

note of meeting

Long Covid Network: Lived Experience Engagement Group

MS Teams on 14-08-2025, 12-2pm

Present:

Alison Gilhooly (AG)	Senior Programme Manager	NHS NSS (Chair)
		The Alliance
		Chest Heart and Stroke Scotland (CHSS)
		The Alliance

In Attendance:

	Programme Manager	NHS NSS
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1 Welcome, Apologies & Introductions

AG welcomed all to the meeting. The resignation of Long Covid Scotland and Long Covid Kids from the network was noted, and resulted in a reduced attendance at the meeting.

2 Action Log

The action log was reviewed and updates were provided.

There were some actions assigned to those who had resigned from the network, and an update was not available. These will be looked into by the Programme Team to ensure that any action required was taken forward.

3 Clinical Lead Update

AG advised the group that Dr Janet Scott from NHS Highland had been appointed as the Clinical Lead for the network, starting 28th July 2025. She will be taking forward some of the key priorities for the network up to 31st March 2026. Unfortunately, she was not able to join this meeting due to diary conflicts.

4 Lived Experience and Transitioning

■ noted that as the network moves forwards in this transition year, with some overlap in agendas, as well as group membership, it was proposed that a streamlined governance structure is put in place for the final two meeting cycles of the network. ■ presented the two options that were proposed, one with all working groups combining into the Service Planners and Subject Experts Group and then reporting into the Steering Group and Oversight Board from the next meeting cycle and then moving into a combined Steering Group for the final cycle of meetings in

February/March 2026. The second option would involve moving directly into a combined Steering Group from the next governance cycle.

There was some discussion around this, and how those workstreams that continue to be productive can be supported to continue and complete their tasks. ■ reassured the group that these workstreams would continue to work through agreed tasks, reporting in through the new streamlined governance.

It was also noted that very clear terms of reference would be required for the Steering Group to ensure that members know their remit and the role of the group in supporting the completion of activity across the network. It was noted that there are currently around five priorities being looked at across the network, ■ agreed to share the delivery plan with the group for information.

Action: ■ to share the network delivery plan with this group for information.

The group agreed that moving to the second option would be the preferred option, i.e. to move directly into a two-group structure (i.e. Steering Group and Oversight Board) from the next meeting cycle. ■ noted that the Service Planners and Subject Experts group was due to meet the later the same day, and that following that meeting a decision would be ratified through the Steering Group and Oversight Board in the following weeks.

5 Programme: Lessons Learned and Benefit survey

■ advised that a number of responses had been received to the survey, and that he had been pulling together a report to record the lessons learned and benefits realized through the network. Although the survey had officially closed, any further points that members felt should be included can still be shared through the survey, or by email to the network mailbox.

Action: All to provide a feedback on Lessons Learned and Benefits survey

6 Workstream Documents

- Risks and Issues

■ noted that a risk relating to the governance transition would be added to the risk log, and asked members to advise if there are any further risks that they would like to raise.

■ asked if there was any further information in relation to the new funding being made available to the Boards, in particular whether any funding was being top sliced to provide governance/oversight of new services.

■ asked whether information in relation to how the funding is being allocated could be shared with the group. AG and ■ agreed to check with Scottish Government what information could be shared.

■ to check what information can be shared with the LEEG around allocating long term conditions funding to NHS Boards.

It was noted that this funding was outwith the scope of this network, as it relates to wider long term conditions services, and therefore governance of allocating funding does not sit with the network.

No further business was raised, and the meeting closed.

The next Steering Group meeting is on Wednesday, 19 November 2025, 12-2pm.