



Urgent Request for Parliamentary Scrutiny: Long Covid Policy Collapse Following Charity Resignations

Dear Convener and Committee Members,

On 5 August 2025, Long Covid Scotland and Long Covid Kids—the two leading patient-led charities representing thousands of people in Scotland living with Long Covid—resigned from the Scottish Government’s Strategic Network for the Long-Term Effects of COVID-19.

This decision followed over a year of repeated and constructive warnings to the NHS National Services Scotland (NSS) regarding network failure, broken trust, and collapse of policy delivery. These warnings highlighted governance breakdowns, exclusion of lived experience voices, lack of transparency, and delivery delays stretching years beyond stated commitments.

The Health and Social Care Alliance Scotland, a key umbrella organisation for third sector health voices, has publicly confirmed that it “recognises and shares” our concerns.

The departure of the two main patient-led voices removes the Network’s primary source of independent lived experience input, leaving its credibility in question and requiring urgent parliamentary intervention.

Headline Failings

£4.5m Long Covid Support Fund unspent

- Announced in the 2024-25 budget to improve access to multidisciplinary services.
- Not a single pound has yet reached patients; NSS now indicates services will not be operational until well into 2026—almost two years after the funds were allocated.

- No clear explanation for the delay or assurances on safeguarding these funds.

No national standards or clinical pathway

- Despite repeated commitments, no Scotland-wide pathway exists for diagnosis, management, or referral.
- Access remains a postcode lottery: some health boards provide clinics, others offer none.
- Several services have been scaled back or decommissioned without replacement provision.

No public health messaging

- Public Health Scotland has issued no targeted campaigns, warnings, or risk reduction advice since 2022.
- This absence fuels ignorance, delays diagnosis, and increases stigma.

Dilution of focus and funding

- Long Covid is now grouped with “other long-term conditions funding” aligned to a generic strategy, with no ring-fenced budget.
- This erodes visibility, accountability, and urgency.

Performative engagement with lived experience

- Dissenting voices have been sidelined from decision-making.
- Meetings were used to showcase patient involvement externally while excluding meaningful influence.

No Ministerial accountability

- The Minister for Public Health has not addressed documented governance and delivery failures.

- NSS framed our evidence as “how we feel,” rather than engaging with the substantive facts presented.

Background and Evidence

In August 2025, after over a year of raising concerns privately and constructively, the two leading Long Covid charities concluded that continued participation in the Network was no longer ethical or effective.

Our resignation letter documented:

- The unspent £4.5m fund and projected delays to 2026.
- The absence of any national clinical pathway.
- Lack of transparency—including failure to share minutes, papers, and progress reports.
- Exclusion of critical lived experience voices from decision-making.
- Total absence of public health messaging.

Neither the Scottish Government nor NSS has denied any factual element of our evidence. Their responses—regret at our departure and meetings offered—do not address a single substantive failing.

The Recovery Committee’s own 2023 report called for:

- National standards of care.
- Ring-fenced investment.
- Sustained public awareness campaigns.
- Robust lived experience involvement.

Two years on, none of these have been delivered.

Our Requests to the Committee

We respectfully ask the Committee to:

1. Seek immediate written evidence from the Scottish Government and NSS detailing:

- Governance arrangements, decision-making processes, and strategic oversight of the Long Covid Strategic Network.
- All milestones, spending plans, and delivery timelines linked to the £4.5m Long Covid Support Fund, including explanations for the current delay and safeguards for allocated funds.
- Measures ensuring compliance with the NHS Recovery Plan, COVID-19 Recovery Committee recommendations, and statutory duties for children and equality under the Equality Act 2010 and UNCRC Article 24.

2. Hold oral evidence sessions with the Minister for Public Health, the NHS Scotland Chief Operating Officer, and NSS leadership to establish:

- Why the Network has failed to deliver national standards, clinical pathways, and equitable services.
- Why lived experience input has been sidelined, and how future engagement will be meaningful, independent, and protected from retaliation.
- Why public awareness campaigns have not been implemented and what immediate actions will address ongoing stigma, misinformation, and delayed diagnosis.
- Why some services have been paused or closed, including child and adolescent provision, and what accountability exists for these closures.

3. Investigate the £4.5m Support Fund to assess risks of underspend, misallocation, or repurposing, and ensure ring-fenced delivery to front-line services.

4. Assess delivery against the Recovery Committee's 2023 recommendations, including:

- National standards of care and equitable access.
- Children's inclusion and protection of their rights.

- Robust lived experience co-production.
- Transparent reporting and public accountability.

5. Review governance safeguards to ensure:

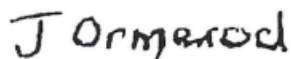
- Lived experience input cannot be tokenised or used to deflect legitimate criticism.
 - Engagement is resourced, independent, and protected from retaliation.
 - Ministerial and senior leadership accountability is clear for delivery failures.
 - All future national health networks adhere to these principles.
-

Conclusion

Thousands of people in Scotland remain severely unwell with Long Covid, facing debilitating symptoms, no access to specialist care, and no national strategy to meet their needs. Public understanding is minimal, stigma is increasing, and yet the Government continues to cite engagement while ignoring what that engagement consistently tells them.

This is not a policy gap—it is a policy collapse. Without parliamentary scrutiny, the failures of governance, delivery, and accountability within the Strategic Network will continue unchecked. We are ready to provide oral evidence and engage with the Committee as required.

Sincerely,



Jane Ormerod

Chair

Long Covid Scotland