National Services Division (NSD)
Meridian Court, 5 Cadogan Street
Glasgow. G2 6QE
Telephone 0141 300 142
www.nsd.scot.nhs.uk

minutes

Lived Experience Oversight Group

Wednesday 15th June 2022 11:00

MS Teams

Author: [redacted]

Present:

Shaben Begum	Vice Chair	Long Covid Scotland
Joseph Carter	Head of Devolved Nations	NHS Lothian
Helen Goss	Senior Lead Representative	Long COVID Kids Scotland
Rob Gowans	Policy & Public Affairs Manager	Alliance
Margaret McKeith	Assistant Director	Alliance
Davie Morrison (Chair)	Participation & Equalities Manager	NHS 24
Jane Ormerod	Chair	Long Covid Scotland

Apologies:

Allan Cowie	Interim CEO	Chest Heart & Stroke Scotland

In Attendance:

[redacted] (minutes)	Assistant Programme Manager	NHS NSS
Karyn Robertson	Senior Programme Manager	NHS NSS

1 Welcome, Apologies & Introductions

Davie welcomed everyone to the meeting and individual introductions were given.
There was a change in membership as Allan Cowie had stepped down from the group and Emma Knox, Head of Development, Chest Heart & Stroke Scotland (CHSS) would join the group to represent CHSS.
The group agreed that Kerry Ritchie, Alliance could join the group as she was leading on the Alliance's Long Covid Network and various other lived experience programmes.

Today's meeting would be to discuss the importance of the person's voice to ensure that was captured and feeds into the two other working groups - Service Planning and Clinical and Subject Matter Expert groups and the overall action plan

2 Minute and action from previous meeting

Minute from previous meeting (27th April) ratified.

Actions:

22-04-27:03 - Query whether support could be widened out to include other services and not solely NHS within Terms of Reference (ToR). That would be raised at the next Strategic Oversight Board meeting on 4th July. Following that, an update would be provided to the group and the ToR re-circulated. **Action:** [redacted]

22-04-27:04 – Query whether Covid Aid charity be invited onto the group. The suggestion was also put forward by Scottish Government as appropriate to include them. Michael MacLennan, CEO, Covid Aid met with Davie, Karyn and [redacted] and was very pleased to have the opportunity to speak about the work of the charity and be involved in the Network. Following a discussion by the group it was agreed that further consideration would be given to providing access to Covid Aid and to all interested parties. It is important that as a group we gather and share as much information as possible to influence the work of the Service Planning and Clinical and Subject Matter Expert groups. **Action: Davie Morrison**

22-04-27:07 – In order to create a map of services of what was available within 3rd sector organisations, if everyone could share contact details / links that could be incorporated.

Action: All

The map would be a comprehensive one that would include links and resources of what was available within Health Boards and the local communities, which was underway through the Service Planning Group. The map would be an evolving piece of work as new resources and services become available over the next 5-6 months.

22-04-27:09 – Joseph had an action to share any Scottish data from the new Long Covid diagnostic tool. He would enquire into that, although it maybe the data could not be broken down into Scottish specific data. An update would be provided. **Action: Joseph Carter**

3 Update on launch of Network and Reference group

Margaret provided the update. The Steering Group met a few weeks ago and developed a Data Privacy Impact Assessment (DPIA), an Equality Impact Assessment (EQIA) and a purpose statement. The launch of the Long Covid Network would be held around the beginning of August, with contributions from colleagues in Scottish Government and NHS NSS.

Once the draft programme for the launch was available, that would be shared with the group for comments prior to finalising. It was emphasised group members need to have oversight of the planning process for that event. Margaret requested that all members of the group provide support in publicising and promoting the event through their own communities.

The Network would be made up of people with lived experience, affected by Long Covid and organisations. Examples of some of the activities that would be asked of Network members would be to participate in short term Reference Groups looking at, for example, something for children that would require Long Covid Kids Scotland input. Work with some of the organisations to share expertise on how to reach out to the seldom heard voices.

Davie commented that NHS Scotland has to work within community engagement guidance, particularly in relation to service change, and once the Steering Group within our Strategic Network was established that they would need to understand how objectives would be met within that service change.

Addendum *– Karyn met with colleagues from Healthcare Improvement Scotland (HIS) to identify if what was discussed was a service change and would there be a requirement for a formal consultation. Initial discussions indicated that that was not a service change and Karyn to complete and submit a form for definitive clarification.*

In NHS 24, at the beginning of each board meeting they hear of people's experiences of how they accessed their services and that was minuted and shared with other groups. The group agreed that as an excellent idea and would be the first agenda item going forward.

Those minutes would be shared with the Service Planning and Clinical & Subject Matter Expert groups to provide them with some insight of the experience stories / case studies. Also ask both the aforementioned groups if they would each consider having experience stories at the start of each meeting **Action:** [redacted]

Identify if Alliance had a template that would be useful as a format to gather case studies and share with the group. If not, Alliance Comms team could create one. **Action: Margaret McKeith**

Once the template was shared, each of the organisations to begin completing that with case studies / experience stories. **Action: All**
Another approach could be videos of experiences rather than only in written format, and that could support building a bank of videos that could be shared with other groups or at events. Videos would only be created with the person on the video very clear on the purpose and where and who the videos could potentially be shared. NSS had a consent form and DPIA that could be used for that purpose.

4 Communication strategy

The Alliance Research paper that was shared via email with the group yesterday, was also shared on the Teams channels for both the Service Planning and Clinical Subject Matter Expert groups.

The communication strategy would be to ensure information is shared with people with lived experience or affected by Long Covid, and particularly aiming to reach those who may not want to be part of the Alliance Network but should equally be receiving the same information and messages as those who do. Also, ensuring that diverse communities had the opportunity to input into the strategy going forward, and understanding that it would be an evolving piece as the Network evolves.

The Alliance Network had a Steering Group with representation from Chest Heart & Stroke Scotland and Asthma & Lung UK who would be looking at the operational process of their Network. One item outstanding was finalising a Terms of Reference between NSS and the Alliance, and it was agreed Karyn to be invited to the next Steering Group meeting to support finalising the ToR.

There were comments received from some members regarding the purpose of the group as it was thought that meetings would be a two-way process of communication. The group's understanding was that they would feed in the collective voice from members of their organisations and that would be shared with the Service Planning and Clinical Expert groups. Equally, this group would receive updates of the work within the Service Planning and Clinical Expert groups to be in a position to offer effective feedback to their organisations.

A meeting to be arranged between Davie and Jane for a more detailed explanation in the role and purpose of the group. **Action:** [redacted]

5 Digital tools

Resource has been centrally held for a digital tool which the Strategic Oversight Board agreed would be used in a "once for Scotland" approach, rather than individual Health Boards developing their own resources. There were a number of tools available, and what was asked of the group was to understand, from a Lived Experience perspective, what would be the most important aspects of that tool. Most of the tools available have patient reported outcome measures, looking at symptoms and how they evolve over time. Therefore, for a person to be able to measure that both for themselves and be able to share that with a clinician to enable them to understand the person's journey would be important.
Long Covid Scotland suggested a poll to their Steering Group, in the first instance, then possibly widen that to other members to identify which tool(s) people were currently using and which one would they would recommend. **Action: Jane Ormerod and Shaben Begum**
Helen expressed that the feedback from families on the question of a digital tool would be 'why would we need another one' when there were many already on the market. The families were fundamentally wanting children to receive medical care. Karyn explained that NHS England were reporting saving clinical time through the use of a digital tool and that would be used to see more people. The digital tool gathered information that would be shared with the clinical team.

Add to the agenda as a standing item, an update on progress from the Service Planning and Clinical and Subject Matter Expert groups. In addition, prior to each meeting that update would be provided in writing for the organisations to share with members. **Action:** [redacted]

6 Evaluation

The ask of the group was to think around what the priorities would be when evaluating the digital tool from a Lived Experience perspective.

7 Any other business

The length of the meeting was agreed to be reduced to 1 hour and be more concise.

9 Date and Time of Next Meeting

The meeting should be held soon after the other two groups meetings to allow capture of activities that could be shared with the group. A doodle poll of dates would be circulated.