

minutes

Long Covid Network: Steering Group Meeting

MS Teams on 20-08-2025, 12-2pm (recorded)

Apologies: [REDACTED]

Present:

Janet Scott (JTS) (Chair)	National Clinical Lead	Long Covid Network (Chair)
[REDACTED]	[REDACTED]	University of Glasgow
[REDACTED]		NHS GG&C
[REDACTED]		Scottish Government
[REDACTED]		Scottish Government
[REDACTED]		Health & Social Care Alliance Scotland
[REDACTED]		Scottish Government
[REDACTED]		NHS Lanarkshire
[REDACTED]		

In Attendance:

[REDACTED]	[REDACTED]	NHS NSS
Alison Gilhooly (AG)	Senior Programme Manager	NHS NSS
[REDACTED]	[REDACTED]	NHS NSS

Welcome, Apologies & Introductions

[REDACTED] welcomed attendees to the meeting and went through apologies.

Action Log & Approval of Minutes From Last Meeting

The action log was reviewed and updates were provided. Minutes from the last meeting were shared by [REDACTED] and agreed by attendees for sign off.

Agenda Item 3- Returning to Work Pack (Adult) – Vocational Rehab

[REDACTED] advised pack was approved at a previous meeting has been tested informally in terms of AHP community and still requires some editing on that for the best improvements. Recommendation is that it is accepted and goes into general use. Pack is designed for long Covid however can be used for any long term sickness and this piece of work will be looked at for continuous improvement. [REDACTED] advised that pack has gone through a pilot phase and feedback has been received. The plan is to incorporate feedback, and this will be presented to the Vocational Rehab Subgroup then presented to the Strategic Oversight Board for final sign off. It was agreed that sign off would be delegated to the VR group. [REDACTED] advised that fix term nature of the programme

presents a risk of reduced service, decline and reduction in the growth of more effective vocational rehabilitation for people with long COVID.

Action- [REDACTED] to incorporate feedback

Action- [REDACTED] to send the document to VR group for sign off, following pilot feedback, the pack can go to the SOB on 3rd September.

[REDACTED] informed that a draft sustainability plan is expected to accompany the pack to the SOB.

JTS asked if the pack can be published after signing off. [REDACTED] informed that the pack requires further developments, for example, it needs to be tested with non-NHS employers and requires a formal evaluation from the end user perspective prior to publishing it. The group agreed that signing off this pack will mark the end of phase one and beginning of phase two that includes and development of a sustainability plan and further testing and evaluation.

Agenda Item 4- LE Engagement Moving Forward

JTS advised that two of the charities representing Lived Experience (LE) have resigned. JTS added we must still include stakeholders with lived experience. Due to the network's short duration there can't be further recruitment due to the lengthy process and ALLIANCE can have input on the two remaining meetings up until March 2026 if ALLIANCE are willing to do so. [REDACTED] advised they are happy to be the only Lived Experience input, however may possibly need to seek support from the network to address concerns from the Lived Experience network. [REDACTED] added she is having one-to-one discussions with anyone raising queries and she would like to bring these queries back to the group to keep the Lived Experience network engaged.

Agenda Item 5- Service Evaluation

JTS is leading on Service Evaluation within NHS Highland and they have created a 10 work package proposal, this will be a much broader proposal than the report completed last year. Module 1 focusing on quantitative data will replicate last year's "Leeds report", but will include more data and Public Health Scotland will be carrying out the analysis. JTS added there is a small issue with data retention and maintaining compliance with Scottish Guidelines however looking in to extending storage of data to 7 years to comply with Scottish Governments code of practice. There is a further module looking at quantitative and qualitative data in a different way, taking individual analysis from each board. Other modules also have a range of different focus and summary of the Vocational Rehab Report has been requested. There is a Lived Experience section with which Long Covid Kids and Long Covid Scotland are still engaged, and ALLIANCE have produced a resource on signposting. There is also engagement from academic colleagues for the qualitative side, drawing on experience from the academics at the Universities of Stirling and Aberdeen. The purpose of the modules is to give a picture of what has occurred and how patients feel about it to conclude on how we may be able to better record patient outcomes going forward. It was confirmed by JTS that the full report should be completed before Christmas. JB advised would be interested in seeing the proposal, JTS will send this.

Action – [REDACTED] to provide Vocational Rehab Report for Service Evaluation modules.

Action – JTS to send [REDACTED] proposal

Agenda Item 6- Governance Transition

As the network approaches the end of its transition plan, there have been some discussions around streamlining the governance structure to ensure that it is sustainable over the last six months of the network. ■ presented a slide which showed the current governance structure. Next slide was a document providing two possible options. Option 1 being a two-stage governance restructure process where all groups roll into the Service Planning Group in stage 1 and in stage 2 the Service Planning and Subject Matter groups would roll into the Steering Group by 2026. Option 2 is a single stage process and all groups roll into the Steering group by 19/11. ■ added from all workstreams it is unanimous that option 2 would be the best option. Attendees were asked if they are happy to move forward with approving option 2. JTS queried the intentions for the Operational Peer and Resource Network (OPRN), ■ advised that group is not part of the governance, it is a stand-alone group which feeds information into the service planning and delivery groups. There has been discussion around this and it was agreed to continue with the OPRN as a separate group until the end of the network. ■ added it was discussed that the OPRN is very beneficial and if everything was moved into a steering group this may be lost and conversation may become very strategic. It was confirmed that all other meeting groups will essentially lead into this group except the OPRN which will continue with their current structure until the end of the NSS Network. All attendees recommend option 2 to be referred to the programme board for sign off.

Agenda Item 7- Lessons Learned and Benefits Survey

■ thanked attendees for completing the benefits survey and shared that great feedback has been received. Early indications from the survey suggest that peer education has been the most valuable platform for supporting professionals. ■ added professionals have added measurable and non-measurable benefits and it has helped the professionals gain knowledge and skill. It was found that there was a compassion and passion for making changes and there is shared vision to improve service for the Lived Experience. ■ advised that a report is being drafted for this, but he has pulled together a summary to share with the group, this will be sent to AG to review before sharing with all other groups and the final stage would be to submit to the programme's Oversight Board. ■ advised the survey has already completed but feedback is welcome up until Friday 22nd 2025.

Actions – AG to review survey summary before being showed to other groups and submitted to the programme's Oversight Board.

Actions – Feedback to be sent to ■ by Friday 22nd 2025.

Agenda Item 8- Long Term Conditions

■ shared update on the long term conditions framework. Public consultation was held and closed on 20th July 2025. Responses from the consultation are currently being analysed with an analysis report being published around October 2025. ■ stated there was 371 validated responses. The drafting of the framework has commenced and this should be published before the end of December 2025.

Agenda Item 9- Additional £4.5 Million Funding

■ advised that in addition to the agreed £4.5million for 2025/26, this has been signed off as three year's funding, i.e. up to 2027/28. Boards have been asked to submit bids on what they would like funding for these bids are to include proposals on what they could spend in this financial year and also plans for the following two financial years.

■ added current bids are being worked through and should be included in August's allocation. ■ queried if the allocation would go through the long-term conditions governance structure as she is keen to know how the 3rd sector and Lived Experience voice will continue to influence the allocation of funds with the new governance structure. ■ advised just now these are being looked at as two separate different pieces of work, however it is going to be investigated. ■ added the framework itself will be published by end of December, this will set out outcomes for areas of improvement and there will be action plans against each board. ■ queried how much money is allocated to evaluation. ■ advised nothing has been allocated yet as boards have been asked to propose what they can spend this year, ultimately it will depend on what boards request and what money is left over.

■ added he feels it is vital that there is evaluation of any new service. ■ advised evaluation is one of the areas recommended through lessons learned for consideration for funds.

■ shared she feels this is a great opportunity to consider data and the ELAROS tool and how data is going to be collected consistently across the NHS boards. JTS advised that the data and appraisal is very important as drives clinical improvement and services moving forward.

JTS, ■ and ■ have been in discussion around a plan on the absence of the ELAROS tool and received input from the Peer Support group and the Data and Intelligence group from these discussions. It is found there is a commitment to come together and have a coordinated approach but it is a lot more challenging from a governance perspective. JTS advised to bring all data together it requires the data sharing agreements in place and in the absence of the ELAROS app there is no central data collecting tool. JTS added due to funding coming so late in the year the timeframe is too tight for coordination.

■ advised she is going to investigate cost on using red cap as an in-house tool as well as using a financially sustainable tool.

■ advised GGC have commented on evaluation tools in their bid so would think lots of bids will continue the evaluation piece. From GGC experience the administrative staff needed to complete each component of the ELAROS pathway was huge and there was very few service users to complete the outcome measure so it was felt the process was slightly flawed.

■ noted that going forward we need to look at patients who get back to work or patients who don't get back to work and how does this compare to the population of individuals with long Covid who did not go through the NHS.

■ added if we are counting the number of people who formally come through as a service, it is not to be over medicalized. Due to the online information that can be found there will be a number of people who have self-directed that information without going through a referral

process and that is equally valuable as many people will feel that is adequate to meet their needs and that wider resource should be looked at.

Agenda Item 10- Feedback From Service Planning

■ shared that there has been a lot of conversation around the legacy piece and have been encouraging the service leads and subject matter expert group to celebrate this. The PoTs pathway along with the GP Assessment Toolkit are being reviewed. Feedback on the Self Management Workbook has been very positive and it has been recognised when we move into long term conditions framework service, the digital version of the workbook could be reworded to reflect its use for all long term conditions as this is such a valued resource. Although £4.5 million funding is appreciated the boards feeling is that they are double running money and now being asked to extend further funding. Boards believe there will be a very low spend against this year's £4.5 million funding as proposals need to be agreed and cannot determine when these proposals will be submitted and then need to go through a recruitment process with staff who would start from January 2026 so this will possibly be around 20-25% spend so need a recognition around this. ■ advised a challenge they do have is around 3-year funding, Ideally they would like to continue with the skilled staff already in post however a lot of these employees will be reaching the right to be provided with permanent contracts and this creates a huge financial risk for boards. Due to the financial position for boards across Scotland there a very few boards who will be prepared to take on a financial risk so there is expectations a lot of services will lose their current staff, will have to advertise for new contracts and when advertising short term contracts or secondments there is a limitation in the number of individuals who will be in a position to take on these roles.

JTS queried how many years is it colleagues can be on a contract basis until they are due permanency? ■ advised it is against policy within GG&C to provide a contract over 2 years without providing permanency and as things move forward these colleagues will go into redeployment rights. The proposal put forward from GGC is that current staff are offered permanency but noting the financial risk this will create after 3 years and if there is no further funding at that point these permanent staff would need to be redeployed. For any additional posts these will be advertised as short term contracts or secondments as this will protect the board again that financial risk.

Agenda Item 11- Digital Tool Data Retention

■ clarified that there are two sets of data, one downloaded by PHS for purpose of this report which NSS are the data owners of and there is a larger piece of data that is on the ELAROS tool and the boards own this piece of data. We need to engage with NSS IG colleagues to understand if PHS hand this data to NSS where it will go for safekeeping. ■ can speak to colleagues at SG for a better understanding of the implications of this and what can be done to make sure the data is not deleted and figure out if there is a way for PHS to amend this so they can potentially download it to the safe haven. ■ added she will look at the document around a 7 year retention period required for data this type of work. ■ advised the data retention clause is in the current DPA and has been agreed with NSS ELAROS and PHS so wants to understand from the experts what this means and what the exact process is. JTS advised

the Records Management Code of Practice Health and Social Care Guide states health services appraisal requires a database that needs to be retained for 7 years, JTS has requested a second opinion of this from [REDACTED] [REDACTED] added that the data processing agreement is signed off and the Data Processing Impact Assessment is under development. [REDACTED] will share this with [REDACTED]

Action – [REDACTED] to engage with NSS IG colleagues for clarification and [REDACTED] to engage with SG

Action – [REDACTED] to share the Data Processing Agreement with [REDACTED]

Action – [REDACTED] to provide second opinion on Records Management Code of Practice Health and Social Care Guide JTS has shared

Agenda Item 12- PoTS Pathway Review

JTS advised this is a large piece of work and the work that has been done so far has been sent to SIGN to see whether they would take on this work and it was advised they may be able to accommodate however they have a substantial workload. It would be useful to have a SIGN document in the future so will continue to work with them until there is a time they can fit this in their workload. JTS shared she has received governance advice regarding producing a pathway through an NSS network. This document needs to be read over to see how feasible this will be. It will be difficult to have this piece of work completed within the life of this network although this may be a disappointment for patients this is moving forward especially in the new framework. Next steps are to look at the governance and would be useful to know if there are any colleagues interested in this piece of work. If there are any interested colleagues within the network and within the NHS. JTS has requested that names of interested colleagues can be sent via email.

Action – Attendees to send names of colleagues who may be interested in this piece of work to JTS

Agenda Item 13- Workstream Documents – Risks and Issues

Risk register was touched on during action log point. If any risks are to be added attendees will advise [REDACTED]

Action – Attendees to advise IU of any risks that need to be added to the risk register

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