

Designing Long Covid support for staff: Information for participants

KeepingWell NCL staff wellbeing Hub Experience Based Co-Design Project, Autumn 2022



Designing Long Covid support for staff

Have you supported colleagues or patients with Long Covid, or experienced it yourself?

Help health and care staff like you get the support they need.

Get involved at

www.keepingwellncl.nhs.uk/longcovid-staff

North Central London
Integrated Care System



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What is an Experience Based Co-Design support project?

Experience Based Co-Design is a project that ensures that the people who are using our services are at the centre of the design process. It helps service users and practitioners to design their support together, with both groups' experience and expertise seen as equally important. This makes it an ideal method for creating support for conditions with varied experiences, such as Long Covid.

This is an adapted version of the Point of Care Foundation's Experience Based Co-Design methodology. If you would like to learn more about Experience Based Co-Design, you can [find out more via the Point of Care Foundation website.](#)

What will I be asked to do if I agree to take part?

Participating in an Experience Based Co-Design support project includes attending a discussion group to share your experience with the practitioners. During the discussion, we will ask to record the session so that we can use the recording to draw out important themes which will be anonymised. We may also ask for your consent to use a clip from the recording to put together a touch point film so that others can get a greater understanding of the issues. However your informed written permission would be sought for this with information on how the film will be used. Participants from all the discussion groups will be invited to attend a screening of the touchpoint film, and agree next steps for designing resources for supporting staff with Long Covid with the project practitioners.

The discussion groups will take place over Zoom. Participants do not need to turn their camera on unless you are comfortable to do so.

This film will be used only within the project, and the project leaders will always ask you before recording a response or sharing any part of the recording beyond the discussion groups. You can find out more about why we make this brief touchpoint film to inform our support, and how it will be used, [via the Point of Care Foundation's Experience Based Co-Design toolkit](#).

Who can participate?

We are hoping to collect data and experiences from three groups of staff with experiences of Long Covid:

1. Staff who work as part of a Long Covid service or work with Long Covid patients/ staff regularly. This includes Human Resources personnel and staff working in Occupational Health services as well as clinicians.
2. Staff in managerial roles who have staff members in their team(s) with Long Covid.
3. Health and social care staff who are currently suffering from Long Covid or who have recovered from Long Covid.

The project is open to any health and social care staff member, in any role, who lives or works in one of the boroughs of Camden, Islington, Barnet, Enfield, or Haringey. [Please visit the website for individual group dates.](#)

What will I be asked?

The discussion groups will be left open for participants to shape the discussion as they choose, based on what they feel is important. As a starting point, however, the facilitators will ask about:

1. Staff working in a Long Covid service or with Long Covid patients:
 - What challenges you feel you face working in this area
 - What are the challenges for people returning to work with Long Covid?
 - What are the gaps in knowledge, support and resources?
 - What else is needed in this area?
 - What currently works well in this area?
2. Managers supporting colleagues with Long Covid in their team(s):
 - Your experience of working with and supporting staff with Long Covid
 - Any support you may have had in your role as a manager in relation to Long Covid
 - The potential gaps in what you feel you need to support/ manage staff with Long Covid
 - What needs to happen to better support staff with Long Covid and those that are managing them?
3. Staff who have experienced or recovered from Long Covid themselves:
 - Your experience of Long Covid (any psychological, cognitive, or physical impacts it may have had)
 - Your experiences of being unable to work
 - Your return to work

- Support at work
- What are the gaps in support?
- Is there any additional support you would like to see around Long Covid support in the workplace?

What will happen to the results of the discussion group?

The discussion groups will be used to inform discussions and design of new wellbeing support for North Central London health and social care staff with a variety of experiences of Long Covid.

The touchpoint film will only be used by participants and KeepingWell Hub practitioners involved in the project, to inform their discussion and design of Long Covid support for staff. However, if the group decides that it would be useful to show all or parts of the touch point film outside of the group, if there is a clip of you used in the film we would ask your specific permission for this. If you do not want it shared the clip can be edited out.

Can I change my mind?

Yes, you can change your mind at any time and withdraw without explanation, disadvantage or consequence. If you would like to withdraw from the discussion group at any time, you can do so by contacting the Hub team at keepingwell.ncl@nhs.net. If you withdraw, your data will not be used as part of the project. Separately, you can also request to withdraw your data from being used even after you have taken part in the study, provided that this request is made within 4 weeks of the data being collected.

What will happen with my data?

Recording of the discussion groups will be securely stored by the Keeping Well NCL hub and will be destroyed once the themes have been drawn from them. Anonymized data will be securely stored by the KeepingWell NCL Hub. Any transferring of data will happen via secure NHS.net or NHS.uk email.

The only instance where confidentiality may need to be broken is when the group facilitator feels there is a risk of harm to them, the participant or others. The facilitator will inform the participant about this break in confidentiality. For the purposes of data protection, the KeepingWell NCL Hub/Tavistock and Portman NHS Foundation Trust is the Data Controller for the personal information processed as part of this project. The Hub/Tavistock processes this information under the 'public task' condition contained in the General Data Protection Regulation (GDPR). Where the Hub/Tavistock processes particularly sensitive data (known as 'special category data' in the GDPR), it does so because the processing is necessary for archiving purposes in the public interest, or scientific and historical data purposes or statistical purposes. The Hub/Tavistock will ensure that the personal data it processes is held securely and processed in accordance with the GDPR and the Data Protection Act 2018. For more information about how the Hub/Tavistock processes personal data please visit <https://tavistockandportman.nhs.uk/about-us/contact-us/about-this-website/your-privacy/>.

How can I sign up to participate?

To participate in the project, please visit www.keepingwellncl.nhs.uk/longcovid-staff and sign up to one of our initial discussion groups via the Eventbrite checkout.

Please ensure that you only sign up to one discussion group (choose the group you most associate with), and that you will also be available to participate in the cross-group screening and discussion session. [Please visit the website for all the session dates.](#)

Contact us

If you have any questions regarding participating in the project, please contact our team [via the health chat on our website](#), or email us at keepingwell.ncl@nhs.uk.