**Privacy statement and participant information sheet for the Long Covid Lived Experience disengagement from services online engagement sessions.**

**About the disengagement from services research and engagement work.**

The ALLIANCE, in partnership with NHS National Services Scotland (NSS), are engaging in research around why people in Scotland who are living with Long Covid are disengaging from healthcare and support services.

We are looking to engage with adults who are living with Long Covid, or supporting someone living with Long Covid, to give their views on service disengagement through discussion at an online engagement session.

The online sessions will be held via Zoom.

This is to support NSS, and other third sector organisations, to include the perspective and feedback from people with lived experience of Long Covid in their service provisions, and to re-engage people in their services.

Information collected from these sessions will be used to create a report which will be shared directly with NSS, and published on the ALLIANCE website and social media channels. All information will be we will not attribute any information to specific individuals and remove identifiable information within the survey.

If you have any further questions, or require further information, please contact Olivia Friend-Spencer at [longcovid@alliance-scotland.org.uk](mailto:longcovid@alliance-scotland.org.uk) or on 0141 404 0231.

**How you can get involved?**

If you wish to attend the session, please email [longcovid@alliance-scotland.org.uk](mailto:longcovid@alliance-scotland.org.uk) to sign up or request more information.

**What Personal [and special category] Information do we need from you?**

If you consent to take part, Health and Social Care Alliance Scotland (the ALLIANCE) will require the following information, to sign you up to the event:

* Your name
* Your email address

During the session you will be asked for the following information via a set of discussion questions:

We will ask:

* Whether you or someone you care for has experienced Long Covid
* Whether you or someone you care for has accessed healthcare services for their Long Covid symptoms
* Your experiences of healthcare services (including Long Covid specific services)
* How long you, or someone you care for, have had symptoms of Long Covid

We will not directly ask for the following information, but you will be able to share this if you wish:

* Your age
* Your Health Board area
* Your gender identity
* Your ethnic group

The level of detail you provide is entirely up to you. There is the option not to speak or respond to questions, as well as the option to keep your camera off for the duration of the session.

**What happens with the information in the project?**

The information provided during these sessions will be recorded through notetaking, and the information will be used to inform a report on the reasons and feedback for why adults in Scotland living with Long Covid are disengaging from services, which will be shared with NSS and on the ALLIANCE website and social media channels.

Information will not be attributed to an individual, and we will not attribute any information to specific individuals and remove identifiable information in the final report.

The ALLIANCE may use the findings in other relevant reports, publications and on social media

**How the information will be used?**

The findings of the survey will be published in a report on the ALLIANCE website and social media channels, which will be used to inform public policy discussions and the development of Long Covid services. These will be shared with NSS.

The reports will not include personally identifiable information or detail about individual cases. You may request a copy of these reports by contacting [longcovid@alliance-scotland.org.uk](mailto:longcovid@alliance-scotland.org.uk) or by visiting the ALLIANCE website once published.

**How will we contact you?**

We will generally contact you by e-mail unless you have stated a different preferred method of contact.

**With Whom will the information be shared including transfer of data to a third country or internationally**

The final published report will be shared via social media and the ALLIANCE website are international platforms that will result in the information being transferred overseas.

The ALLIANCE will be using Zoom to host the engagement sessions. Should you register to attend you must be aware that Zoom.us transfers personal data to the USA and that any personal data you choose to share will be transferred to a country that does not provide adequate protection and that no adequate safeguards aimed at providing protection for the data are being implemented.

**Retention of Data**

Published data will be shared worldwide and retained permanently.

The ALLIANCE will keep the notes from the sessions for two years from the publication of the ALLIANCE report. Any meeting chat recorded by Zoom will be deleted from the platform after one year.

**What are the potential risks to you in taking part?**

We aim to minimise any risk to participants, but you should be aware of the following risk factors:

* Risk of participants being unsettled by questions asked about their personal lives and health conditions.
* Confidentiality cannot always be guaranteed in a group setting because other participants may discuss what they have heard. However, the expectation for all focus group members is that confidentiality should be upheld and we ask all participants to adhere to this.
* Zoom.us transfers personal data to the USA and that any personal data you choose to share will be transferred to a country that does not provide adequate protection and that no adequate safeguards aimed at providing protection for the data are being implemented.

**Your rights**

You have the right to withdraw your consent at any time. However, you must note that should you withdraw your consent after information is published on the ALLIANCE website and social media channels, the ALLIANCE will only be able to stop using the information in future reports etc. The ALLIANCE can withdraw information from where it was posted on the internet but will not be able to control how others have used this. We will not be able to remove information already included in statistical information that is no longer identifiable.

You also have the right to object to how we process your personal information, the right to access, correct, sometimes delete and restrict the personal and special category personal information we use. Together with the right to receive your information in a machine-readable format for transfer to another organisation and not to be subject to a decision based solely on automated processing, including profiling.

**Data Protection**

The ALLIANCE and its sub-contractors will not distribute or disclose your personal information to third parties unless we have your written permission or are required by law to do so. We comply with the Data Protection Act 2018 and GDPR 2018 when handling your personal information. If you have any concerns about how we use your personal information, contact DPO at: DPO@alliance-scotland.org.uk. Alternatively, you have the right to complain to the ICO https://ico.org.uk/concerns/

For our full [privacy policy](file:///C:\Users\susan.young\AppData\Local\Microsoft\Windows\INetCache\Content.Outlook\73HK5DWN\Privacy%20Policy%20updated%20DRAFT%20ONLY.docx), please visit our website.

By participating you are consenting to us processing your personal and special category personal information for the above purposes, which is our legal basis for processing your personal information.

**Consent**

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