28th August 2025

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

Dear Convener and Committee Members,

On 5 August 2025, Long Covid Kids (LCK) and Long Covid Scotland (LCS), the leading charities representing tens of thousands of adults, children and young people living with Long Covid, formally 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 NHS National Services Scotland (NSS) regarding the Network's 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.

Right now in Scotland, thousands of children and young people with Long Covid are missing school, have lost friends, and enduring disabling symptoms with no access to specialist care. Families are left to navigate stigma and disbelief while watching their children's futures erode.

Despite repeated promises, there is still no functioning national paediatric clinical pathway, no single point of contact, and no meaningful public health campaign to help families recognise the condition. Services, where they exist, are inconsistent, fragile, and in some areas, already being withdrawn. Parents speak of a postcode lottery; many children receive no referral at all.

This failure reflects structural issues within the Scottish Government's Long Covid Strategic Network, where governance collapsed, lived experience voices were sidelined, and transparency never materialised. **The departure of the only charity representing children and young people with Long Covid removes the Network's sole independent lived experience input for this group. This leaves its credibility in question and requires urgent parliamentary intervention.**

Why We Resigned

Most importantly, continuing to sit at a table where evidence was dismissed as “feelings,” minutes were withheld, and projects stalled indefinitely was no longer ethical or effective, and does not align with our charity mission or objectives.

From the outset, there was secrecy around subgroup membership [Appendix 1.], with parents and children rarely told who was making decisions on their behalf. At one point, lived experience representatives were even asked to sign confidentiality agreements. Access to key information was sporadic and unreliable: SharePoint was often unavailable, minutes and reports were withheld, and there were long silences between sparse updates. The Network’s own structure, which appears to position lived experience alongside clinical and planning groups, looked inclusive on paper but in practice created silos that isolated families and denied them meaningful involvement. The diagram in Appendix 1 illustrates the system we were placed into, but in reality we were left at the margins without information, agency, or oversight.

Further, the “Children and Young People pathway” [Appendix 2.] is unfit for purpose. It does not deliver on government policy of a single point of contact, it has not been distributed, and most GPs and paediatricians remain unaware of its existence. Prior to the publishing of the clinical pathway, lived experience feedback outlining these concerns were dismissed and ignored.

The design of the paediatric clinical pathway implicitly assumes that all frontline professionals, including GPs, paediatricians, nurses and allied health practitioners, have a working knowledge of Long Covid in children, including how it presents, how to diagnose it, and what treatment options can improve quality of life. In reality, no such baseline knowledge exists, and no training or clinical infrastructure has been provided to support implementation. Without a dedicated clinic in each health board to build expertise and offer continuity, the pathway is effectively worthless in practice.

Finally, the £4.5m Support Fund, announced with fanfare in the 2024–25 budget to improve multidisciplinary care, has still not reached a single child or adult. NSS now states services will not be operational until well into 2026. No clear explanation has been given for this delay or whether funds remain safeguarded for paediatric use.

Systemic Failures

No National Standards or Paediatric Pathway
Despite years of commitments, Scotland still lacks a consistent national framework for diagnosing or managing Long Covid in children. The “CYP pathway” exists only in name: it is undistributed, largely unknown to GPs and paediatricians, and does not deliver the promised single point of contact. The result is a postcode lottery, with some families offered limited referrals while others are turned away with nothing.

Opaque and Possibly Misallocated Funding
The £4.5m Long Covid Support Fund remains unspent at national level, and there is no transparency on whether *any* of this allocation will reach paediatric services. Families and charities have never been given sight of spending plans, delivery milestones, or safeguarding mechanisms. At one Network meeting, a health board openly admitted they were unaware they were supposed to provide services for children, a staggering communication failure that raises fundamental questions about where funds were directed and how priorities were set.

Silence from Public Health
Public Health Scotland has failed to issue any child-specific campaigns, information materials, or risk reduction advice since the pandemic began. Parents remain unaware that Long Covid exists in children, delaying recognition and diagnosis. This silence fosters stigma, disbelief, and harm.

Tokenistic Engagement
A strictly regulated number of lived experience participants were invited to meetings as symbolic participants but excluded from shaping decisions. Critical feedback was ignored or reframed. Exclusion was used to silence representatives instead of empowering them.

Absence of Ministerial Accountability
Despite repeated warnings of failure from charities, clinicians, and families, the Minister for Public Health has not addressed the collapse of the Strategic Network. Leadership has deferred responsibility to NSS, which has failed to provide transparency or meaningful action.

These are systemic choices that leave children invisible.

What Must Happen Next

These failures, financial, clinical, and governance, demand urgent parliamentary intervention. Parliamentary scrutiny is the only way to restore credibility and protect children's rights. We urge the Committee to:

1. **Compel full disclosure** from the Scottish Government and NSS on governance structures, decision-making, and delivery of the initial £10m support fund and more recent £4.5m support fund, including safeguards for paediatric allocation. This must include publication of full subgroup membership, release of minutes and documents previously withheld, and a clear account of why confidentiality agreements were used against patient representatives.

2. **Call oral evidence** from the Minister for Public Health, Public Health Scotland, the NHS Scotland leadership, and NSS leadership to explain:
    - ○ Why national paediatric standards and pathways have not been delivered.
    - ○ Why children's voices are sidelined and lived experience input undervalued and ignored.
    - ○ Why public awareness campaigns never materialised.

3. **Commission an independent review** by Audit Scotland into both the governance, culture and the financial management of the Strategic Network, including:
    - ○ Whether the initial £10m Support Fund is at risk of misallocation or underspend.
    - ○ Whether terms of reference for children have been met.
    - ○ Whether lived experience involvement has been tokenised, excluded, or retaliated against.

4. **Secure accountability for the £4.5m Support Fund**, ensuring it is not misallocated or absorbed into broader budgets, but ring-fenced and delivered to front-line paediatric Long Covid services without further delay.

5. **Assess compliance with statutory duties** under the Equality Act 2010 and the UNCRC, recognising that children's right to the highest attainable standard of health (Article 24) is currently being breached.

Conclusion

This is a governance failure that has left sick and disabled children abandoned. Without urgent intervention, Scotland risks presiding over a generation of young people disabled by Long Covid, excluded from education, and denied their rights.

We ask the Committee to act now, in this Parliament, not the next, to bring transparency, accountability, and justice to children with Long Covid.

Long Covid Kids Scotland stands ready to give oral evidence and provide testimony from families across Scotland.

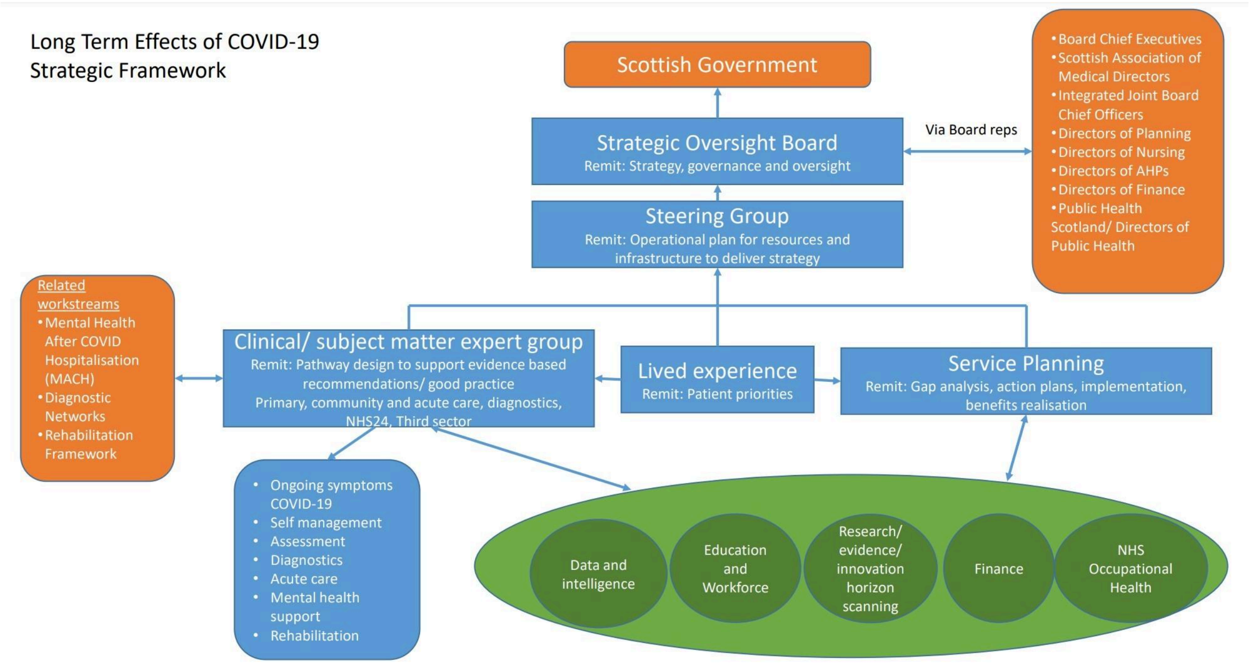
Yours sincerely,

HGoss

Helen Goss
Long Covid Kids Scotland

Appendix.

1.



Long Term Effects of COVID-19
Strategic Framework

Scottish Government

Strategic Oversight Board
Remit: Strategy, governance and oversight

Via Board reps

- Board Chief Executives
- Scottish Association of Medical Directors
- Integrated Joint Board Chief Officers
- Directors of Planning
- Directors of Nursing
- Directors of AHPs
- Directors of Finance
- Public Health Scotland/ Directors of Public Health

Steering Group
Remit: Operational plan for resources and infrastructure to deliver strategy

Related workstreams
- Mental Health After COVID Hospitalisation (MACH)
- Diagnostic Networks
- Rehabilitation Framework

Clinical/ subject matter expert group
Remit: Pathway design to support evidence based recommendations/ good practice
Primary, community and acute care, diagnostics, NHS24, Third sector

Lived experience
Remit: Patient priorities

Service Planning
Remit: Gap analysis, action plans, implementation, benefits realisation

- Ongoing symptoms COVID-19
- Self management
- Assessment
- Diagnostics
- Acute care
- Mental health support
- Rehabilitation

Data and intelligence

Education and Workforce

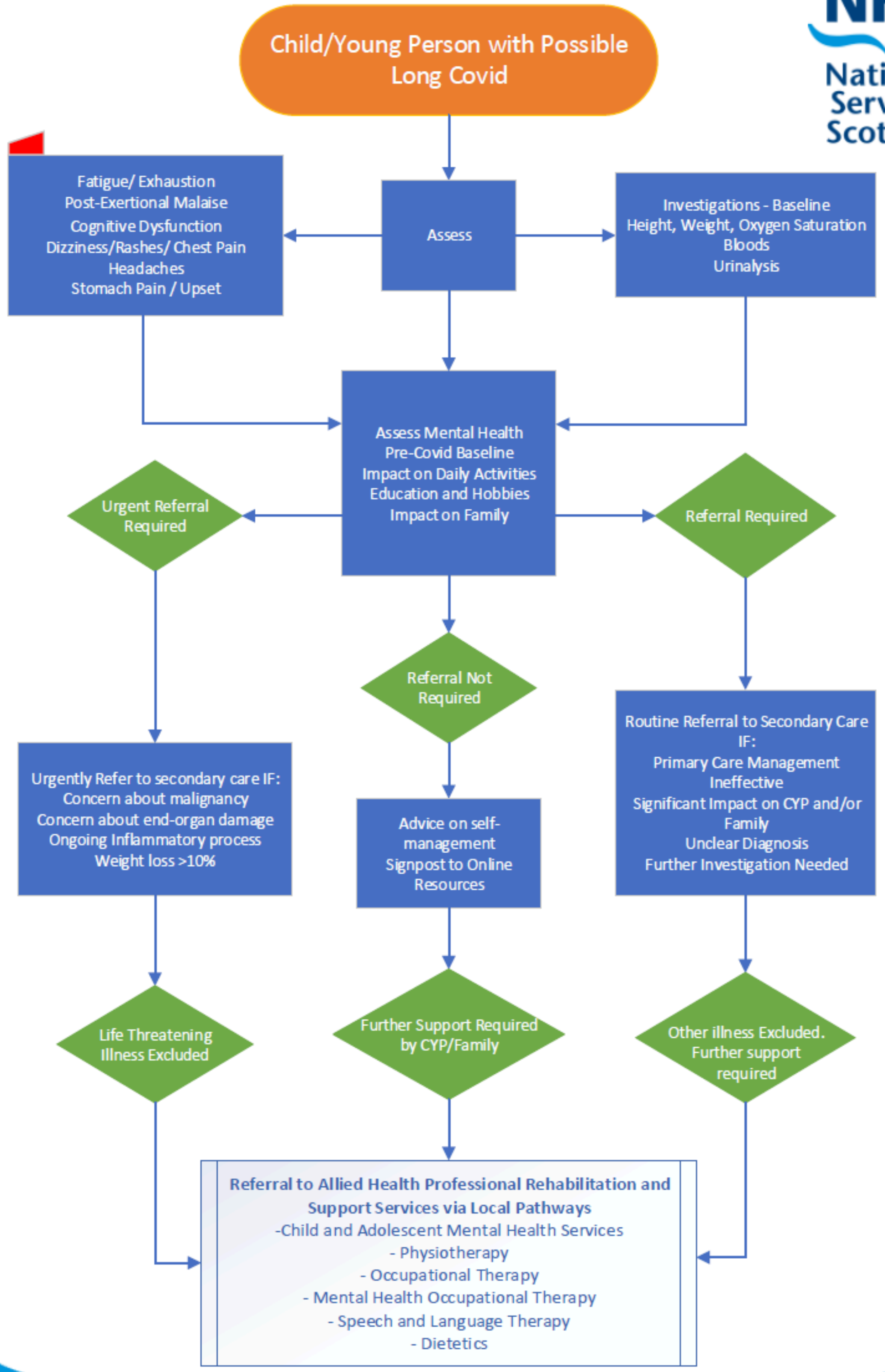
Research/ evidence/ innovation horizon scanning

Finance

NHS Occupational Health

2.

NHS
National Services Scotland



Child/Young Person with Possible Long Covid

Assess

Fatigue/ Exhaustion
Post-Exertional Malaise
Cognitive Dysfunction
Dizziness/Rashes/ Chest Pain
Headaches
Stomach Pain / Upset

Investigations - Baseline
Height, Weight, Oxygen Saturation
Bloods
Urinalysis

Assess Mental Health
Pre-Covid Baseline
Impact on Daily Activities
Education and Hobbies
Impact on Family

Urgent Referral Required

Referral Not Required

Referral Required

Urgently Refer to secondary care IF:
Concern about malignancy
Concern about end-organ damage
Ongoing Inflammatory process
Weight loss >10%

Advice on self-management
Signpost to Online Resources

Routine Referral to Secondary Care IF:
Primary Care Management Ineffective
Significant Impact on CYP and/or Family
Unclear Diagnosis
Further Investigation Needed

Life Threatening Illness Excluded

Further Support Required by CYP/Family

Other illness Excluded. Further support required

Referral to Allied Health Professional Rehabilitation and Support Services via Local Pathways
-Child and Adolescent Mental Health Services
- Physiotherapy
- Occupational Therapy
- Mental Health Occupational Therapy
- Speech and Language Therapy
- Dietetics