

Enabling Lived Experience Involvement in the Long COVID network

The Strategic Network for the long-term effects of COVID-19 (the Long COVID network) programme team has made several adjustments to ensure meaningful Lived Experience (LE) involvement, taking into account feedback from representatives from Long COVID Scotland and Long COVID Kids.

- **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 network approached the ALLIANCE to represent LE interest at Strategic Oversight Board (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 network Long COVID (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
 - CYP pathway status summary across Scotland
 - Draft CYP return-to-education guidance
 - A regional service provision proposal presented to SOB
- **Vocational Rehabilitation:**
 - On 21/11/2024, Jane Ormerod and Ewan Macdonald began collaboration to explore the lived experiences of individuals returning to work without attending LC clinics, with input from the Occupational Health community.
 - 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.
 - LE requested LC pathway guidelines from boards; a team member reviewed board websites and provided feedback.

- The Baseline Service Evaluation lay summary was published in March 2024.
 - LE co-chairing GP education sessions through Project ECHO.
- **Sustainability Recommendations:** The network developed 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 contributed to the completion of the original self-management workbook and provided feedback on the phase 1 review of the self-management workbook. They were invited to participate in a digital tool usability survey.
- **Webinars and Ministerial Engagement:**
 - 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.