde; Professor Kay Cooper, clinical professor of allied health professions at Robert Gordon University and NHS Grampian; and Professor Edward Duncan from the Nursing, Midwifery and Allied Health Professions Research Unit at the University of Stirling. Dr Janet Scott, who is a consultant in infectious diseases at NHS Highland and an affiliate senior clinical lecturer at the Medical Research Council-University of Glasgow centre for virus research, is joining us online. Thank you for giving us your time this morning.

We estimate that this evidence session will run up to about 20 to 11. Members will probably have about 12 minutes each to ask questions. As Janet Scott is attending the meeting remotely, she should type an R in the chat box, please, if she would like to respond to an issue that is being discussed, and we will bring her in. I am keen for everybody to get an opportunity to speak so, if time runs on too much, I might have to interrupt members or witnesses in the interests of brevity. I apologise in advance for that.

I ask the witnesses briefly to introduce themselves and the work that they have been doing. I will start with Dr Scott because, like me, she is online.

Dr Janet Scott (University of Glasgow and NHS Highland): I started just yesterday as a consultant in infectious disease and clinical pharmacology at Raigmore hospital in Inverness. I am part of the long Covid team here and principal investigator of the long Covid multidisciplinary consortium optimising treatments and services across the NHS—LOCOMOTION—study. I am also an affiliate senior clinical lecturer at the centre for virus research in Glasgow, where I have worked until now and where I have studied post-viral conditions since 2015.

Euan Dick (Scottish Government): I head up the chief scientist office, which is part of the director general for health and social care in the Scottish Government. Our responsibilities are to look after health research, development and innovation in the national health service in Scotland.

Professor Dame Anna Dominiczak (Scottish Government): I am a relatively new chief scientist for health in the Scottish Government. I work with Euan Dick and the chief scientist office. I started on 1 July 2022, so I have had six months in the role. That is a seconded role, as I am also a regius chair of medicine at the University of Glasgow. My research and clinical work over the past 25-plus years in Glasgow has been in cardiovascular medicine and cardiovascular prevention.

Professor Kay Cooper (Robert Gordon University and NHS Grampian): I am a clinical professor of allied health professions, which is a joint post that is based across Robert Gordon University in Aberdeen and NHS Grampian. I am a physiotherapist by background, but I am really an applied health researcher. My field of research is quite varied. To date, it has been largely on self-management of chronic conditions. I am jointly leading a study that is looking at evaluating emerging models of community rehabilitation for people with long Covid, along with my colleague Professor Duncan.

09:45

Professor Edward Duncan (University of Stirling): Good morning. I am professor of applied health research at the University of Stirling, in the chief scientist office’s research unit for nurses, midwives and allied health professionals. Professor Cooper and I are leading the study that is looking at different models of service delivery for rehabilitation in long Covid research.

Professor Chris Robertson (University of Strathclyde): Hello there. I am a statistician by trade. I work in the maths and stats department at the University of Strathclyde. I have a joint appointment within Public Health Scotland. For the past three or four years, I have been working on a big study of electronic health records in Scotland—the EAVE II study. In relation to long Covid, I have been working on the CSO-funded long Covid study, using electronic health records from general practitioner data in Scotland.

The Convener: Thank you very much. We will move to questions from members, starting with Murdo Fraser.

Murdo Fraser (Mid Scotland and Fife) (Con): Good morning. I will start with a question that is probably best directed to Professor Dame Anna Dominiczak or to Euan Dick from the chief scientist office; it is about the research into long Covid that you have been funding. Could you tell us a bit about how you have taken decisions about the areas in which to fund research and what you view as the priority areas for research to be done in?

Professor Dame Anna Dominiczak: Are you asking about all research or just research that falls within the topic of today's discussion?

Murdo Fraser: I am asking only about research on long Covid.

Professor Dame Anna Dominiczak: Euan Dick will add to this. In late 2020—so relatively early on, and before I started in this role—a call was made for long Covid research. As we described in our written submission, there were 35 excellent applications. They were assessed by an expert panel, which is normally chaired by an independent chair and which includes a number of experts in the area. Nine projects have been funded. Those projects are still in progress. We have described the projects, and people who have contributed to them are here with us today.

At that stage, as it was the very early days of long Covid, the projects focused on descriptive research that described the prevalence and the symptoms. The symptomatology includes multiple symptoms that affect all organs and systems in the body. As we have already heard, efforts were also made to assess rehabilitation—there were two projects on that. Among a number of very interesting projects, there was the data linkage project that is published—in fact, it might not have been published yet, but it is available for all of us to look at in *The Lancet*.

The projects in question were selected by an expert panel. From what we have seen so far—the majority of the projects have not yet reached the final report stage; when that happens and the reports are ready, they will be available online on our website—the linkage studies and the rehabilitation work have been very well chosen and extremely useful.

Murdo Fraser: Thank you—that is very helpful. We have your written submission, which provides some more detail on the projects that you are funding.

Can you tell us about the findings that are emerging at this stage? Are there any themes that are coming through from the research that has been done so far?

Professor Dame Anna Dominiczak: The EAVE II study was mentioned. What has been released in *The Lancet* as a pre-final review study is exceptional, because it looked at 5.1 million adult Scots. I am not aware of previous linkage studies of that size, power or potential, and it is extremely exciting not only that such linkage is possible but that it is possible to repeat that and review what has happened in the long term. My colleague Professor Robertson will be much more expert at describing the linkage platform. It is extremely interesting that a platform can now be used to repeat the linkages in order to follow up what is happening in Scotland with long Covid.

It is the same for rehabilitation, which my colleagues on my left are involved in. We now know what is happening across Scotland in all 14 territorial health boards, so we have a baseline. We would not have known that without early stage results from that study, so very useful things have happened.

There was another, smaller, linkage study performed by colleagues, including Professor Jill Pell, at the University of Glasgow. It, too, was CSO funded. It is interesting that it looked at the issue longitudinally over six, 12 and 18 months.

There is already useful work to be seen, but it is not finished. We must wait for the final reports of all nine studies. Only then can we fully assess what has been produced.

Would Euan Dick like to add to that?

Euan Dick: You have covered the matter very well. As you said at the end, we are awaiting final reports and peer-reviewed articles before we make conclusions on the findings of the studies.

Murdo Fraser: I have one more question on that before I move on. Are there any gaps in areas of research that you need to address through future funding rounds?

Professor Dame Anna Dominiczak: There are always gaps in the research; that is what research is all about.

It is clear to me—not as chief scientist for health, but as a clinician with years of experience—that we need to understand the mechanism of disease. What is coming out internationally is that there is more than one mechanism. We need to find the biomarkers that would allow us to stratify patients and, through precision medicine, provide treatments that truly address the underpinning mechanism, which might be different in different groups of patients.

There is still a lot to do, but it will be done through international effort rather than our local effort. It has to be part of international work.

Murdo Fraser: That is very helpful.

I have a question on a slightly different topic for Professor Cooper and Professor Duncan. I was interested to read the comments in your written submission about self-management strategies for people with long Covid. You suggest that the evidence base for the effectiveness of those strategies is “limited”, and you say that your study

> “found that many people who present for assessment for Long Covid Rehabilitation are considered unsuitable for self-management”.

That is interesting, because it reflects some of the feedback that we, as a committee, have had from long Covid sufferers. Will you elaborate a little bit on what your research in that field has been telling you?

Professor Duncan: I will go first; Kay Cooper can then feed in.

Great importance has been given to funding self-management strategies, in part to make interventions accessible to as wide a group of people as possible. That is to be commended. Research for self-management per se, outwith long Covid, is fairly well established for people with long-term conditions. As a baseline way forward, there is logic in doing that. Self-management has to be seen in the context of the wider breadth of rehabilitation therapies that are on offer to people.

On one of our case study sites in particular, there is probably the most well-developed rehabilitation service for people with long Covid, in which people are triaged to self-management, individualised therapies and group therapies. It has found that very few of the people who have been referred to the services have been applicable for the self-management strategies. That begs the question of how appropriate self-management is as a sole means of therapeutic offer for people with quite complex needs.

Professor Cooper: That summed things up really nicely. I will add only one thing, which links to looking at who is appropriate for self-management.

Our written response to the committee should not be interpreted as saying that nobody with long Covid is suitable for self-management. However, perhaps more research and evaluation need to be done on how we work out who is most appropriate for that and who needs more complex multidisciplinary or professionally led rehabilitation services, and on what the outcomes are for those who go down the self-management route. Does that fulfil their needs in respect of quality of life and symptom management?

Murdo Fraser: So what you are saying is that you have done some research, but you have only skimmed the surface, in effect, and a lot more work needs to be done in that field,

Professor Duncan: Absolutely.

Professor Cooper: Yes. We have emerging findings on that topic, but we have not fully evaluated it.

Professor Duncan: There is the question of the effectiveness of the breadth of delivery of self-management. A longer-term follow-up that asks whether it meets patients’ needs and whether there are other needs that are not being met would be highly valuable.

Alex Rowley (Mid Scotland and Fife) (Lab): Good morning. I will ask about future research. In the responses to the committee, there have been suggestions to look at, for example, the implications of Covid on national health services workers in the longer term. We have heard from NHS workers who are already being impacted in many ways.

Many written submissions have suggested that treatment trials need to start now, with existing medications. How do you prioritise research, and are there any plans for commissioning further research in Scotland?

Long Covid Scotland told us:

> “In 2020, nine research projects were funded in Scotland, but there has not been any further funding for Scottish research projects since then.”—[*Official Report*, *Covid-19 Recovery Committee*, 9 February 2023; c 16.]

Given that there are a lot of suggestions about what needs to be researched, how do you prioritise, and do you have any plans?

Professor Dame Anna Dominiczak: That is a difficult question for any research system, anywhere in the world.

During 2020-21, no other research was taking place and therefore research on Covid was commissioned. All our universities and all clinician scientists in universities and the NHS completely moved to Covid research—they did not do any other research—so it was appropriate to commission research on that.

Under normal circumstances, we do not—or rarely—do that. The chief scientist office’s funds two standing committees that deal with research: the health improvement protection and services research committee and the translational clinical studies research committee. Those two committees are open to all research—on long Covid or anything else—and researchers across Scotland are well aware of that. In fact, a large project was recently accepted and will be funded. That has not quite been signed off on yet, so we cannot talk about that; the details will be on the website when it is.

It is also important to say that the majority of health research, clinical research and public health research in Scotland is not funded locally through Scottish funding but funded through other sources.

We proactively empower and inform all our stakeholders across Scotland about opportunities with UK Research and Innovation, the Medical Research Council and the National Institute for Health and Care Research.

10:00

Our clinician scientists have been very successful. For example, the NIHR provided very large sums of money to fund Scottish projects, which are in progress. We have been bringing together chief executives and medical directors through UK-wide bodies that have substantial funding, so that our researchers are aware of opportunities. That work is on-going. The same is true in relation to major charities that fund Covid research, such as the British Heart Foundation.

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

Alex Rowley: Yes. Does anyone want to add to that?

Euan Dick: I will re-emphasise some of the helpful points that were made by Anna. As she said, in normal times, we run two research committees, which contain expert scientific advisers who advise us on the best projects to fund to meet the needs of the people of Scotland. As she said, we work within wide international and UK systems in which Scottish research projects can access a range of funders. Those systems work in a very similar way to how we work—there are expert committees to make sure that the research that will have the most impact in the long term is funded. Our prioritisation for studies comes from those committees and is based on expert advice. That is what we have done for many years.

The situation with Covid was a little bit different. As Anna Dominiczak said, at the time, the NHS had stopped quite a lot of research, and it was not feasible to start research on other conditions, why is why we focused particularly on an emerging condition. We did that during quite an unusual time.

Alex Rowley: In relation to previous research, I was struck that, when long Covid started to emerge and people started to highlight that they were suffering from it, I began to receive a lot of emails from people who have suffered for years with myalgic encephalomyelitis. We can draw comparisons between that and a lot of the symptoms that are described by people suffering from long Covid.

I assume that research projects on ME, for example, have been done in Scotland. If there are similarities between long Covid and other conditions, are you able to use previous research? How do you go about doing that? Nurses and other people who work in the NHS are being laid off, but people are looking for an immediate response. Are you able to consider other conditions and then give advice?

Dr Scott: We can definitely draw comparisons with other post-viral conditions. In, I think, April 2020, I started to advise the World Health Organization on long Covid because I had been working with it for the previous five years on post-Ebola syndrome. I also treat patients with chronic fatigue syndrome, but that is not my particular area.

Every post-viral condition is slightly different, but there are similarities. The challenges that patients with post-Ebola syndrome faced in getting clinical care, in getting dedicated clinics and in leveraging research were quite similar to those that have been faced by our long Covid patients. Such challenges relate to stigma and gaslighting. It was said that people were feeling unwell just because life is hard in west Africa, but our research has shown that they were suffering from a persistent virus.

With post-Ebola syndrome, the research did not continue so that we could understand important aspects about the underlying aetiology and treatment. At the end of every epidemic, research funding moves on to focus on the next pandemic. It happened with sudden acute respiratory syndrome—SARS—and it happened with Ebola: all the money subsequently went into Zika. We know that, when money goes into research during a pandemic, it will move on when people stop feeling quite as scared of the disease. It seems to me that that is what is happening with Covid.

However, we can draw from our previous experience and try to do two things: first, we can move things forward from where we were with the previous disease and, secondly, we can try to do better the next time that something new comes along. Therefore, we have to start research on survivors or long-haulers—whatever you want to call them—at the beginning of outbreaks, not six months in or at the end of them, and we have to learn to provide adequate clinical care at the same time as characterising research.

I am not convinced that that second part has happened in Scotland. We have some excellent rehabilitation facilities, but the service is mostly virtual and we do not have long Covid clinics. As well as being difficult from a clinical perspective, not seeing face to face patients who have difficult, multi-organ disease makes it more difficult to participate in the broader clinical trials and the research that has been funded throughout the UK.

For example, there is a platform for drug trials in long Covid. STIMULATE-ICP, which is run out of Imperial College London, runs through the long Covid clinics in England. We will try to bring it up to the Highlands, but that is a big ask when we do not have a face-to-face clinical service.

The LOCOMOTION study, which is potentially a UK-wide study, is looking at different provision of care, but we are not really able to participate in the more proactive arms of that—such as testing exactly which interventions are useful and exactly what tests to do with patients in clinic—to the same extent as our English colleagues because of lack of clinics in which patients are seen face to face.

We have done a great job in Scotland with the linkage studies. I am a co-investigator on the long Covid study led by Jill Pell. It has been an amazing exercise with good big data. We are able to talk about questions such as what the true prevalence, the impact of vaccination and the natural history are, which is all fabulous. However, when it comes down to what we do with the patient in clinic, we need to think on a practical level about questions such as whether you do a sit-stand test or a lean test; whether it is useful to screen for cardiomyopathy, such as came out of Colin Berry’s study in Glasgow; and whether everybody needs screened or whether it is just those with symptoms.

We are not really doing that in Scotland because we are trying to treat everybody at a distance. We are just using their GP records, using their numbers or trying to do linkage. That is cost-effective research, but, at some point, we have to develop experts in long Covid, which means seeing the patients so that we can come up with the right studies and the right questions to move things from characterising—which is what we did in 2020—on to, as Professor Dominiczak says, understanding the underlying aetiology and then providing proper management strategies and treatments.

Alex Rowley: Thank you. That is very helpful.

The Convener: I will ask a quick question, Dr Scott, regarding the STIMULATE-ICP programme, which I have not heard of before. You said that it is being rolled out in England. Is it being rolled out in Wales? The Welsh have a similar approach to the way that Scotland is doing things.

Dr Scott: It is open to investigators throughout the UK, but, so far, it has not stretched further north than, I think, Manchester. I am in discussions with the project team. If we can get a site in Inverness, we will certainly broaden the project’s geographic spread, but, as I said, there are some challenges with that.

The project’s remit is across the UK, but, in practice, it mostly recruits in England, and around southern England at that.

Brian Whittle (South Scotland) (Con): Good morning. My interest in health is around the gathering and deployment of data. Do we have a system that allows for the effective deployment of data? We gather data, but do we have a system that, in practice, allows that data to be crunched and deployed, such that effectiveness is measured as we consider how the data ends up being used in the treatment of patients? To date, we have heard from clinicians and from sufferers of long Covid that the investigation and the data are not allowing for effective treatment on the front line.

I put that to you first, Professor Robertson, as a statistician and a non-clinician. Is that right?

Professor Robertson: Absolutely.

Brian Whittle: Do we have an information technology system in Scotland that allows for the proper deployment and sharing of data across the whole system?

Professor Robertson: The answer is yes and no.

Brian Whittle: Excellent.

Professor Robertson: That has been feasible. The large EAVE II study that I worked on has data from health records and GPs—from pretty well everybody in Scotland. The permissions that we had to adopt in order to get access to that data involved negotiations with GPs, who were very helpful at the beginning of the pandemic, as they realised the importance of the data. However, the ethical and governance permissions meant that we were not allowed to interrogate the GP data itself. We had to pre-specify clinical risk groups that would be important, as well as vaccination data. Having pre-specified that amount of data, we were then able to extract it and move it into Public Health Scotland for surveillance and studies on vaccine effect during the pandemic. A copy of the data also went into the electronic data research and innovation service—eDRIS—platform for other researchers to access.

That worked. We had a kind of rolling static extract, as we got repeated extracts through Albasoft from the GP data. Once that is there, because we have the community health index number in Scotland, we can link that to all the other data that is available. That gives Scotland a phenomenal resource not just for research but for management and surveillance of Covid and almost any other disease in Scotland.

I am not an expert on this, but there have been recent changes to move all the GP data that used to reside in individual general practices on to a cloud-based server. NHS National Services Scotland is getting a copy of that, and moves are afoot to get permissions for all researchers, Public Health Scotland and different groups to access that data. When that is in place, it will be a phenomenal resource for Scotland. There are others who have more understanding of the exact details of that.

Brian Whittle: I will broaden out that question to you, Euan. We have always heard that Scotland is fantastic at gathering data—that we have a phenomenal ability to do that. However, given the practicalities of informing our GPs at the front line about what to look for in Covid and of deploying resources to help patients at the front line, our ability to deploy that data is not good. That is what we are hearing just now—that that element is not good.

Where are we with that, and what do we need to do to ensure that our healthcare professionals are properly informed about the issues around long Covid? We have even heard that some of them still do not believe in long Covid—they feel that there is a mental health issue around long Covid. The reality is that long Covid exists. How are we going to get to a point at which all that gathered data is available to our healthcare professionals so that they can deploy the resources?

Euan Dick: The chief scientist office works within the research, development and innovation area of the NHS. Our focus is on the use of data for research, development and innovation rather than on the use of data for more operational reasons. I will therefore not be able to address operational elements of your question, unfortunately, although I would be happy to take that point back to the Scottish Government and have my colleagues answer that, if that would be helpful.

From a research perspective, we put mechanisms in place to help researchers to use the data at a national level. I think that Chris Robertson mentioned one of the projects that has been funded through the CSO, and it has done that on GP data very successfully.

10:15

We have a range of data safe havens across Scotland—a national one and regional ones—and their role is to pull together data to allow it to be used in research projects. They do that on a bespoke basis when research projects come forward and require that data. We all recognise that we want that to be more efficient and effective in the future, and we continue to work to make that happen.

Brian Whittle: That leads me to another question. As I have said, the quality of research in Scotland is world renowned, but, at the end of the day, it is about how you deploy that effectively on the ground. Can any of the other witnesses—I am looking at you, Dr Scott—help me understand how that data is being deployed to help patients, because that is what we are trying to do?

Dr Scott: That is part of my role here in the Highlands. I have two sessions for research and one session for clinical long Covid. We cover a huge geographical area, so the only way that we can do that is by collaborating closely with our GP colleagues. As part of the long Covid service, we plan education and outreach with GPs and other clinicians—the allied health professionals, including physiotherapists and occupational therapists.

My job is to keep on top of all that research and to transmit it into clinical practice. I transmit it into my own clinical practice, but I also help to disseminate that to my colleagues. I hope that that works, but I only started yesterday, so I will tell you in a few months.

Brian Whittle: That seems fair.

Professor Dominiczak, we have heard what Dr Scott said about how that information is now being deployed. How are we ensuring that that good practice is being reflected across the whole of each NHS board? We are hearing that it is patchy and that it is a bit of a postcode lottery with regard to whether people can access any treatment for long Covid, let alone diagnosis. How are we ensuring that that practice is deployed across the whole country?

Professor Dame Anna Dominiczak: I will come back to the issue of data for a minute. Outside my activity in the chief scientist office, which is dedicated to research, development and innovation, I am also engaged in the standing committee on pandemic preparedness, which looks at precisely what you talked about: data being ready to deploy across the system—in case there is another emergency, although, of course, it must be deployed every day in normal practice to be useful. Therefore, as my colleague said, there are safe havens—a central Scottish one and regional ones—through Public Health Scotland. There is an enormous effort on the part of all colleagues across the Scottish Government, the NHS and everywhere else to make data useful not only for research and innovation but for everyday practice. That is crucial.

As we heard, and as was recorded in previous evidence sessions, the issue is how long it takes from the point at which a certain set of data is requested to the point at which someone is able to use it. We are not there yet, but the ambition would be to be able to do that within two or three weeks.

Brian Whittle: I was interested to hear you say that you have access to data on 5.1 million Scots. That is a significant pool of data from which you can draw. However, for that to be useful, people would first have to suspect or know that they have long Covid and they would then have to access a GP to be diagnosed, or at least be signposted somewhere by their GP to be diagnosed. They would then have to be able to identify a treatment.

You gave the figure of 5.1 million people, but the research that we have done and the evidence that we have taken suggest that there is a problem, especially in more deprived areas, to do with people who potentially have long Covid coming forward.

Professor Dame Anna Dominiczak: My colleague Chris Robertson did the work, so he will be better able to tell you about it. However, I have looked at the EAVE II paper that was published—it is available to look at today—and it used not just a diagnosis but words from a GP's computer to evaluate whether a person might have long Covid. It was not just about whether a diagnosis had been made; there were other ways of looking at the 5.1 million people. I would like my colleague Chris Robertson, who is an expert on the matter, to describe what happened, but I think that it was a huge achievement.

There is always the problem that, if a patient has no contact with the health service—they never come to complain—there will be no data to look at. However, the majority of people with the plethora of symptoms that are associated with long Covid would have had some contact with their GP. They would at least have described a series of symptoms, which allow us to identify that they might have long Covid.

However, we need to hear from the expert.

Professor Robertson: The 5.1 million figure is the adult population in Scotland. Our study looked in detail at the health records of about half a million people who tested positive—the same as Jill Scott's study—and we matched the records of the people who had had Covid at at least one point during the period with those of people who had tested but did not have Covid at the time. We compared their contact with GPs in the periods of four to 12 weeks and 12 to 26 weeks after having Covid, which allowed us to identify symptoms that were not necessarily recorded in GP coding as long Covid. There is a code that GPs can use for long Covid, but they do not use it very often.

We found that people were being treated for, or reporting symptoms of, fatigue or mental health issues, and a number of other symptoms were much more common among people who had tested positive for Covid than they were among those who had tested but did not have it. That gives you an idea of the symptoms that people reported.

GPs also asked people to go for further tests such as blood tests and echocardiographs or something like that—I am showing my lack of medical knowledge—and people were also prescribed antibiotics and stuff like that.

Through those groupings of conditions, we were able to postulate that a person with long Covid, after testing, might have had two or three of those types of interactions with their GP. That is how we estimated what the prevalence of long Covid might be, but we recognise that that will be an underestimate because there will be people with the coronavirus who never bother going to their GP. That might be what Brian Whittle was referring to when he talked about the lack of engagement in particular communities. If someone does not think that their GP will treat them, they might think that there is not much point in going to see a doctor.

We are going to expand on the work that we have done. Having got a working definition, we will now look at whether we can identify symptoms that might predict whether somebody has the condition. That approach could then be used in the future, given that Covid testing has now diminished, as the types of symptoms that people present with might be commensurate with the symptoms of long Covid.

John Mason (Glasgow Shettleston) (SNP): I will continue Brian Whittle's line of questioning. We have heard different evidence from down south. Is one of the problems that some GPs are not familiar with the codes, which is why they are going through the free text route? I am not a medic or a scientist, so will you explain what free text is?

Professor Robertson: When GPs have a clinical consultation, there is a facility in the computer system for them to pick a code for what they are consulting on. If someone goes to their GP with a severe headache, the GP will click on the code to say that they are consulting about that. In Scotland, GPs get a little read code, which is great for us to use as researchers. Alongside that, the GP will type in notes that say "Severe headache" and maybe something like "Reports falling down two weeks ago". They might add "Query concussion" or something like that. The free text is everything else that the doctor writes in the notes at that time.

Among the people whom we surveyed, we found that, although the long Covid code was not used very often, the doctor would quite often write

"Query long Covid" or "Covid positive a while ago" in the free text, so that facility is being used. In particular, fit-for-work notes, which are free text, are being used. That may give you an idea.

John Mason: I found your paper interesting. I confess that I did not understand some of it, but it is good. I will press you on the issue. What is the prevalence of long Covid? At one point in your paper, the figure of 1.8 per cent is mentioned, which would be, perhaps, 90,000 people.

Professor Robertson: Yes—that is what we estimated at that time. Other surveys will have looked at things differently. I think that Jill Scott's paper has a figure of 3 per cent to 5 per cent, because things are being done in a slightly different way in some areas.

John Mason: Right. I will come to Dr Scott next.

Professor Robertson: That was our approach. As I explained, we think that that figure is likely to be an underestimate because, if someone does not go to their GP, they will not feature in it.

John Mason: The commonly used figure is about 170,000. Do you feel that that figure would be reasonable, if you are underestimating the prevalence?

Professor Robertson: I know that I am underestimating, but I do not know by how much. It is simply that, as statisticians, we are incredibly cautious about the biases that might exist in our data.

John Mason: That is fair—that is what we want to hear.

I will come to Dr Scott, but first I have another question for Professor Robertson. I was interested to see that more of the long Covid seems to have come from the alpha and delta variants, with less of it coming from omicron. Is that what you found?

Professor Robertson: Yes. Again, there is a potential bias, although we think that we corrected for it. Omicron is around just now, at a time when people are heavily vaccinated. I know that Jill's study looked at the impact of vaccination on whether individuals developed long Covid.

John Mason: Okay. I have a question for Dr Scott, but I think that she wants to comment on the previous question first.

Dr Scott: Professor Jill Pell did the long Covid study, and I am one of the co-investigators. We have already published a paper that looks at some of the natural history of long Covid, and we have a paper on true prevalence that is about to come out.

The way that the Covid in Scotland study worked is that it sent out text prompts to everybody who tested positive and it got feedback from patients. In our next study, there are just over 41,000 positive cases, with a control group of 35,000 who were tested but were found to be negative. That data has not been published yet, but in our true prevalence estimates we are looking at somewhere between 6 per cent and 10 per cent of people who tested positive for Covid. That is not a population estimate; it is a proportion of people who tested positive.

There is also the Office for National Statistics data. The ONS has done things in a very different way and it has an estimate of about 2.2 per cent to 3 per cent of the population. No matter which way we cut it, however, we are talking about a lot of people. Whether it is 3 per cent or 1.6 per cent of the population, there are a lot of people out there with a large range of disease.

John Mason: You are quite keen on long Covid clinics, about which it would be fair to say that we have had mixed evidence. For example, we have heard that they are extremely costly per patient and that people with other conditions might be diverted away from GPs to long Covid clinics, so other illnesses could be missed. Are GPs key to all of this? In England, GPs refer people to long Covid clinics, so they are the key people.

10:30

Dr Scott: Yes. GPs are key not only in relation to long Covid, but across the board in our healthcare system. As I understand it, the English clinics take referrals from general practice and the Welsh ones accept direct referrals. If we had long Covid clinics in Scotland, people would be referred to them by GPs. For post-Ebola syndrome, we took referrals from Ebola treatment units and directly from individuals, but that was because there was such stigma associated with Ebola that patients were not even able to go into their local healthcare provider.

Whether a secondary care doctor adds value to a patient's outcome is a testable hypothesis. That is exactly the sort of thing that health systems research and the LOCOMOTION study could look at.

I have only had one multidisciplinary team meeting with the long Covid team in Inverness, but during that meeting the team highlighted four individuals with complex disease. Three of them will need a secondary care outpatient appointment and one will probably need to be admitted. However, it is not clear whether all of what they have has been caused by long Covid or whether some of it has been caused by something else. We would have to rewind and become general physicians to find that out. That is where secondary care could come in.

There are a range of symptoms that relate to long Covid. Some can be self-managed, some can be managed through primary care and some will need face-to-face meetings at a secondary care clinic. We have to be pragmatic about it.

John Mason: On the point about face-to-face meetings with people, does that vary between different health boards in Scotland? Do some do more face-to-face meetings than others, or is it a national problem?

Dr Scott: I do not know of anybody who is funded to do a face-to-face long Covid clinic. There is a private GP who has given evidence to this inquiry and has a very good reputation, and I know of a few other colleagues who are seeing people ad hoc in other clinics, but we do not have anything on the scale of the English long Covid clinics.

In the Highlands, we have other issues that could also do with rehab—we have a lot of Lyme disease up here—and I would not want to miss those patients out of any service. We have to be equitable about what we are offering and try to target it at people to whose care we can make a difference.

John Mason: Lyme disease is an interesting example to bring up. As a hillwalker, I am always a bit wary of that.

I move on to some questions for Professor Duncan and Professor Cooper. Your paper suggests that GPs are reacting to long Covid in different ways. Are some of them wary of diagnosing people with it?

Professor Cooper: I should say that our findings are initial ones and they have not been peer reviewed and published yet.

John Mason: I was going to ask what your timescale is for that.

Professor Cooper: We are analysing that data and putting papers together, so they should be in the public domain soon.

During our research in the past couple of years, almost, we have interviewed people with long Covid who have had varied experiences of accessing GP services. Some have had very positive experiences—they accessed GPs who were very helpful and who did lots of tests. In some health boards, the difficulty has been that people have not known where the person should be referred to because of a lack of time or knowledge about the services that are available for patients, such as rehabilitation services. In some examples, GP services have not been so helpful. It is fair to say that there is a mixed picture.

We have also interviewed some GPs, but I am not as familiar with that data. Professor Duncan may want to talk about that.

Professor Duncan: There has been a mix of responses. Some GPs have been very supportive of patients. We looked at patient data and GP data and brought those stories together and matched them up, and that data suggests that some GPs are very responsive—they are willing to send people for tests and follow up with them. Some GPs have suggested that they view the condition as something that will resolve naturally over time and which does not need intervention. Some GPs have reported that they do not “believe”—I put that in inverted commas—in long Covid, and that has also been reported in some patient data on GPs. There has been a mix of responses, but I cannot allocate proportions to them. I am not suggesting by any means that all GPs are like that, but we see that breadth of perspectives in the data.

The other thing to say, which speaks to our data, is that, although I am unable to say whether specialist clinics as opposed to non-specialist ones are right or wrong, our evaluation method is a bit more nuanced than that. It uses a methodology called realist evaluation, which asks what works for whom, in what situations, and when. The people of Scotland live in dramatically varying situations. There are people in Highlands and Islands communities and there are people in big cities, and the opportunities to develop services vary dramatically across those systems.

Our four case studies looked at various health boards and different settings. In the two health boards that have had at different times—from a rehabilitation perspective, not with medical expert input—the closest things that we could get to specialist long Covid clinics, the promotion of accessible pathways for people to access that care has clearly been useful. That has involved active publicising to GPs and patients of how to access the services.

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

John Mason: Thanks for that. We could explore that further, but I have to stop as I have used up my time.

Jim Fairlie (Perthshire South and Kinross-shire) (SNP): Thanks very much for coming. I will try to mop up a bit here, but first I will come back to you about the reaction from GPs. It sounds very similar to the reaction from GPs to women who go to them about menopause. Some doctors say, "You'll get over it. It is just a change in your life", but others say, "Let's take this seriously" and go through a whole process. Who monitors the reactions of GPs to patients who go to them and say, "I have a problem", and is there any recourse for a patient who says, "My doctor is just not taking this seriously"?

Professor Duncan: We are not primary care specialists. I am afraid that I do not feel that we are in a position to answer that question on the basis of evidence.

Jim Fairlie: Okay. I am sorry—it was just a thought that came into my head when you gave the previous answer.

Is there enough connectedness between all the research that is going on so that it feeds back into the system for practitioners to use? Is everything that you guys are doing getting to the guys who actually see people who are sitting in waiting rooms?

Professor Dame Anna Dominiczak: Our system—for all diseases and particularly on this—is very well designed to inform. Of course, as is very clear to researchers, every research project aims to publish peer-reviewed papers, which then feed into the guidelines. As you know, this particular condition has unusual guidelines. Guidelines from the Scottish Intercollegiate Guidelines Network combine with guidelines from the National Institute for Health and Care Excellence and the Royal College of General Practitioners. To my knowledge, this is the only situation where all the research is actively monitored to input to the guidelines as quickly as possible. There was a recent edition, in 2021, and something will probably happen again soon to issue new guidelines.

In addition, all researchers—those funded by the CSO and everybody else—participate in national and international meetings and symposia. These nine projects that are funded by the CSO came together to present preliminary data to a symposium some months ago. Therefore, there is a huge effort to make data—everything that comes out of the research—available. Final reports will be published when ready in accessible language—the effort is made. In addition, there is a UK-wide system of reporting all research results through Researchfish so that it is all reported for posterity and available for searching and looking at.

Jim Fairlie: Professor Robertson, did you say whether, in the data that you were looking at, you tried to discriminate whether people were more likely to get long Covid if they had been vaccinated as opposed to if they had not?

Professor Robertson: We have not looked at that in detail. There is a table in the research that suggests that long Covid was more common among people who were unvaccinated at the time that they got coronavirus.

Jim Fairlie: Is the correlation with the fact that they were unvaccinated or with the strain of the virus that they caught? Are you able to discriminate?

Professor Robertson: At present, I will not say yes or no. The two things are confounded, in a way. The unvaccinated largely got coronavirus when the wild type and alpha were around. The vaccinated who got coronavirus were largely infected in the delta and omicron period.

Jim Fairlie: Janet Scott—my apologies, I forgot your name for a second—how are we doing as a country? I am taking the point of view of a patient with long Covid who goes to their GP. How are we doing as a country in getting those people on the right pathway?

Dr Scott: The short answer is that it is pretty dreadful.

Jim Fairlie: How do we sort it? Perhaps I should have started with that question.

Dr Scott: My colleagues in health systems research hit the nail on the head: we need clear and well-publicised pathways. However we do that, whether through primary care or a combination of primary and secondary care, there has to be a clear way.

We do not have a lot of funding for the large geographical area of the Highlands, so there is some reticence to go out and really publicise services because we already have quite a backlog of people to see and we are aware of the huge unmet need out there. We know that, if we properly publicise services, there will be a deluge that we are not equipped to cope with.

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

We do not want to publicise what does not exist and, at the moment, we do not have a clinic to see those patients who need one. We do not have a face-to-face physio service to give to those patients who need it. The need exists—we hear that from patients all the time.

It is not that every patient with long Covid needs all those services any more than every patient with chronic obstructive pulmonary disease needs to come into hospital three times a year. However, some patients with COPD need that and some patients with long Covid need secondary care. You need somebody to advocate to ensure that they get seen by a postural tachycardia syndrome expert or an endocrine expert, get assessed for mast cell activation syndrome or have whatever done that we will do in order to optimise everybody's health.

We do not have the clinical structures in place, and the structures that we have we are loath to advertise. This evidence session is about research, and the situation is hampering our participation in national and international research.

Jim Fairlie: Edward Duncan, I will ask you a quick question. Did your research find anything about whether a single point of contact was desirable?

Professor Duncan: We did not carry out research specifically on a single point of contact. That intervention or service has come out since our study started, as part of long Covid funding, so it is not specific to our study.

Jim Fairlie: Thank you.

10:45

The Convener: I know that we have run a bit over time but, if I may, I will ask a few more quick questions.

How is international research on long Covid being disseminated in Scotland? Dr Scott, you mentioned that issue.

Dr Scott: As is the case with all research, research on long Covid is available through preprints and the published press, but people must have the time to sift through it all and keep active. Every GP has a big workload, and long Covid might not necessarily be their main focus of attention. That is why it is useful to have specialists in a particular area who can get to know patients properly and clinically. If they become experts in the area, their job is to keep up with the literature and the regular international and local research.

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

The Convener: Euan Dick, what level of research funding for long Covid is needed in the short to medium term?

Euan Dick: I do not think that I can give a figure for that. As was said earlier, we are at the next stage of doing research on long Covid. We have opened up our committees, and our colleagues across the UK have opened up their committees, for those in the expert community to propose the future research that they want to carry out. They have access to funds that are available across a range of conditions. Once proposals are made, they will be put in front of scientific committees, which will give expert advice on what we should be funding and what would be of most value.

The Convener: That is great.

I open up my next question to all the witnesses. If someone wants to answer, they can let me know by raising their hand, because, given that I am online, it is difficult for me to see who wants to answer.

Are you aware of any additional or on-going funding streams for long Covid research that could be utilised?

Dr Scott: We have not mentioned the Wellcome Trust, and there is international funding, too. We all go for any money that is available—I do not think that any of us are very proud about that. There is national and international funding, and, wherever it comes from, we apply for it. That funding is not specific to long Covid; it is available for all diseases. You just have to put your case and argue your point.

Professor Dame Anna Dominiczak: I absolutely agree. As I said, we encourage clinicians, scientists and public health researchers across Scotland to apply for any possible funding in order to bring information closer.

We have not mentioned the horizon Europe programme, but there is a big issue in that regard. As you know, currently, our scientists can apply for horizon Europe funding—it is covered by UKRI—but we do not know what will happen in the long term. Long Covid is the perfect condition for research by large co-ordinated international consortia. I hope that horizon Europe funding will come to Scotland and that there will be opportunities for colleagues across Scotland to apply for big internationally agreed funding streams, which could address some of the issues that we have been discussing today.

The Convener: I will stay with you for one final question, Dame Anna. What oversight has there been of how research funding across the UK has been allocated?

Professor Dame Anna Dominiczak: We work closely with colleagues across the four nations. There are a number of ways in which we discuss what we do. There are oversight groups such as the office for strategic co-ordination of health research—OSCHR—where funders of clinical and public health research come together. We discuss things bilaterally with UKRI, including the Medical

Research Council, and major charities, including the Wellcome Trust. However, as we said before, like the CSO, all those bodies, including the National Institute for Health and Care Research, have their own expert committees.

There is normally an open call, proposals come in and, depending on the size of the given call and proposals, there could be two stages—an early expression-of-interest stage and then full proposals—which would always be independently assessed by experts in the area. As Dr Scott said, it is important to have experts in long Covid to assess proposals, but we believe—there is enormous evidence to support this—that open calls produce the best possible research and expert assessment is what we need. There is something called the Haldane principle, which is that what scientists research should not be dictated to them but always decided through peer review by experts, because that produces much better research for patients.

The Convener: That is very helpful. I thank all the witnesses for their evidence and time. If any witness would like to provide further evidence to the committee, they can do so in writing. The clerks will be happy to liaise with witnesses on how to do that.

The committee's next meeting will be on 16 March, when we will conclude our long Covid inquiry with the Cabinet Secretary for Health and Social Care.

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

10:52

Meeting continued in private until 11:01.

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