



National Strategic Network for the Long- Term Effects of COVID-19

**Annual
Report 2024-
2025**

Published: 29 July 2025

Introduction

Advancing Progress and Strengthening Impact: A Milestone Year for the Long COVID Network

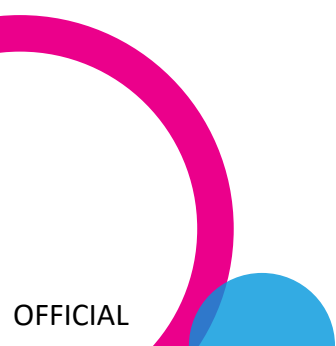
In its third year, the Long COVID Network has continued to evolve, expanding its membership and deepening collaboration across sectors. Strengthened by growing trust among partners, the network has delivered an impressive suite of outputs, demonstrating both maturity and momentum. Highlights include the publication of the first baseline digital tool data evaluation report and the development and formal submission of the *Long COVID Sustainability Recommendations* to the Scottish Government. Throughout, the programme has remained firmly grounded in its core purpose: to support clinicians and amplify the voices of people with lived experience.

Introduction-Cont.

While 2024/25 was originally intended to mark the conclusion of the programme, a strategic decision was made to extend it into 2025/26 using underspend from the 2022/23 budget. This extension reflects the Scottish Government's continued commitment to delivering the full £10 million Long COVID Support Fund. Separately, an additional £4.5 million was announced to enable the development of new, specialist services across Scotland for individuals affected by Long COVID, ME, chronic fatigue, and similar conditions. In February 2025, the network played a key role in supporting the Scottish Government by gathering critical insights from health board service planners to inform this work.

Introduction-Cont.

Two landmark documents the *Long COVID Sustainability Recommendations* and the *NHS Scotland Service Evaluation of Long COVID* were handed over to the Scottish Government in December 2024. Together, these provide a robust evidence base to inform future policy and service planning.



Introduction-Cont.

The expertise, dedication, and collaborative spirit of our network members remain central to our progress. By harnessing the latest qualitative and quantitative evidence, we continue to shape sustainable, person-centred services that respond to the evolving needs of people across Scotland. We are proud of the collective achievements of the past year and look ahead with confidence and ambition as we enter this pivotal transition year.

Manira Ahmad-Chair of Strategic Oversight and Programme Board

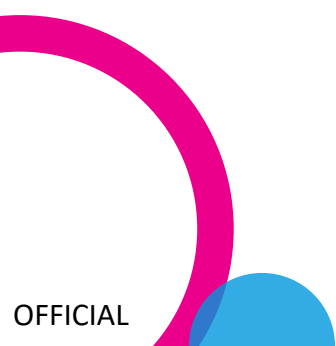
Evolution of the Network

The governance structure of the Network evolved and strengthened throughout 2024:

- Merged Service Planners and Clinical Subject Matter Experts workstreams are fully operational.
- New Vocational Rehabilitation workstream established and developed return to work pack.
- Data and Intelligence and Children and Young People workstreams continued to meet and deliver against their workplan.

Evolution of the Network-Cont.


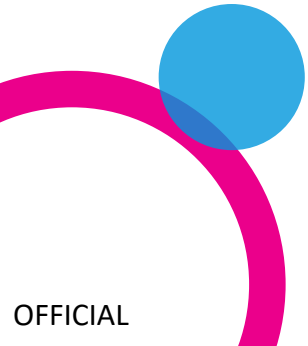
- Year 2023/24 network Business Case was reviewed and signed off for 2024/25. This informed the Network's delivery plans.
- A full internal NSS network review took place to ensure delivery of business case.



The Network Team

The team consists of:

- Lead Clinician-flexible clinician sessions (finished end February 2025, recruitment underway for replacement to cover 2025/26)
- Senior Programme Manager
- Programme Manager
- Programme Support Officer


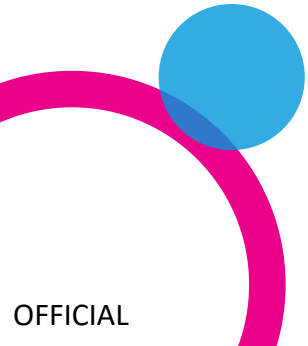


The network's
Steering Group
reconvened in
2023 and
continued to
meet quarterly

Governance, Membership and Attendees

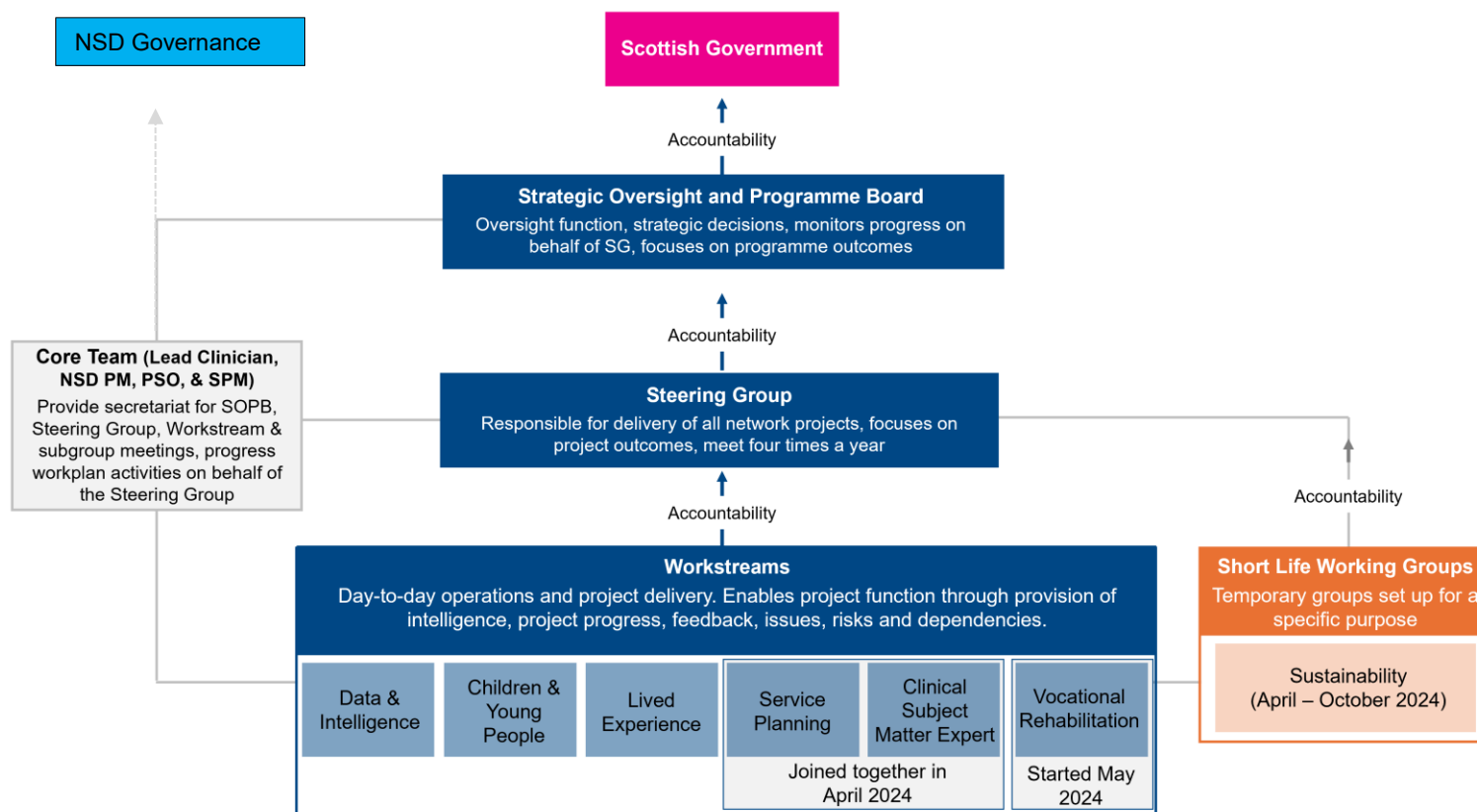
The Network's Oversight Board continued to meet quarterly through year 2024/25, it also consists of:

- Chairs of constituent workstreams, including lived experience.



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Governance Structure



2024-25 Finance

Territorial Boards

- £2.61 million was available across 14 territorial NHS Boards to strengthen and further develop the support they provide to people living with Long COVID. Total resource of £2.5 million was allocated to these Boards in the 2024-25 financial year.

2024-25 Finance-Cont.

NHS NSS (Network)

- £180,916 was allocated to National Services Scotland to deliver the network. This included (£20,000) resource for The ALLIANCE to support the Lived Experience activities.
- NSS was also allocated resource of £124,781 for year two digital tool licensing.



Key Objectives

- Design and ongoing development of an effective Network
- Support the design and delivery of services that are evidence-based
- Effective Stakeholder communication and engagement

Key Objectives-Cont.

- Improved capability and capacity
- Effective systems and processes

Key Achievements

- Completion of digital tool rollout – 10 boards (Ayrshire & Arran, Borders, Dumfries & Galloway, Forth Valley, Grampian, Greater Glasgow & Clyde, NHS Highland, Lanarkshire, Fife and Tayside) fully operational. Total patients registered on the tool 2140.
- Current Status of CYP Long COVID pathway across Scotland survey and summary completed. Summary approved by the Strategic Oversight and Programme Board.



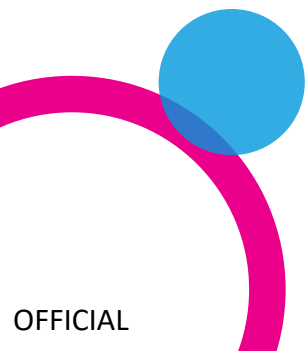
Key Achievements-Cont.

- Vocational Rehab workstream developed a return-to- work pack for health professionals to engage with patients' employer upon discharge from Long COVID support services.
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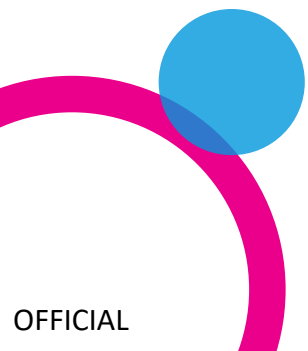
Key Achievements-Cont.

- Long COVID Sustainability recommendations delivered to Scottish Government.
- Two Peer Education network sessions held.
- Project ECHO learning programme delivered and evaluated 3 sessions- Long COVID diagnosis, PoTs and Breathlessness.
- Self-management workbook review phase 1 completed.
- Service evaluation data analysis report published in March 2024.



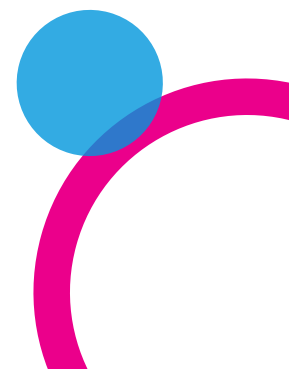
Key Achievements-Cont.

- Long COVID network website went live in November 2024. Attracted over 2000 visitors to home page with 5329 views.
- Digital tool usability survey report completed and approved by SO&PB.
- Collation of Boards' response on how to spend £4.5 million in year 2025/26 on Long COVID, ME/CFS and other similar conditions.



Networking and Engagement of the Network

- Health and Social Care ALLIANCE Long COVID network supported in the self-management workbook review - phase 1.
- Network supporting ALLIANCE in Long COVID webinars.
- Annual report 2023/24 published on Long COVID network website.
- Network research symposium on 11 February 2025.



Service Planning Workstream

This group consists of Service Planning representatives from across the Territorial Health Boards, with a key role in agreeing how pathways will be established, the operational delivery of the pathways and how funds would be distributed.

2024/25 Deliverable

2024/25 deliverable

- LC (adult) Long COVID pathway monitoring
- Resources allocated to add most value
- Digital tool rollout monitoring and collected
- Support sustainability recommendations

Progress and Next Steps

Progress and next steps

- Implemented pathway locally
- 25/26: Supporting Service evaluation
- Transitioning
- Provided funding update bi-monthly to network team
- Merged with CSME workstream
- 2025-26: Provide funding update quarterly to the network team
- Set up data centres
- Quarterly feedback monitoring
- 2025-26: Develop an exit strategy from digital tool.
- Service evaluation of existing data 2024/25
- Discontinuation of the tool
- Contribute to transition of the network

Anticipated Benefits

Anticipated benefits

- Measurable improvement in service delivery
- Visibility of projected spend
- Consistent data collection for future planning
- Data contributing to service evaluation
- Service continuity

Data & Intelligence Workstream

This group consists of representatives from Public Health Scotland, one member from each workstream, members of the Network Team, and the Clinical Lead. It reviews data sources, analyses data, gathers insights, and is developing an evaluation framework

2024/25 Deliverable

- Baseline data analysis published

Progress and Next Steps

- 2024-25: Provided oversight of data collected by ELAROS C-19 Yorkshire Rehabilitation Scale (YRS) to produce a service evaluation report
- Stakeholder engagement and development of a lay summary of the service evaluation.
- 2025/26: Oversight of service evaluation report
- Transitioning of the workstream

Anticipated Benefits

- Consistent collection and availability of Patient Reported Outcome Measures (PROMs) data
- Measurable improvement in rehabilitation interventions
- Large scale remote data collection can drive research
- Inclusive service evaluation report
- Streamlining governance structure in final year of the network

Data and Intelligence -Cont.

2024/25 Deliverable

- Network evaluation report
- Sustainability and Long COVID surveillance beyond programme lifecycle
- Benefits realisation plan developed

Progress and Next Steps

- NSS network report reviewed
- Completion of data evaluation to determine the efficacy of the model
- Theory of Change developed
- 2025-26 Support the programme's transition plan
- 2025-26 Support in benefits realisation plan in formulating pertinent questions

Anticipated Benefits

- Increased knowledge about the performance against the business case
- Solid foundation for future planning
- Streamlined governance structure
- Evidence of effectiveness and value for money
- Measurement will drive improvement

Lived Experience Group

The Lived Experience group was led by a representative from NHS 24, and works with Third Sector organisations such as Long COVID Scotland, Long COVID Kids, Chest Heart and Stroke Scotland and The ALLIANCE. It provides an important insight into the experience of those living with Long COVID which informs the work of all groups in the Network.

2024/25 Deliverable	Progress and Next Steps	Anticipated Benefits
<ul style="list-style-type: none">• Capture lived experience stories• Accessing Long COVID Services in Scotland survey• Patient disengagement with Long COVID service survey report• Increase lived experience involvement in the network structures	<ul style="list-style-type: none">• Lived experience stories played at every network meeting 24/25• Tracked progress of the report• Supported the development of a lay summary of the report.• Final report from the ALLIANCE delivered and shared with workstreams• Disseminated findings of disengagement report to the network and relevant agencies• Improved transparency and communication throughout the network, this ensured the Lived Experience Group could contribute substantively to decision making• 2025/26: support the programme's transition plan	<ul style="list-style-type: none">• Focus thoughts and a reminder of purpose of the network• Inform sustainability decisions• Patients with Long COVID feel listened to and have improved self-advocacy• Improvements in service provision.• Improved accountability and involvement• Streamlining of governance structure in programme's final year

Education & Workforce

The network team is responsible for the development of the education strategy, and organising peer education sessions to share best practice and signpost to resources

2024/25 Deliverable

- Identify existing resources and stakeholder education needs
- Develop a mechanism for sharing practice in a new and evolving area
- Implement and evaluate education strategy

Progress and Next Steps

- Established peer education support network:
 - Focused on different aspects of Long COVID
 - Shared case studies
 - Heard from specialist speakers on related topics
 - Discussed practice
- Continued topic and case study sessions and engage with relevant agencies ie ECHO project.
- Developed SharePoint Hub
- A repository of Online resource uploaded on webpage.
- Shared information and signposting to materials.
- Evaluation of education sessions and satisfaction survey
- 2025/26: Transitioning

Anticipated Benefits

- Staff in primary and secondary care trained on LC and other Long term/post-viral conditions
- Relevant evidence on LC and best practice made available/accessible to network/wider stakeholders e.g. employers.
- Improved staff confidence and capability in managing LC patients
- Improved consistency of information provision
- Improved self-management of LC
- Sustainability in LC education

Clinical and Subject Matter Experts

Our Clinical and Subject Matter Experts are a group of medical consultants and associated health professionals who develop clinical pathways to support evidence-based recommendations and good practice

2024/25 Deliverable

- Development of care pathways for those living with the long-term effects of Covid-19

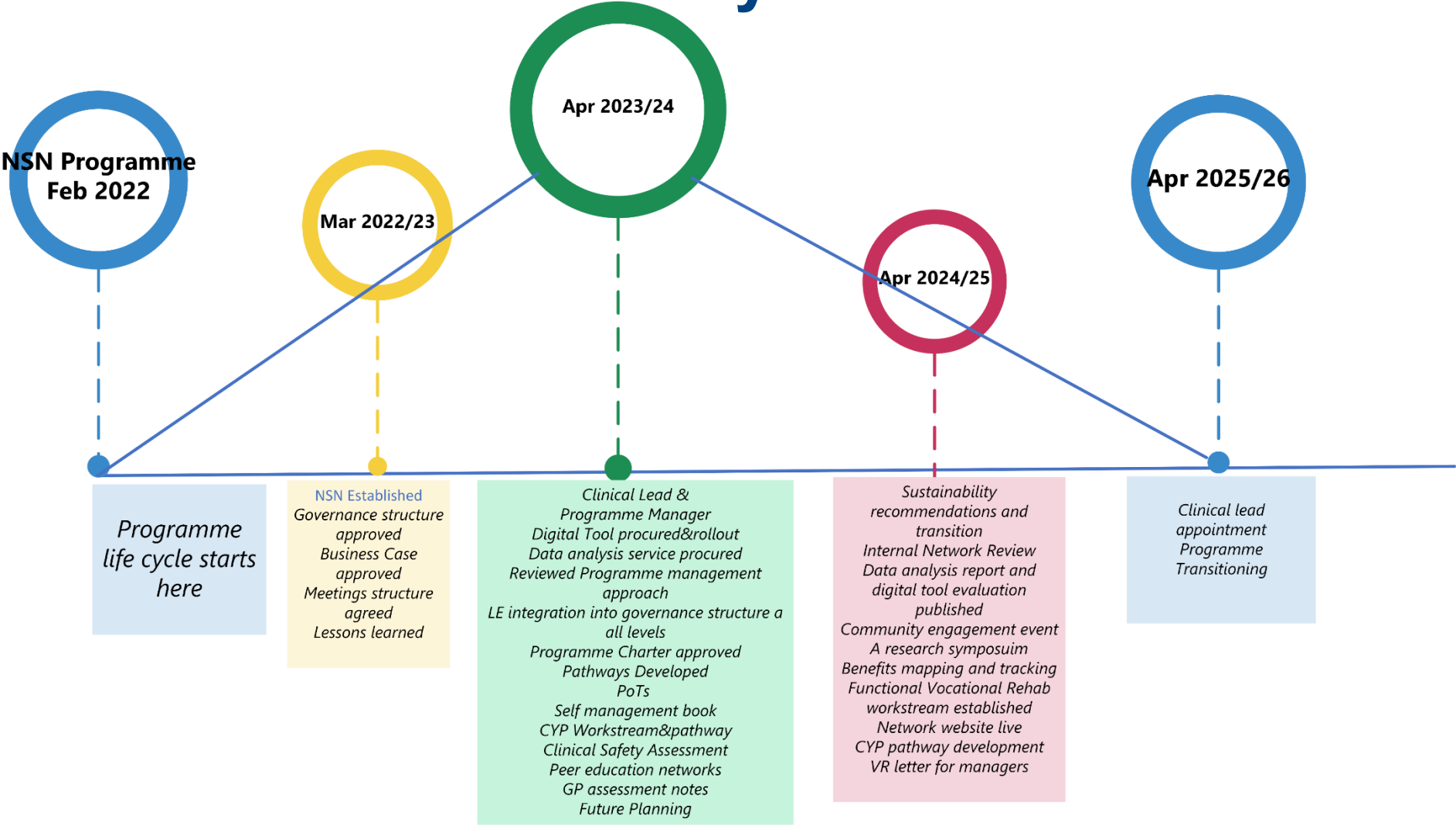
Progress and Next Steps

- Completed and delivered a Self-management Workbook with input from the Lived Experience Group and the ALLIANCE lived experience network.
- Delivered both physical and digital copy for patients across NHS Scotland
- Developed and implemented a non-medical treatment pathway for Postural Orthostatic Tachycardia Syndrome (PoTS) **ON HOLD**
- 24/25: Developed and implemented pathway for Children and Young People-Established CYP workstream
- Merged with Service Planning workstream
- 2025/26: Support transitioning plan of the programme

Anticipated Benefits

- Patient centred pathways established
- Improved self-management of Long Covid
- Informs ongoing service improvement activities
- Improved staff confidence and capability in managing people living with Long COVID
- Streamlining and capacity building
- Streamlining and service sustainability

Current Network Lifecycle



25/26 Workplan

Deliverable	Q1	Q2	Q3	Q4
Mandate for transition and stakeholder engagement	●			
Programme transition plan developed, signed off and implemented		●		
Long COVID Service evaluation report 2024/25 completed		●		
Benefits review plan delivered				●
Governance structure streamlined			●	
Lessons learned and handed over				●
Vocational Rehab Return to Work Pack completed				●
End programme report completed				●
PoTs guidance relaunched				●
GP Assessment Guidance (assessing LC in PC) evaluated				●

**Long COVID
Network**
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**Annual Report
2024-25**