

Hi Alison

Thanks, it was good to have a bit of break. In addition to what we have already stated, here is a list of things the network has done or implemented in due to LE involvement.

To ensure meaningful LE involvement, the network has made several adjustments. There is some overlap with what we have already stated:

- Meeting Structure: Meeting times and durations were rearranged to better accommodate LE participation.
- Governance Enhancements: LE members asked to be involved at decision making level. The network revised its governance
 structure to embed LE representation at both executive and non-executive levels. Terms of reference were updated to reflect
 this commitment. The invite to be a board member was declined by the network LE members, however, the network kept this
 invite open and finally approached the ALLIANCE to represent LE interest at SOB level.
- LE Storytelling: LE videos have featured at the start of each meeting, although sourcing a story for every cycle has presented challenges.
- Research Symposium: LE members actively participated in the LC research symposium, expanding beyond professional-only
 attendance. The recording, slides, and feedback summary (published on website) were shared with all attendees. Unanswered
 questions were prioritized for follow-up, though many pertained to service delivery, which falls outside the network's remit.
- Annual Report: The LC annual report was published on our website, as requested by LE members.
- Information Sharing: A SharePoint site was created to promote transparency. Despite ongoing access challenges, a dedicated
 "General" channel was established for LE members to stay informed.
- Web Development: The LC webpage was designed with LE input to ensure relevance and accessibility.
- CYP Workstream: A dedicated workstream was launched to focus on children and young people (CYP), resulting in:
 - LC CYP pathway
 - o CYP pathway status summary across Scotland
 - o Draft CYP return-to-education guidance
 - o A regional service provision proposal presented to SOB (currently on hold due to programme constraints)
- Vocational Rehabilitation:
 - On 21/11/2024, and and began collaboration to explore the lived experiences of individuals returning to work without attending LC clinics, with potential input from the Occupational Health community.
 - o LE members were engaged in the development and pilot phase of the Return to Work Pack.
- LE Contributions:
 - LE members formulated questions about local LE involvement within health boards; responses were circulated back to
 - LE requested LC pathway guidelines from boards; a team member reviewed board websites and provided feedback, despite this being outside the network's remit.
 - o The Baseline Service Evaluation lay summary was published in March 2024.
- Sustainability Recommendations: Although not within our remit, a network team member supported the development of LC sustainability proposals. Key LE-informed recommendations were included in the final document submitted to the Scottish Government, such as: "SLWG recommends that Boards should commit to long COVID alongside other long-term conditions such as fibromyalgia, pain management and rheumatology. However, there needs to be a wider consultation process with NHS Boards, Stakeholders, and the Third sector organisations representing those with lived experience, to appraise this approach".
- Self-Management Tools: LE members provided feedback on the phase 1 review of the self-management workbook and were
 invited to participate in a digital tool usability survey.
- Webinars and Ministerial Engagement:
 - $\circ~$ The LC network agreed to participate in LE-led webinars hosted by the ALLIANCE.
 - At LE members' request, the lead clinician engaged directly with LE, and an LE representative agreed to attend a meeting with the Minister.
- Equality Impact Assessment: The network and boards revisited the EQIA to ensure inclusivity.
- Meeting Format: LE meetings evolved into themed discussions, occasionally diverging from LC network business. The network supported this shift to maintain LE engagement.
- Resource Allocation: Despite misalignment with the governance structure and absence from the business case, the network
 invested resources into the LE workstream to uphold its commitment to inclusive collaboration.

I hope this helps, we can discuss it on Wednesday.

National Strategic Network for Long term effects of COVID-19
National Specialist and Screening Services
NHS National Services Scotland isaac.umeed@nss.nhs.scot
Tel:

@nhs.scot

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From: Alison Gilhooly @nhs.scot>
Sent: Monday, August 11, 2025 4:08 PM
To: @nhs.scot>

Subject: FW: Long Covid Scotland and Long Covid Kids

Hi

I hope you had a good weekend.

I could find anything that we'd already started on this, although have been trying to think of things that we can put in here – unfortunately I hit a mental block as I could just think of things they'd asked us and we hadn't taken forward (at least in the way they wanted).

If you can have a think through, and we can have a look together on Wednesday. I'm off tomorrow as we've no other childcare for Thanks

Alison

Alison Gilhooly

Senior Programme Manager

POC3 – Neuro, Trauma, Population Specific

National Services Directorate (NSD)

NHS National Services Scotland

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From: Janis Heaney @nhs.scot> Sent: 08 August 2025 10:46

To: Alison Gilhooly @nhs.scot>; @nhs.scot>

Subject: FW: Long Covid Scotland and Long Covid Kids

Importance: High

Hi both,

See below. Appreciate this is yet another ask of us but can you start to pull some information together please? I'm thinking that the results of the research symposium might be useful to consider and please engage with Service planning and SME groups to get their views and input – it can't all come from the programme team. I think we should also highlight that weaving lived experience representation into every layer of governance was as a direct result of feedback from lived experience groups – as well as our lived experience stories at the top of every oversight board meeting.

- it would be helpful if you could provide some input to this as well if possible - appreciate you're very busy!

Happy to have a discussion if helpful.

Best wishes,

Janis

Janis Heaney

Associate Director National Services Directorate (NSD)

NHS National Services Scotland

NHS National Services Scotland
Tel:
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 From
 @gov.scot>

 Sent: 08 August 2025 10:38
 @gov.scot>

 To: Janis Heaney
 @nhs.scot>;
 @gov.scot>

 Cc
 gov.scot;
 @gov.scot>;
 @gov.scot>

 Subject: RE: Long Covid Scotland and Long Covid Kids

Hi Janis,

Wanted to update you that Ms Minto wrote to LCK and LCS yesterday in response to their letter expressing regret at their decision, offering a meeting with Christine McLaughlin to discuss issues they raise and confirming that due diligence on £4.5 million now complete with commitment in principle to a multi-year funding, which has been communicated to NHS boards to allow them to progress towards recruitment (this communication to boards shared w yesterday).

Thinking ahead to the potential meeting between LCK, LCS and Christine, should they take up this offer, we will be providing Christine with a briefing. Much of the content for that is already in place, thanks to the work of the NSD team. It would be helpful to be able to add to that a short section on the impact of the contributions of LCK and LCS to the work of the Network and that of Boards. Whilst we have a clear sense from the background Isaac and your team provided of the many areas of work where NSD and the Network have involved LCK and LCS, it would be helpful to have, in addition, a brief section on what the Network and Boards have done, or done differently, in response to feedback/ input from LCK and LCS – and/or other lived experience, including influencing service delivery. I am conscious that LCK have called the work 'performative engagement' and would be keen that we include in Christine's brief examples illustrating that engagement has not been 'performative', but rather listening and adapting in the light of lived experience engagement, in areas where this is achievable. Perhaps a 'You Said, We Did' type format or similar. I am sorry to place yet a further ask, but do think it would be helpful. As yet we have no date for the meeting with Christine, grateful if you could let me know when the team would be able to provide this – perhaps later next week if suits. Best regards,

Healthcare Quality and Improvement sh Government | St Andrew's House | Regent Road | Edinburgh | EH1 3DG

From: Janis Heaney

@nhs.scot>
Sent: 07 August 2025 16:11

To: @gov.scot>; @gov.scot>
Cc: @gov.scot>; @gov.scot>; @gov.scot>;
Subject: RE: Long Covid Scotland and Long Covid Kids

Me for the weekend. Mobile number below and I'll keep an eye on emails.

Janis

Janis Heaney
Associate Director
National Services Directorate (NSD)
NHS National Services Scotland

NHS National Services Scotland

Tel:

@nhs.scot | Chat with me on Teams

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 From:
 @gov.scot>

 Sent: 07 August 2025 15:43
 @gov.scot

 To: Janis Heaney
 @nhs.scot>;
 @gov.scot

 Cc
 @gov.scot;
 @gov.scot>

 Subject: RE: Long Covid Scotland and Long Covid Kids

Thanks for this Janis.

Please let us know if there is a contact over the weekend - in case anything comes in.

will cover from our side of things.

Subject: RE: Long Covid Scotland and Long Covid Kids

Hi

Grateful if you can keep us updated on any further discussion/communication with LCK and LCS. Given their resignation from the network, we need to consider their access to Teams channels and stakeholder communication as they will no longer be operating under the Terms of Reference for the network and associated groups. I would propose that we respond formally to them on behalf of the network expressing our disappointment in their decision and offering them our ongoing support and engagement if they felt at any point they would want to re-engage?

We received a very supportive email from ALLIANCE expressing their commitment to continuing their work with the network which is very much welcomed.

Best wishes,

Janis





Hi Christine.

Further to the below, with thanks to the team NSD, their additions are in blue for ease, providing further detail on the relevant engagement work and progress NSD and the Network have been making in the areas raised by stakeholders in the letter/ press release.

Sharing at this point for your information, and in case useful for meetings should further questions arise.

Please let us know if you have any questions and we can take forward.

Best regards,



Collapse of Services

- Funding letters and allocations for 2025/26 have been issued as swiftly as possible to support the continuity of service
 delivery across 2025/26. We recognise the importance of providing assurance to Boards regarding available funding
 beyond the end of this financial year in a timely manner. We are progressing an template for multi-year funding through the
 AO process and will communicate the outcome to Boards as soon as a decision has been reached.
- Some boards have transitioned services rather than fully decommissioning. For example, NHS Lanarkshire has integrated
 its Long Covid Service into broader pathways and continues to accept referrals.
- NHS Greater Glasgow & Clyde is considering decommissioning without an alternative pathway in place. We've engaged
 with them to encourage pausing decisions pending the outcome of the £4.5M funding allocation on a multiyear basis.
- · Services for children with Long Covid are available, typically via primary care and general paediatrics

Ignored Evidence.

- The claim that evidence has been ignored is inaccurate. The ALLIANCE report commissioned by the Network has been discussed with service leads to inform development.
- The Alliance report was shared with Lived Experience group and Steering group in February of 2024 through a presentation. It was then uploaded on the Network's Teams channel and was also shared by an email to service leads. The Chest Heart report was shared by a presentation to LE group and then uploaded on MS Teams channel for wider circulation. It was never the intention for the network to formally respond to either report, particularly as the network commissioned the ALLIANCE report.

Public Communication

- The suggestion that NSS advised stakeholders to "use Google" is a misrepresentation. NSS demonstrated that service information is accessible online and shared this as a practical example. In response to concerns raised by Lived Experience representatives that there was a lack of ongoing signposting to local services the network carried an action to task health boards with ensuring information on Long Covid services were easily available. We highlighted that most health boards have a web page dedicated to Long Covid services which was straightforward to find using a simple web search. At no point did we advise "using google". We also asked what else the network could do to support and if any further clarity was required.
- NSS have confirmed that Boards were tasked with ensuring that their local services are well signposted (this was discussed
 at the Service Planners/Subject Experts Group meeting in November 2024, and added to action log, and reviewed in
 February 2025).
- We wrote to these organisations in January providing information on public health messaging on respiratory infection supported by SG, and how this supports health behaviours related to COVID-19.
- Scottish Government officials participate in many governance groups in the Network and have provided updates on the
 funding commitment and associated progress, including to the Lived Experience Group where these two organisations are
 represented.

No National Standards or Oversight

- The Network has delivered a Pathway for GP Assessment and a Pathway for the Management of Children with Long Covid, for use in boards. Additionally, the Network delivered a programme of education webinars for healthcare professionals hosted by the Chair of Long COVID Scotland.
- . In addition to above the network has produced several national work products including:
 - o CYP Pathway development and fit note
 - o Return to Work Pack with Vocational Rehabilitation workstream
 - o Long COVID research symposium-with Data and Intelligence
 - o Long COVID network website
 - o Alliance-Workbook phase 1 Self Management Workbook and Review phase
 - o GP assessment guidelines
 - o Project ECHO sessions education events
- The network has a priority to focus on updating the Postural Tachycardia Syndrome (PoTS) pathway now that our new clinical lead is in post
- . There are no NICE or HIS quality standards for Long Covid, this has not been an aim of the network
- It is at boards' discretion in regard to how services are delivered, in order to allow them to best meet the needs of their local populations

Partner Disengagement

- It is not accurate to say that most health boards have stepped away. Most health boards remain active in the Network.
- . Engagement with third-sector partners continues via The ALLIANCE, though LCS and LCK have resigned.
- NSS has addressed turnover by appointing a new Clinical Lead and a new Co-Chair for Lived Experience (Rishma Maini, PHS).

Concerns raised by LCS and LCK regarding public health campaigning were addressed in prior correspondence.

- Some third sector bodies have stepped away because they feel the network is no long relevant for them. Members of the
 Lived Experience group have thus far not identified relevant organisations to invite them to join.
- The capacity of service providers to attend the meetings and sometimes the scheduling of the various working groups
 meetings, has been a particular challenge throughout the network's lifecycle. However there is adequate and proportional
 engagement.
- Operational Peer group meets quarterly, with at least 6-7 boards represented in each meeting. The peer education network is attended by 40-50 people per session with four sessions held a year.
- Average attendance is recorded at 30-35 professionals in each Project Echo session.
- In the service planning group, usually 8 boards are represented (out of 10 regular boards) with approximately 16 people in attendance at regular meetings. The meeting schedule was changed from monthly to quarterly to ensure robust discussion and 2 groups were merged based on feedback from members as the agendas were often overlapping

Marginalised Lived Experience

- Lived experience is embedded at all levels of the Network, including the Strategic Oversight Board and via the ALLIANCE network
- Additional detail will be provided later today
- Lived Experience members attended and co-chaired research symposium on 11 February 2025 attended by over 100 people.
- Lived Experience member chair collated questions asked in the symposium and reviewed feedback summary- this was
 then shared with Service Planning group and uploaded on our long COVID website.
- Risks and issues are a standing item on Lived Experience group agenda since June 2023. Any risk identified is either
 escalated through standard NSS risk escalation process, i.e. to SG or Strategic Oversight Board directly or through
 quarterly highlight report. Risk logs can be provided if required
- Actions from each meeting are logged, tracked, and followed up. Each group meeting is recorded. Every document requiring approval goes through Lived Experience group along with other groups.

Transparency Breakdown

- Lived Experience representatives have long had access to all Network working groups to support transparency.
- To reduce the burden of meetings and the fact that only a handful of projects remain to be completed, the network needs to ensure proportionate governance. A proposal for restructuring the governance was developed with full engagement with stakeholders. The engagement started in April 2025. A meeting with the chair of each group was arranged on 16th July, it was agreed that the current meeting cycle would be used to share the revised governance structure with each workstream. Here are the aims and objectives for streamlining governance structure to be fit for purpose:
 - Aims:
 - · to ensure smooth transition of the programme
 - Objectives:
 - · governance remains proportionate
 - Improve efficiency and
 - Improve capacity for all stakeholders
 - Purpose:
 - To ensure the network remains fit for purpose as we approach the programme's conclusion on 31 March 2026.
 - Once we restructure, the network team will revise existing TOR with the relevant group.
- In the Strategic Oversight Board Terms of Reference, Lived Experience members are noted as observers. The network team and Scottish Government colleagues strongly advocated for Lived Experience members to be represented on the oversight board and they are well knitted throughout the governance structure:
- · Lived Experience Members sit on
 - Children & Young People work stream and sub-group,
 - Data & Intelligence group,
 - PoTS group,
 - · SLWG for Sustainability Recommendations,
 - Steering Group.
- · Lived Experience were part of the clinical safety assessment workshop for the digital tool.
- The network has additional sources of Lived Experience engagement for example; ALLIANCE is represented on the development of Return to Work Pack sub-group and are engaged through professionals/clinicians.

From:

Sent: 05 August 2025 11:07

To: Christine McLaughlin

Cc:

@gov.scot>;

@gov.scot>; Janis Heaney

@nhs.scot>; Susan Buchanan

@nhs.scot>;

@gov.scot>;

@gov.scot>;

Subject: RE: Long Covid Scotland and Long Covid Kids

Importance: High

Hello Christine,

Please find interim update below.

We will provide additional detail later today with the help of colleagues at NSD, who run the Network and have been providing

valuable insight and support on this matter.

Overview of key timings and ministerial engagement

- On Monday 5 August the charities Long Covid Scotland and Long Covid Kids Scotland submitted a letter and issued an
 embargoed press release indicating their resignation as participants in NHS National Services Scotland's Long COVID
 Strategic Network.
- They cite "systemic failure, lack of leadership, and a breakdown in trust" as the reasons for stepping away.
- Long Covid Scotland and Long Covid Kids Scotland are organisations that Ministers and officials have engaged with on a number of occasions since their establishment during the pandemic. The most recent Ministerial meeting was with Cabinet Secretary on 5 December 2024, and last official level meeting was in May.
- NHS National Service Scotland established the Long COVID Strategic Network under commission from Scottish
 Government in March 2022. It is expected that 2025/26 will be the last operational year of the Network, noting that a
 different governance structure may be required to oversee the wider commitment to deliver new specialist support for Long
 COVID, ME/CFS and other similar conditions.

Whilst more complete feedback on each of the points in the press release from stakeholders is in train – NSD are looking at this with us – interim update below on the points raised by LCS and LCK:

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 delivery across 2025/26. We recognise the importance of providing assurance to Boards regarding available funding
 beyond the end of this financial year in a timely manner. We are progressing an template for multi-year funding through the
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· Lived Experience representatives have long had access to all Network working groups to support transparency.

Please let us know any questions

Best regards,



Healthcare Quality and Improvement

Scottish Government | St Andrew's House | Regent Road | Edinburgh | EH1 3DG

From:	gov.scot>		
Sent: 05 August 2025 0	09:21		
To: Janis Heaney	@nhs.scot>; Susan Buchanan	ns.scot>	
Cc:	@gov.scot>; Chr	ristine McLaughlin @gov.scot>;	
	@gov.scot>		
Subject: Re: Long Covid	d Scotland and Long Covid Kids		
Thanks Janis,			
Could we do a quick o	call at 9:35?		
From: Janis Heaney	@nhs.scot>		_
Sent: Tuesday, August 5,	5, 2025 9:16:30 AM		
To:	@gov.scot>; Susan Buchanan		
Cc:	@gov.scot>; @gov.scot>; Christine	McLaughlin @gov.scot>	
@gov.sco			
Subject: RF: Long Covid S	Scotland and Long Covid Kids		

Subject: RE. Long Covid Scotland and Long Covid Rids



Thanks for this. I've asked Isaac to start pulling together information on all the points raised in the letter. Happy to discuss further with you or Nicci and team.

Best wishes,

Janis





Janis, Susi,

Thank you to Janis for your time today with the team discussing the press release from LCS and LCK regarding their resignation from the network.

I just wanted to flag that Ministers (including the FM and Cabinet Secretary) are taking a keen interest in what has led LCS and LCK to this resignation. We have provided reassurance that:

- The NSS Long Covid Network has regularly engaged closely with both these stakeholders
- However, unfortunately, the Network did not receive any advance notice of the intention of Long Covid Scotland and Long Covid Kids to resign
- . Lived experience is represented at every level of the Network (including the Strategic Oversight Board) and through the ALLIANCE lived experience network.

However, we may need some further information from you on each of the asks of LCS/LCK and what the barriers to achieving them are. I'd be happy to have a conversation early morning, if helpful. Otherwise or morning.

Thanks





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