

(Long Covid - Lived Experience Oversight Group) Action Tracker

NSD608-006.01

Note: this action list is also now capturing actions identified within the business area that need to be progressed

Last updated on:	15/02/2023
Last updated by:	

Template: V3

Prior to using this template, you must refer to Q-Pulse to ensure that you are using the most up to date version.

Action Log Reference	Date of Meeting	Description	Status	Comments	Owner	Completion Date
3	27/04/2022	Query with SG whether the support could be widened out to include other services and not solely NHS within ToR	Ongoing	05/04/23 - circulated for comment 28/02/2023 - the updated draft ToR would be circulated with the updated action note. 08/12/2022 - Agreement to widen the scope. Update the ToR and re-circulate. 05/09/2022 - To be raised at the next Strategic Oversight Board meeting for further clarity. ToR to be re-circulated to the group		
7	27/04/2022	Create a map of services of what is available within 3rd sector orgs and if everyone could share contact details / links that could be incorporated.	Ongoing	28/02/23 - ALISS presented at the meeting. Agreed to close this point as other actions came out of the discussion. 08/12/2022 - ALISS (A local information system for Scotland) is a web resource service to help you find support close to your locality. This would be an excellent resource to add links to resources the group would deem useful and appropriate. A demonstration of the system to be planned for the next meeting 05/09/2022 - A plea for each member to send links to resources from each of their platforms to support building the map. When sending links, if [REDACTED] could ensure there was some info from Scottish Ballet who linked into the launch, and if there were other links external to the Alliance as well		28/02/2023
16	05/09/2022	Liaise with Care Opinion to understand if a Long Covid specific hashtag could be created that could be used when sharing stories and easier to collate https://www.careopinion.org.uk/info/care-opinion-scotland	Ongoing	28/02/23 - Postcards printed. Some of the group opted for a pdf of the postcard to add to websites. Alliance requested both. All completed 08/12/2022 - Draft postcard to be circulated for comments prior to full sign off and printing.		06/03/2023
17	05/09/2022	Consider requesting Humans of Scotland tailor their guidance to support people sharing stories specifically related to Long Covid	Oct	28/02/23 - A link to a lived experience story was recently shared with the group to allow everyone to see how that looked. 08/12/2022 - Once a lived experience story of living with Long Covid was published, that would be shared with the group as an example. Following that, next steps to be considered.		
18	08/12/2022	Invite a person with Lived Experience to become a member of the NHS Network's Steering Group	Jan	28/02/23 - This request relates to the Risk Log in point 14. Close this point		28/02/2023
19	08/12/2022	Risk log - people with Long Covid represented in the Network, need to have the credibility to be able to influence change, so that that was recognised amongst their communities and with healthcare professionals. Consider a representative from the group be invited onto the Steering group.	Feb-Mar	28/02/23 - Risk log updated and would be re-shared.	DM / AG	
20	08/12/2022	The opportunity to receive voices training from HIS was offered and if anyone interested to email the Long Covid mailbox	Jan	28/02/23 - The opportunity was re-offered, and if anyone from this group and their wider communities were interested to let [REDACTED] know. More info on what Voices Training is to be circulated		

22	28/02/2023	Circulate a communication to announce the Lead Clinician of the Network	March	Email circulated on 6th March	█/AG	06/03/2023
23	28/02/2023	Invite a second member of Long Covid Scotland to join the group	March		█	
24	28/02/2023	Interested to have a progress update on the lived experience story from the Thistle Foundation (█ story)	Aug-Dec		█	
25	28/02/2023	Link to private Youtube video shared by LCK to be cascaded through the Network but with a clear statement - not for onward sharing.	March	Completed	█	03/03/2023
26	28/02/2023	All members of groups/charities were encouraged to add info onto ALISS, if not already done so and to claim it. Equally, to raise awareness with their members about ALISS and encourage others to add more Long Covid related info	Apr-May		ALL	
27	28/02/2023	Request SG Policy team to encourage groups/charities that were awarded funding from SG to support Long Covid to add their info and services to ALISS	Apr		AG	
28	28/02/2023	Request with NHS Inform if they could have a link to ALISS from the Long Covid microsite as that was the NHS patient facing information platform.	Apr		AG/DM	
29	28/02/2023	Comments / feedback to the draft education strategy were invited via email	Apr	No comments received. Strategy signed off by the group.	All	21/04/2023
30	28/02/2023	Invite the Lead Clinician to this group's next meeting	March	Invited and accepted	█	21/04/2023
30	28/02/2023	Each of the groups / networks to share a brief update on what is happening / progressing for the whole group to have an understanding	Mar-Apr		All	

Date of Meeting	Description	Comments	Status	Completion date
15/06/2022	Poll Steering Group members to identify which digital tools are being used and which they would recommend to use in Scotland	05/09/2022 Three members of the group would work with SIGN to further develop the app, as originally there was no Lived Experience within it and that should be helpful for future iterations of the app.	Completed - [REDACTED] / Shaben	05/09/2022
05/09/2022	Circulate the survey link from Alliance around Long Covid care priorities	https://www.smartsurvey.co.uk/s/LongCOVIDLivedExperience/	Completed - [REDACTED]	05/09/2022
05/09/2022	The group to provide direction on what is their ask of the Service Planning and Clinical Experts groups i.e. what should they be focussing on and considering	01/12/22 - Close this point for now. This will be discussed in a wider context in an agenda item at the meeting on 08/12.	Completed	01/12/2022
27/04/2022	Share any Scottish data from the new My Long COVID diagnostic tool - https://mylongcovid.org.uk/ This is an assessment tool that will help people to understand their current Long COVID symptoms, their needs, what to do next and what help people can get. The results from the assessment will help people when explaining their Long COVID symptoms to a GP. The GP would then be able to understand more and advise what to do next. It could be helpful to share the results with other health care professionals and employers for them to understand what a persons needs are.	08/12/2022 - A graph was shared via email (8/12/22) sharing topline UK data from Feb until October '22 where it had shown a significant improvement in numbers of people now having NHS support 05/09/2022 - Agreed to leave the point open as keen to see the data once analysed. 24/08/2022 - 1,670 people across Scotland have taken our My Long Covid Needs tests. It is collecting all the time and haven't had the opportunity to analyse it. Once analysed it will be shared.	Complete	08/12/2022
08/12/2022	A flier promoting the Alliance Lived Experience Network to be circulated to the group for wider dissemination	Flier sent to the group for onward dissemination through their groups and communities	Complete	15/02/2023

Date of Meeting	Topic	Discussion
05/09/2022	Lived Experience story	The story of a friend/colleague from a member of the group was shared, which was highlighted as not an untypical one. An up and down journey through Long Covid. Spending a lot of time in bed. Prior to Covid was in full-time employment and held a senior job and was sacked due to sickness with Long Covid. A single person with a house and mortgage and worried about how to cope with savings dwindling. Initially decided to sell the house and move back to England and live with her sister. Now decided to rent the house, and has spent last few months packing up the house and becoming increasingly unwell with symptoms including Postural Tachycardia Syndrome (PoTS). In the last few months obtained part time work (16hrs), and was trying to fulfill that role while packing up the house and increasingly feeling unwell. Long Covid had devastated her life. Hope health improves. It was queried whether the person received any social support. It was noted that although not fully aware, but believed the person applied for Personal Independence Payment (PIP) but unsure whether that was successful. A link to Youtube was shared which contained a montage of children from around Scotland explaining their experiences. The mum of the second child on the video posted a message on Long Covid Kids platform and it was agreed that it could be shared with this group today. "It's almost the 6th of September when our lives changed forever and my once healthy fun loving daughter became disabled and pretty much bed bound after getting covid - now a year on. POTs, headaches and extreme fatigue that allows her to whisper for a few minutes before her energy is spent. After being taken into hospital for a few weeks assessment - well she seems to be at a new baseline that her body seems unable to generate any energy. She is on propranolol, vitamins, ATP 360, an anti histamine and the pill. I'm home full time now to care for her and still fighting for the proper wheelchair and help she needs and may need down the road. Don't want to mark this one year anniversary except to mark how proud myself and my husband are of her as she has had to navigate this life altering journey. Her 16th birthday is coming up and that's another day that will be so difficult. I can't bear a second Christmas where we are all gathered while she is alone in her bed unable to cope with the noise and light. But I might just have to deal with it again. Hugs to you all going through this difficult journey. If I've learned anything it's just to get through one day at a time and try not to think of the future - I'm working on it 🙏 haven't posted for a while cos just have no news to report except #stillhere" It was emphasised that sharing the stories / case studies was something to continue with at the beginning of each meeting.
05/09/2022	Previous minutes and action tracker	Minutes signed off. within "actions" tab. Action Tracker updated
05/09/2022	Alliance - Lived Experience Network summary report discussion including a Network update	The Long Covid Launch event summary report was circulated to the group on 30th August for information. An overview was presented of the launch including an up to date position with the Network (slides attached to email of 12th October). At present, 23 people joined the Lived Experience Network and they were keen to increase that number. Not everyone with experience of Long Covid had to join the Alliance Network, one approach could be that people may already be a member of other 3rd sector organisations, and with the Alliance Network having strong relationships with other organisations, Alliance would work with them to ensure people's voices were heard. Shortly after the launch event a survey was circulated to those who attended and to different organisations to disseminate amongst their communities, to identify people's Long Covid priorities and priorities around what people want from the Lived Experience Network. The link would be shared with the group for anyone to complete. Humans of Scotland - stories were short and provide a snapshot of people's experience to raise awareness. Members of the Alliance interview people either in-person or via Teams for their stories. There was no clear framework set out for that, it was very flexible to accommodate the person telling their story, although there was guidance to follow. All the stories were shared on Alliance website and various social media platforms. Humans of Scotland have a booklet on one of the short stories on Long Covid available - should anyone wish a copy to contact Kerry and/or Olivia. That process could be transferrable across to Long Covid and could be tailored to individuals and the Humans of Scotland project could develop their current guidance to fit our scope that could be shared with people to use as a template. It was explained that no one from Long Covid Kids charity took up the offer of sharing their story with Humans of Scotland as they were essentially tired of telling their story and their only focus was on finding treatments and advocating for paediatric research to begin.
05/09/2022	Next steps - "what is our ask of the Service Planning and Clinical & Subject Matter Expert groups?"	It would be useful if the group could provide some direction as to what they want the Service Planning and Clinical groups to be considering and focussing on. Maintaining the theme from today's meeting around sharing stories, as they could provide deep clues as to what the group want e.g. from the stories told today, think if the best care possible was in place what would be the different experiences from before and after? That may help to inform both groups on what to focus on. Care Opinion was another platform for people to share their stories and experiences of health services across Scotland and with all Health Boards using it, someone from each Health Board should respond to the local query and that would show where improvements were being made as a result. Agreed to liaise with Care Opinion around next steps in creating a hashtag that everyone could use to ensure all the Long Covid stories were easily captured. Care Opinion were doing a session with Alliance's Heart Disease Network looking at the key themes from their stories and there may be learning from that to incorporate into the Long Covid Network.

08/12/2022	Lived Experience story	A voice recording of the collective feelings and experiences from members of Long Covid Scotland was shared.	
08/12/2022	Previous action note	Action note ratified by the group. within "actions" tab.	Tracker updated
08/12/2022	Summary of Lived Experience engagement approach	A framework was presented which drew together the lived experience priorities (framework attached to email of 13/12/22). Once the group agreed the approach it could be developed into a document with more detail provided. Employment, for example, is an area not directly within the remit of the Network, but it was important to be able to influence that where possible to support people. It was highlighted, that people with lived experience were not represented on the other groups within the Network and there was a feeling of disconnect between the groups. Also, not being able to be directly involved in the groups, for example, on development of educational resources for healthcare professionals. It was explained, the other 2 main working groups of the Network, the Service Planning Group had representatives from all the planners in each Health Board and the Clinical & Subject Matter Expert group had a diverse representation from those who provide the clinical advice. A meeting was being scheduled in late January to bring together service users and the Service Planning Group for a meeting in the format of a Q&A. There was also the facets/workstreams to be developed, and one was around education. In the interim, there have been meetings with NHS Education for Scotland (NES) to understand what their role would be within the Network and it was understood they were doing a scoping piece around education with NHS England. In the near future, a person with lived experience would also be invited onto the Steering Group of the Alliance Lived Experience Network. A risk to be noted and brought back at the next meeting- people with Long Covid represented in the Network, need to have the credibility to be able to influence change, so that that was recognised amongst their communities and with healthcare professionals. A further risk was that organisations representing the views of people with Long Covid would become disengaged from this group unless a representative was also invited to attend the Steering Group. CHSS was recently awarded additional funding to continue with the Long Covid advice line. The link provides more detail - https://www.gov.scot/news/boost-for-long-covid-support-hotline/	
08/12/2022	Care Opinion update	The Network agreed to move forward by encouraging people to share stories/experiences on Care Opinion. To easily collate these stories it would be useful to start those with #LongCovid. The stories and experiences would inform the Network with potential areas for improvement, or gaps to be addressed. One way to promote this hashtag was to have a postcard that could be given out at clinics and available electronically for the group to have a link on their sites. A draft postcard was presented at the meeting and would be shared for comments / amendments.	
08/12/2022	Voices Training	This had been raised in a previous meeting and was now being re-offered for anyone who would like the opportunity to receive voices training from Healthcare Improvement Scotland. It could also be extended to those involved in the Alliance Lived Experience Network for people to understand how the NHS is structured and how to work collaboratively with professionals in driving change. https://www.hisengage.scot/supporting-communities/voices-scotland-training/ . Anyone who was interested to email the Network mailbox - nss.longcovid@nhs.scot	
08/12/2022	Alliance - Lived Experience Network update	The Alliance Lived Experience Network was mapping key anchor points with one being signposting to resources and who is doing what where. Holistic wraparound support, stigma assumptions on what Long Covid is and breaking down barriers, the impact of Long Covid in terms of employability and workforce. Developing a flexible approach to engagement so that as many people as possible could get involved is key. The Network was now in a position to move forward with their identified key areas and the offer of voices training would be shared with members. Ways in which the Network was being promoted as widely as possible was through membership organisations, social media, websites and fliers. The flier would be circulated to the group for wider cascading through other networks and communities. Alliance had completed a piece of work on the cost of living crisis, not specifically for people with Long Covid but for people with Long Term Conditions. Link to the report - https://www.alliance-scotland.org.uk/blog/news/alliance-cost-of-living-report-calls-for-further-emergency-support/ . A further link to cost of Living support campaign which maybe of interest - https://costofliving.campaign.gov.scot/	
08/12/2022	AOB	On 28th November an email was circulated to the group with an invite from the UK Commission on Covid Commemoration to respond to a consultation on marking the COVID-19 pandemic, at a national and community level, which had a closing date of 5th Dec. It was hoped that everyone had the opportunity to respond to that and share within their communities.	

28/02/2023	Welcome & introductions	The group were informed Asthma & Lung UK (Joseph Carter) had stepped down from the group following a review of their Long COVID work and have decided to scale back and allow organisations like Long COVID Scotland take the lead The Lead Clinician of the Network would be in post from 1st March and a communication would be circulated at the end of the week informing the Network On 23rd Feb at Scottish Parliament - NSS Associate Director for Strategic Networks, Chair of the Strategic Oversight Board, colleagues from NES and some Health Board reps were providing evidence at the Covid-19 Recovery meeting The group agreed that a further representative from Long Covid Scotland could join the group to support Jane and/or deputise on her behalf.
28/02/2023	Lived Experience story	Thistle Foundation provided a written experience that was shared with the group. The group would be interested to have an update on the person's progress at a future meeting. A private Youtube link to a case study from Long Covid Kids was received and would be shared with the wider Network but with the caveat that it was not to be shared beyond members of the Network.
28/02/2023	Demonstration of ALISS (A local information system for Scotland)	Two reps from ALISS presented to the group (slides and additional info would be shared via email). ALISS was funded by Scottish Government and managed by Alliance. By adding groups or organisations to ALISS helps people looking for more local or national support or to get involved in community activities more easily. People can also 'claim' their organisation on ALISS to take editorial responsibility for managing the information to ensure it stays accurate and up to date. The information within ALISS.org is open data and can be freely available to anyone who wishes to copy it and display it on their own group websites. Only recently, there was now a specific category for Long Covid on ALISS and the team would encourage all the groups represented on this group if they are not already on ALISS to consider doing so and claim and share info, and for the group to raise awareness of ALISS with their members. Request our Scottish Government Policy Team to encourage organisations awarded funding by SG for Long Covid support to add their services to ALISS. Also it would be useful to have a link to ALISS from the NHS Inform Long Covid microsite as that was the NHS patient facing information platform.
28/02/2023	Actions from previous meeting	Most of the actions were updated directly on the Actions tab. Alliance highlighted that the lady whose story was on the shared link reported that she found it a very positive experience and she has shared it with colleagues and her GP which meant she didn't have to repeat her story to numerous people. Members of the group reported it would be great to gather more stories, however, there isn't much of an appetite from members of LCK, particularly, as they are so fatigued and have told their stories multiple times. Action 19 - Alliance wished to note that it was more than inviting a member to join a group/workstream of the National Network, it was about ensuring the person had wraparound support to be able to give commitment to being part of a group, but also wider engagement on groups was also required to ensure the wider views. Communications through wider communities was also challenging and need to consider different ways to do that.
28/02/2023	Draft education strategy	Comments / feedback were invited to the draft education strategy via email.
28/02/2023	Community/ group / Network updates	Time didn't allow a conversation around this. There was a request if each of the groups represented could provide a short statement / paragraph on what was happening / progressing for the whole group to have an understanding. LCK were reviewing their support guide to break that into smaller chunks with more pdfs to make it more concise for families to use and share with healthcare providers. Another focus for LCK is working on responding to the Covid Enquiry and that was the same for Long Covid Scotland.

Attendee Name	Initials	[05/09/2022] Attended Y/N	[08/12/2022] Attended Y/N	[28/02/2023] Attended Y/N
Helen Goss	HG	Y	N	Y
Rob Gowans	RG	Y	Y	Y
[REDACTED]	T	Y [REDACTED]	Y	N
[REDACTED]	T	Y	Y	N
[REDACTED]	T	Y	N	N
Davie Morrison (Chair)	DM	Y	Y	Y
[REDACTED]	[REDACTED]	Y	Y	Y
[REDACTED]	[REDACTED]			N
[REDACTED]	[REDACTED]		Y	Y
[REDACTED]	[REDACTED]	Y	Y	Y
[REDACTED]	[REDACTED]			
In attendance				
[REDACTED] (Note taker)	[REDACTED]	Y	Y	Y
Alison Gilhooly	AG		Y	Y