

Long Covid Service User Q&A
30 January 2023

Welcome

Nic Richardson, Director of Allied Health Professionals, NHS Tayside, chaired the session and she is the current Chair of service planning group.

Everyone was welcomed and thanked for taking the time to attend the session.

By taking part in the session, it would support people to have a better understanding of what is being planned and delivered nationally and in local board areas.

Housekeeping

Through your communities and groups, everyone had been informed that due to data privacy challenges, the session will not be recorded. Feedback will be provided in a variety of formats and shared with your communities / groups for onward sharing.

It was acknowledged that by not recording today's session may not be everyone's preference, however, options were circulated that included:

- Full recording but that would require data consent forms from everyone attending
- Full recording with cameras off
- Full recording with a mixture of cameras on and off
- Not record, but that allows the opportunity for everyone to be on camera should they wish.

Very little response received to those options. The Service Planning group discussed the pro's and con's of each option and decided to have an interactive session where everyone could be on camera, and find ways to ensure the information could be shared with everyone in accessible formats.

The plan so far is that there will be a summary video animation and a summary document.

Acknowledging that not everyone could attend on this day and time and sent an invite through the communities / groups for anyone to submit questions prior to today. The questions received will be discussed today, in addition to other questions from the attendees. Any questions related to an individual's care would not be answered today but would offer to link anyone into a representative from your local health board.

The session will be formally evaluated and the outcomes will be shared within your communities / groups via the Lived Experience group of this Network.

We will begin with questions that were submitted prior to today, then open it up for further questions.

Introduction

Most of the Health Boards were represented today.

John Dennis – NHS Ayrshire and Arran
Linda Gray – NHS Borders
Pauline Beirne – NHS Forth Valley
Fiona Smith – NHS GGC
Sharon Hammell – NHS Highland
Linda Currie – NHS Highland
Abbie Campbell – NHS Lanarkshire
Hannah Cairns – NHS Lothian
Kevin Fox – NHS Orkney

Catherine Coutts – NHS Shetland
Nic Richardson – NHS Tayside

The Network was established in March 2022 with a £10m funding package over three years from Scottish Government. The National Strategic Network's remit is to provide national support to building the capacity, capability and co-ordination of health and social care services for people with long-term effects of COVID-19.

The Service Planning group is looking at a consistent national approach to collecting and use of data, sharing good practice, collating educational resources, both for professionals and people we are supporting, and about to roll out the national use of a digital tool. Whilst we are a single national group, the structures that have been embedded in each board do differ and that depends on the structures in existence. The current development of each service within a Board also differs as recruitment processes are worked through. There is not a single structural model that is the same in every Board, however, we do have a consistent aim to work together to provide services to support people.

Questions

Is there or will there be a long covid centre for those in the West of Scotland?

NHS GG&C reported the national approach is to ensure services are provided within boards rather than on a regional basis. To ensure any services developing are linked into communities and localities. Boards started from different points but wanted to ensure they were creating strong, robust pathways in areas. NHS GG&C had rehabilitation services and services within local communities but had the opportunity to add specific service to layer with that through the funding. The Board is currently recruiting to vacancies and hoping to have a service commence in mid March.

The approach in NHS Tayside was to embed services within existing community rehabilitation services.

NHS Highland has a board wide service which covers a large geographical area. Recognising the need for close working relationships and pathways across clinical and rehab teams as well as into local community services e.g. leisure, 3rd sector groups.

In NHS Ayrshire & Arran there had been quite a lot of training within generic teams, community rehab teams to provide services. Due to start this year with a specialist Long Covid teams for people who are struggling and needing additional support.

The Network was enabling conversations around how research and data will work over time as NHS Lanarkshire would want to have longevity in their models and to consider models for the future.

■■■■■■■■■■ initially thanked Abi for all the support to her family.

People need medical intervention before rehab and is the funding able to establish the medical intervention which is critical, particularly for those severely impacted?

Also, to holistically look at a person with a myriad of ailments and to have a joined-up approach and service where clinicians speak to one another. The work from the team in Lanarkshire has been amazing, but families want to know that the longevity is and is there resourcing around that. Is there a plan in place to fund this in the longer term?

As a general overview, Nic explained about current guidance - SIGN161 guideline that clearly states the need for medical intervention to guide tests and investigation to rule out alternative diagnosis to understand if a person has Long Covid. All Boards have had conversations with primary care colleagues around how to strengthen relationships.

Linda Currie reported that through the funding, NHS Highland has a Respiratory Consultant who the team can discuss some of the more complex cases with. The Consultant supports the navigation of the reporting of a person's journey and the various investigations they have.

██████ – How do people with lived experience get involved in development of services at a local health board level. ██████ is involved in her own board but understands it continues to be a struggle for people to be heard and involved in development of services in a legitimate way. There is gap between what you are telling us is existing in health boards and what members of Long Covid Scotland are experiencing. No-one is that self-absorbed to be unaware of what is happening in the NHS generally and how busy it is. Some of the things being described sound great but they're not being offered to those with Long Covid. There is a huge spectrum around our experience of not being able to access services and going to GPs who do not understand Long Covid, and they would be keen to be involved in the education piece. These questions have been asked for the last two years with no answers, so it's good to have this today and hope we get more of them. People want to be involved and use our experience to develop health services that are effective and efficient.

Q. to the Network - How can we be better involved? How do you use our experience to develop health services?

Boards are developing services and are in different stages through the recruitment process but consistently moving towards having services available. Through today's session we hope this is the start of us building better relationships to be able to work together. There is a mixed picture in terms of local lived experience group representatives being more involved, and Boards are looking at and planning how to build and strengthen those structures. Potentially first action for us to build how to make stronger links between two groups.

Action: Boards to consider how to make stronger links between the lived experience and service planning group to share information.

██████ – his experience has been mixed in Forth Valley, but he has an excellent Neurologist. What is frustrating is when he visits his GP, they have not heard of the top 5 symptoms that people experience which is unbelievable. Echoing ██████ point in that how can we be involved in service development Have an interest and keen to improve this situation. Many of those with long covid have been significantly impaired, and will not be aware of the Network, The Alliance, and will have given up after going to doctor and not getting anywhere. An effort must be made to reach people and, in my opinion, Scottish Government's efforts have been nowhere near the magnitude required. If people could be more involved that would be fantastic.

Pauline B offered to put ██████ in touch with Suzanne Gray, Chair of the Lived Experience Group in Forth Valley, and her and other colleagues also sit on the Oversight Group. It was important for that group to link in with the Strategic Group who look at service delivery and design. There is also a simulation centre in Forth Valley with the Clinical Lead working with people from the Long Covid Cuppa group to develop learning sessions for our medics, with the plan to make these sessions available nationally. In Forth Valley, they are committed to having people with Long Covid central to development of their service. The Long Covid Cuppa Group have been linked with LOCO RISE research taking place in the University of Stirling. Pauline is happy for ██████ to contact her directly.

██████ felt it was like the slow grinding of an institution that hasn't really been set up to handle a problem like this, so the NHS is having to innovate, and it needs to be on a scale that's

much bigger as we're talking about rehab, but this is a clinical problem with insufficient knowledge, insufficient diagnostic tools and non-existent treatments. It's a tough hill to climb but was pleased for the work that is being done and to keep it up.

Fiona Smith - Thank you [REDACTED] and [REDACTED] for your comments. Research and emerging evidence is being looked at, what the services will allow to emerge and linking with GP colleagues around this as our expert medical generalists with the aim of maximising what information is being given to GP practices. In GG&C, there are some active GPs who have supported in creating multidisciplinary networks and what does that look like in our communities. Open to any suggestions and anything else we can improve.

[REDACTED] queried "why not have a national patient cohort"? and that way all the patients are on one list ready to talk to, be part of research etc. It was not something that could be answered today as unaware of the intricacies of holding a national database, but willing to have a conversation about it in a forthcoming Service Planning group meeting. **Action: SPG**

Q. If any of the Health Boards could comment on the integration of paediatric services?

In Lanarkshire, it has been regretful as they have struggled to make some of that connection and the pathway for Long Covid identifying paediatrics with a diagnosis of Long Covid or with symptoms that would be a reasonable diagnosis to make and then connecting them into a cohort. On paper it looks like there are no paediatrics with Long Covid in Lanarkshire, but we know that is not the case. We understand the frustration around that but we cannot understand what is out there to give something coherent, our hope is that paediatrics are engaging with rehab, respiratory clinics or the potential they are on a CAMHS waiting list and we don't know that to identify them and connect them in.

In Lanarkshire there is lot of work to be done, particularly around raising awareness, and currently our focus is around awareness of PoTS as some people have had a poor experience around that and we are looking to improve that in our clinical offer. It doesn't take away from the problem that we do not understand paediatric numbers and data. There is a Paediatric sub group in the Network to have that expert focus but again it is something this forum is really helpful to know. Just want to identify need and connecting in is the interest of this.

[REDACTED] responded to confirm there was an initial scoping meeting with clinicians with a paediatric background to understand numbers of children and young people in each health board are and what the need was. The plan following that scoping meeting is to now formally establish a group and confirm that representatives with lived experience would be invited to join.

Action: Ensure children and young people are included in the children and young people workstream.

Ayrshire & Arran in a similar position to Lanarkshire. There are conversations going on in the Board trying to elicit what is happening as the Paediatric specialists have had isolated cases but not a pattern of referrals and not significant numbers that would make them think this needs special attention. Having conversations how to identify children with Long Covid that need different support from general paediatric services and take it from there.

[REDACTED] said that's why it's so important to have lived experience because Long Covid Kids has hundreds of members not getting through, so clearly there is a barrier and disconnect from what is being seen in clinical practice to what is actually happening on the ground. John suspects the barrier is that it is not being perceived as a significant issue in primary care that is requiring a referral into secondary services. There needs to be significant awareness, particularly with Lived experience from a children's perspective about what it is like as it's not filtering through to a health boards providing specialist care.

Highland was responding to the previous point. The clinical team came into post in November and that is 1.5 staff for the whole board area (an OT from mental health services and a physio from general rehab). The staff need time to build their skills and expertise around Long Covid as they are not coming into post as clinical experts. Then there is the time to educate others, primary care, consultant colleagues, AHPs but the team needs to feel confident with their skills to do that. In our relationship setting with patients while things are being set up is to have open and honest conversations with our patients. Involved in the LOCOMOTION study that has 9 other UK health boards involved and that is the Long Covid multidisciplinary consortium optimising treatments and services across the NHS. The funding that comes with that and the research, we will be doing a huge amount of work with our patients and clinicians to understand what is the impact on the outcomes and linking back to the research trial but also to the national group that we are all part of.

██████ - We have had a brilliant experience through our GPs and could not be more supportive, and some of them have lived experience themselves and the stumbling blocks is that they have no one to refer to. My son was 14 when fell ill, but when he turned 16/17yrs he was no longer in paediatrics, but not old enough for others to see him. Real issue around how do we actually get to see one of these so called specialists, there wasn't a clear pathway and that is what patients experience. There's been a lot of talk about education and training that is required, but we've been here for 3years and we've had to go down the private route just to get answers and that was really to answer, yes, he has POTs. There is piece around lack of education and things are not moving fast enough and the lack of pace. What are the implementation plans? What are we doing to give people access to holistic care professionals? The best thing we did was to pay to see a Long Covid specialist who is a GP that set up their own practice and the answers we got there have turned my son's life around in treating some of the symptoms, although he is still pretty much bed bound but starting to see progress. My son received a clinical diagnosis of Long covid, severe ME, PoTS and MCAS that allowed him to start medication to treat symptoms which have helped cognitive function and fatigue. These diagnoses have also impacted rehab treatment as these can now be tailored to his needs. There was a comment in the chat function about how the funding has been made available for over a year now and what is being done with it? Who are the people we need to influence to make this happen and quickly for patients. When people go to their GP, where is the pathway, that link is broken, and for children it's non-existent? How do we as a group make this happen faster?

Nic – There is no one in this call that wouldn't agree that the pace is frustrating and we are all fighting for clarity of a pathway, which is what the team and services are working on. In terms of timescales, as a general overview, the funding was available from May but then a big part was to agree and decide on best routes for services and then recruitment processes. I'm trying to explain the steps that everyone has been working on and appreciate people would like it to be faster. In terms of the funding, there is the £10m Long Covid fund for Scotland to be spent over 3 years. Highland had alluded to that fact that that is 1.5 staff in their health board and that is the reality that £10m across 3 years may only mean 1.5 staff, so that is why teams are trying to be creative to get the biggest bang for the buck. Acknowledge that it has taken a while to progress recruitment but hoping to have all that in place by end of March. Discussions and plans on how to make best use of any money which has not been spent on recruitment, and there are some national projects and solutions that we have been working on. There is resource for the digital tool which is being rolled out nationally in a "once for Scotland" approach, and all of these things will be able to help us to give you clear pathways around what services are available. Acknowledging that this been hard for everyone, in particular, those with lived experience.

██████ commented the funding from Scottish Government is not enough. NHS is not being supported to help Long Covid in Scotland. It needs investment.

What is being offered for both physical and mental rehabilitation and support in the West of Scotland?

I can't comment on the West of Scotland but having national network conversations I'm fairly confident we are all moving forward in a similar way, although staffing may not look the same everyone we are trying to make a good connection between what we are adding as a long covid pathway with the services we already have. In GG&C, the service proposal is based around advanced practice occupational therapy model with connections into other teams. In our service proposal we identified an OT to support our paediatric population, although as other boards have said, the evidence is that numbers on paper look very low but suspect that is not the case. The OT will support both in our health services but linking in with our localities, social care services and education colleagues to understand from an educational perspective what their experiences are within Long Covid for children and young people.

For the mental and physical health approach that is why we chose an occupational therapy led model, as OTs are dual trained in the assessment of physical and mental health therapies. We will have a combined approach and that would support the holistic approach, signposting long term condition management and accessing resources being developed nationally.

Q. I have seen two GPs in the last week and both have told me (again) that nothing is available at all in Lothian, just what is going on?

This relates to the points that others have made earlier, that GPs are not aware of services. There are several clinical services that meet various needs. There is the ME Chronic Fatigue syndrome service which has seen a lot of people with post covid syndrome – this service is unfunded. There are services that have continued funding e.g. post hospitalisation service which is psychology run with other allied health professions. Fatigue management for funding which have come into acute services over the last few years which then stopped and now we are seeing variants in terms of what is available in each area. Lothian has 4 Health & Social Care Partnerships (HSCP) and in 2 of the HSCPS, the community teams have picked up Long Covid work but the other 2 hasn't. Depending on where the question came from, it could be a lack of awareness, or it could be in that area a service doesn't exist. Our Speech & Language service has seen an increase in the number of referrals for breathing and voice work. There is an overall problem around coding and the uncertainty whether a person has a covid related symptom or whether it's something else.

Setting up conversations between GPs and Cardiology in terms of PoTS which isn't accepted within Cardiology that is well known in Long Covid.

Rheumatology / MSK / Orthopaedic conversation to determine differential diagnosis to determine what is the cause of the presentation and then who would manage it.

The Neuropsychiatry service who see a significant number under a research study but also under the regular studies when people don't meet the eligibility criteria. There are quite a few things going on across services, although things might have changed when funding stopped which may give the presumption there were no service but actually other teams have picked it up. We have an important and immediate job to do to make everybody aware of what is available and delivery of the new services.

Long Covid Kids commented that a high number of these additional services e.g ME/CFS services, only accept age 16+ which compounds the issue of children and young people having no support available to them.

Lothian is only part way through developing their pathway and have gone through a process to test a digital self-management platform with a small cohort of GPs across Lothian. The pathway has been evaluated to be successful and anticipate that later this year it would be available across Lothian. It could be that the person who asked the question, their GP was not part of the testing group. In terms of us upskilling GPs to be able to provide them with a

rapid access to a self-management platform and support from colleagues in Chest Heart & Stroke.

Q. I would like to know what the advice was that has allowed all the health boards to go their own ways in delivering services which seem not to be working or even delivering on a basic level, and who is actually advising the Cabinet Secretary for Health on this? Who is accountable for this?

Colleagues from Scottish Government were unable to be on the call today but did provide a response to the questions.

Whilst the Scottish Government provides the strategic policy for the NHS in Scotland, it is for each NHS Board to ensure the provision of a safe, sustainable and high quality healthcare service that best meets the needs of their local population. Rather than mandating one single model, we need to give NHS Boards the flexibility to design and deliver the best models of care tailored to the specific needs of their populations.

Our approach is informed by the long COVID Strategic Network, which brings together clinical experts, NHS Boards and lived experience to provide information on where improvements can be made.

■■■■ – I struggle with transparency within the Strategic Network. I've seen the flow chart with all the groups laid out, but why can't we see who is in each group?

Action: Offered to look into this and share the response with everybody

■■■■ feels the Network is compartmentalised and each group cannot combine with another and I don't think that's a good way of working – everyone should be collaborating.

Q. Why isn't a Minister answering this at a committee?

I hope you'll appreciate that the workplans of Committees of the Scottish Parliament are independent of the work of the long COVID Strategic Network. Contact details and workplans for Scottish Parliament Committees can be found on the Scottish Parliament website.

Q. Would like an update from whoever didn't speak or attend today, on what pathways there are for paediatrics?

Long Covid Kids are trying to find out where the barriers are as there are lots of children who have Long Covid who are not getting diagnosed or getting support. Good to find out what is in place, or the stages things are at and how they can access it?

It was explained earlier that people are at different stages, but we will commit to providing a summary of strengths and challenges that people with lived experience could support us to unpick. Some Boards are finalising their pathways at the moment so wouldn't be in a position to share either the paediatric or the adult strand is.

Q. How will feedback be shared?

Initially through the Network's Lived Experience group with those members then cascading the information to their groups / communities / networks.

Q. Is there more funding for research?

The Service Planning group does not have oversight around the funding for research. There is a lot of research underway and aware of the studies through the Chief Scientist Office. There is a Consultant in Public Health involved in the Network who provides us with monthly summary updates on new and emerging research. These updates are shared with the

whole Network which we hope are being cascaded through the lived experience communities.

There is research which should report this summer is Precious (predictors of long term outcomes after Covid). A large study including around 37 countries that have taken around 60,000 individual datasets so the patterns in the data will be valuable.

Website - preciouscovidoutcomes.org

Twitter - @CovidPrecious

To summarise:

- From the information today, Alliance have offered to create an animation type video.
- Will provide feedback to any questions that were not answered today
- The information will be shared with the Lived Experience group for them to disseminate.
- Have conversations with the Lived Experience ground around how to continue strengthening relationships.

Thank you to everyone for being so open, honest, and measured, which is fully appreciated. From some of the comments in the chat function, you are understanding many of the things the Network is trying to work through as quickly and appropriately as we can.

Thank you again for your time today and look forward to meeting in the future.