



FW: Long Covid Scotland and Long Covid Kids

From Janis Heaney [REDACTED]@nhs.scot>

Date Wed 8/6/2025 9:33 AM

To [REDACTED]@nhs.scot>; Alison Gilhooly [REDACTED]@nhs.scot>

[REDACTED] - thanks for all the work yesterday. Below is full update that went to [REDACTED] from the policy team.

J

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

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Tel: [REDACTED] | [REDACTED]@nhs.scot | [Chat with me on Teams](#)

Claudio Guerri

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From: [REDACTED]@gov.scot [REDACTED]@gov.scot>

Sent: 05 August 2025 17:23

To: Christine McLaughlin [REDACTED]@gov.scot>

Cc: [REDACTED]@gov.scot>; [REDACTED]@gov.scot>; Janis Heaney [REDACTED]@nhs.scot>; Susan Buchanan [REDACTED]@nhs.scot>; [REDACTED]@gov.scot>; [REDACTED]@gov.scot>

Subject: RE: Long Covid Scotland and Long Covid Kids

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:
 - CYP Pathway development and fit note
 - Return to Work Pack with Vocational Rehabilitation workstream
 - Long COVID research symposium-with Data and Intelligence
 - Long COVID network website
 - Alliance-Workbook phase 1 - Self Management Workbook and Review phase
 - GP assessment guidelines
 - 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: [REDACTED]@gov.scot>

Sent: 05 August 2025 11:07

To: Christine McLaughlin [REDACTED]@gov.scot>

Cc: [REDACTED]@gov.scot>; [REDACTED]@gov.scot>; Janis Heaney [REDACTED]@nhs.scot>; Susan Buchanan [REDACTED]@nhs.scot>; [REDACTED]@gov.scot>; [REDACTED]@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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Please let us know any questions

Best regards,

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

From: [REDACTED] <[REDACTED]@gov.scot>

Sent: 05 August 2025 09:21

To: Janis Heaney <[REDACTED]@nhs.scot>; Susan Buchanan <[REDACTED]@nhs.scot>

Cc: [REDACTED] <[REDACTED]@gov.scot>; [REDACTED] <[REDACTED]@gov.scot>; [REDACTED] <[REDACTED]@gov.scot>;

Louise Scott <[REDACTED]@gov.scot>

Subject: Re: Long Covid Scotland and Long Covid Kids

Thanks Janis,

Could we do a quick call at 9:35?

From: Janis Heaney <[REDACTED]@nhs.scot>

Sent: Tuesday, August 5, 2025 9:16:30 AM

To: [REDACTED] <[REDACTED]@gov.scot>; Susan Buchanan <[REDACTED]@nhs.scot>

Cc: [REDACTED] <[REDACTED]@gov.scot>; [REDACTED] <[REDACTED]@gov.scot>; Christine McLaughlin <[REDACTED]@gov.scot>; [REDACTED] <[REDACTED]@gov.scot>

Subject: RE: Long Covid Scotland and Long Covid Kids

Hi [REDACTED]

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 Heaney

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

NHS National Services Scotland

Tel: [REDACTED] [REDACTED] @nhs.scot | [Chat with me on Teams](#)

  Claudio Guerri

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From: [REDACTED] @gov.scot>

Sent: 04 August 2025 21:02

To: Janis Heaney [REDACTED] @nhs.scot>; Susan Buchanan [REDACTED] @nhs.scot>

Cc: [REDACTED] @gov.scot>; [REDACTED] @gov.scot>; Christine McLaughlin [REDACTED] @gov.scot>; [REDACTED] @gov.scot>

Subject: Long Covid Scotland and Long Covid Kids

Importance: High

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 Nicci, Louise or Will will be in contact in the morning.

Thanks,

[REDACTED]

[REDACTED]

Healthcare Quality and Improvement Division

 [\[REDACTED\]@gov.scot](mailto:[REDACTED]@gov.scot)

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