

Outlook

Fw: Lived Experience members-Formal resignation

From NSS longCOVID nhs.scot> Date Wed 8/6/2025 4:56 PM Alison Gilhooly @nhs.scot>

FYI

National Strategic Network for Long-term Effects of COVID-19 National Specialist and Screening Services

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nhs.scot> From: Janis Heaney

Sent: 05 August 2025 08:40

To: Janet Scott (NHS Highland) @nhs.scot>; NSS longCOVID @nhs.scot>

phs.scot>

Subject: RE: Lived Experience members-Formal resignation

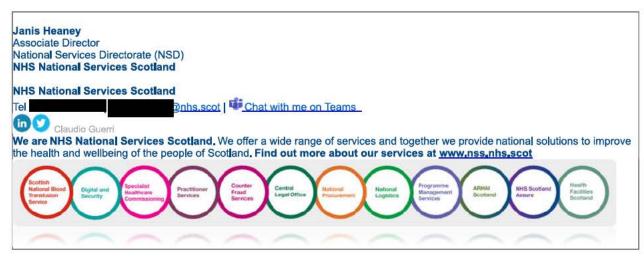
Hi

Thanks for your comments below. We need to ensure that any communication we issue is aligned with SG comms lines (which need to be cleared by the Minister). I have spoken to the policy team at SG and will be discussing further today. The role of NSS is to provide programme management and clinical leadership to national networks and while we have worked closely with SG on funding allocations and management it is an oversight role - NSS cannot expedite the funding.

Appreciate that there are frustrations from lived experience groups however there are statements in their letter that are factually inaccurate, and we need to consider carefully how we respond.

Thanks,

Janis



From: Janet Scott (NHS Highland) @nhs.scot> Sent: 05 August 2025 05:18

To: NSS longCOVID

nhs.scot> @phs.scot>; Janis Heaney

Subject: Re: Lived Experience members-Formal resignation

Importance: High





Thanks for forwarding this. I know were very well and have spoken to her about this last night. They do feel pushed into this - I think the meetings dominated by a committee reorganisation with no news of the reports or further funding were the last straw. The meetings dominated by a committee reorganisation with no news of the reports or further funding were the last straw.

I hope we can use this resignation constructively and reengage.

I'd already scheduled a meeting with them (as I will with all stakeholders) and perhaps a way though can be found.

Of course confirmation for £4.5 mil recurring funding is what really would help.

IN addition, the committee reorganisation, whilst I get where its coming from, feels off topic and has come for them (and for me) out of the blue. The vocational committee already bounced a decision on this until after the appropriate document was circulated so no decision was made.

Might I suggest we take a step back from this and in the next week rethink with the patients and indeed deliverables at the centre of that redraft? I think its important we move forward together.

Sorry if this is a bit direct - I'm on a clinical week this week and less, so my time is very limited.

If you can contact me with the COMMs team, I'm happy to comment on it. I have media training and from previous experience, find responding does better in the long term - will be doing interviews later today so this will be covered.

I suggest with a personal statement from me would benefit from my 'newness'??

I've prepared the following in anticipation - happy to discuss with Comms - after my ward round!! I wish they'd resigned tomorrow, I'm less busy!!

Statement from Dr. Janet Scott, Clinical Lead for Long COVID Services, NHS Scotland

I have today learned of the resignation of Long Covid Scotland and Long Covid Kids from the Strategic Long COVID Network. As the newly appointed Clinical Lead for Long COVID services, I want to acknowledge the concerns raised and respond transparently.

The resignation of these vital patient advocacy groups represents a significant moment that we must take seriously. Their concerns about communication, coordination, and service delivery reflect real challenges that patients with Long COVID continue to face across Scotland.

I recognise that trust has been eroded and that people living with Long COVID have experienced repeated disappointments. The delay in allocating the £4.5 million announced in December 2024 is extremely difficult, particularly when services are being decommissioned while patients continue to be referred. In my own service in NHS Highland, our referral numbers have stabilised post-pandemic and are slightly up in 2025 compared to 2024, demonstrating ongoing need here, although that picture is not the same throughout Scotland.

We very much hope the Scottish Government will continue to engage with these real concerns about service provision and sustainability.

As the new Clinical Lead, there are some immediate priorities:

- · Working urgently with Scottish Government and NSS to expedite funding allocation decisions
- Re-engaging with all stakeholders, particularly patient groups, to rebuild trust and ensure meaningful participation
- Improving transparency and communication about service availability and future plans
- · Ensuring that the voices of people living with Long COVID remain central to all decision-making

My impression, only four days into this role, is that there is substantial goodwill from all stakeholders to build effective health provision for Long COVID and related conditions, albeit this is taking longer than hoped to manifest. I am committed to addressing the issues that have led to this resignation.

I will be reaching out to these organisations immediately to explore how we can work together constructively, even outside the formal network structure if necessary. People with Long COVID deserve better, and I am determined to help deliver meaningful change.

The network cannot function effectively without patient representation. I hope we can find a path forward that restores confidence and delivers the coordinated care that Scots with Long COVID urgently need.

Dr. Janet Scott Clinical Lead for Long COVID Services NHS Scotland

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From: NSS longCOVID nhs.scot> Sent: 04 August 2025 16:01

To: Janet Scott (NHS Highland)

Subject: Lived Experience members-Formal resignation

Hi Janet

Please see attached a joint formal resignation from our lived experience members. Janis is aware of it, she has discussed it with our SG colleagues and also flagged this with our Comms team bueasue Lived experience members (have indicated that it has been shared with the media.

Regard

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