Special Conditions for: NEON Collection

This document describes the Special Conditions for sharing data from the NEON Collection, including selected narratives and associated INCRESE characteristics.

Dataset provider: until the end of the NEON Programme (currently 31.3.23) data will be provided by the NEON Study team.

Overview

The NEON Collection is a managed collection of mental health recovery narratives (hereafter 'narratives'). Each narrative has been donated either by an individual narrator or as part of a narrative collection which had obtained the original narrators' permission for wider use. In the NEON Collection we have (as at July 2021) 610 narratives. Each narrative has been characterised by researchers using the Inventory to Characterize Recorded Mental Health Recovery Narratives (INCRESE). Details of INCRESE are available here. Principles of our internal management procedures for the NEON Collection have been published here. Important elements of our current management procedures for the NEON Collection are summarised here, where they continue to evolve with experience.

The NEON study Chief Investigator (details here), on behalf of the study sponsor, would like to make selected narratives from the NEON Collection and their associated INCRESE characteristics available for secondary analysis outside of the NEON study. This document specifies data access requirements (the "Special Conditions") for data sharing, and identifies the principles that have underpinned them. People requesting access to these data items will also have to sign a NEON dataset license provided separately.

Principles informing data access requirements

Two ethical principles have informed our data access requirements.

Principle 1. To ensure no narrative is shared by us without appropriate consent from the narrator

When we receive a donation of a narrative to the NEON Collection, we also request consent for the wider use of the narrative "*in research activities outside of the NEON study*". This consent is optional, and consent can be given for use of the narrative in the NEON Collection but not for wider use. We will only consider sharing narratives in the NEON Collection for which we have consent for wider use. We requested this optional consent specifically in relation to research, rather than other possible uses such as clinical or educational, because each possible use may raise different issues for narrators.

Principle 2. To ensure all narratives in the NEON Collection are respected, valued and not misused

We have put considerable effort into ensuring that the NEON Collection is respectfully managed and that narratives are not misused. Our Lived Experience Advisory Panel have produced a guide to support people considering telling their story (here), our VOICES framework for curation issues is here, and some of our other papers about ethically managing narrative collections are here, here, here and here. One important ethical issue is identifiability. Some narrators actively wish to be identified in their narrative, some actively wish to not be identified, and some do not specify.

Data access requirements

Data access requirement 1: Your request for access must be solely and specifically for non-commercial research use that does not involve the use of narratives shared by us in an intervention. Other uses, such as for clinical, education or marketing purposes, are not permitted.

By "non-commercial research" we mean research that is not primarily intended for, or directed towards, commercial advantage by an individual or organisation. By "an intervention" we mean any mechanism by which a research participant obtains access to narratives in the NEON Collection, either in electronic or printed form.

If you would like to propose the use of narratives for commercial or intervention research purposes, or if you are in doubt whether your plans constitute commercial or intervention research, please contact us here to discuss your proposal.

Data access requirement 2: All reports need to ensure narrators and narratives cannot be identified from any information reported

We have not collected consent to provide public access to narratives, and hence narratives supplied by us should not be placed into the public domain. Where details from narratives are reported, we require complete (sometimes called 'destructive') anonymisation in all reporting, to ensure that narratives or narrators are not identifiable. Many narratives in the NEON Collection have been placed in the public domain by their narrators, or may be placed into the public domain by the narrator in the future. People reading your work might deliberately try to identify narrators or narratives from it, and so you should test your reporting to ensure that it is not possible for narrators or narratives to be identified. Methods such as "composite narratives" (details here) might be appropriate to use for complete anonymisation, if applied with sufficient care that narrators and narratives cannot be identified from the composite narrative.

Data access requirement 3: All reporting about narratives in the NEON Collection should be respectful, avoiding commodification and be focussed on the research question of interest.

Researchers can forget that stories are not just data but are about the experience of real people. Examples of commodification include the use of narratives to meet organisational needs such as promoting a programme or service, or presenting unnecessarily detailed accounts of suffering or intimate personal details which could be used for voyeuristic purposes. (To learn more about this issue, we recommend this paper.)

Data access requirement 4: As a minimum, there must be meaningful involvement of people with personal experience of mental health issues (who may or may not also be researchers) in reviewing the planned presentation of findings.

We have found that the best approach to avoiding the issue of commodification is meaningful involvement of people with lived experience of mental health issues. In NEON we address this by ensuring our research team includes people who have both research expertise and lived experience (as described here). Additionally, there is active involvement of a Lived Experience Advisory Panel (LEAP) in the NEON Study, who are co-authors on nearly all papers. An alternative approach is to consult with a mental health service user group, providing this is a meaningful consultation, i.e. where the presentation of findings may change as a result. The ideal might be that research is co-produced with people with lived experience of mental health problems. Whilst co-production has a range of meanings, the Mental Health Foundation's description of their approach to research (here) is a useful reference.

Data access requirement 5: INCRESE characteristics can only be published in aggregated form which does not allow the coding of individual narratives to be identified.

Each narrative in the NEON Collection is characterised using INCRESE, which is used to summarise specific narrator and narrative characteristics. It is not used to judge the quality or value of a narrative. INCRESE is described and downloadable here, and our paper outlining how we have addressed the ethical issues involved in characterising narratives is here. Although producing summaries makes it more possible for researchers to learn from the narratives, we recognise the significant harm that might arise for narrators in feeling judged or rated by any characterisation of their story.

Data access requirement 6: On request from the sponsor (Nottinghamshire Healthcare NHS Foundation Trust) you will delete a specific narrative and associated INCRESE characteristics, and where possible (e.g. if informed prior to submission for publication) not include that data in your research findings.

We give all narrators the ongoing option to withdraw their narrative from the NEON Collection. If a narrator exercises this option then we will delete their narrative and associated INCRESE characteristics from the NEON Collection, and we will contact all research groups who have been given access to the NEON Collection to request deletion of their details.

Data access requirement 7: Narrators wishing to withdraw narratives should be directed to contact the Research and Evidence team at Nottinghamshire Healthcare NHS Foundation Trust

The Research and Evidence team will always maintain records of how to withdraw narratives from the NEON Collection. If you create a public web-page describing your work with NEON Collection data, you should include a paragraph indicating that people wishing to withdraw their narrative from the NEON Collection should contact the Research and Evidence team through Research@nottshc.nhs.uk. If you are contacted by a person who believes that their narrative has been included in the NEON Collection and who wishes to withdraw their narrative, then you should direct that person to submit a withdrawal request to Research@nottshc.nhs.uk.

Data access requirement 8: All data we supply will be held securely by you and not distributed more widely.

You must ensure appropriate data management arrangements to ensure data security, including that you do not make narratives or INCRESE characteristics accessible through online search engines such as Google. You may not distribute the narratives or INCRESE characteristics beyond the research unit specified in the Data Access Agreement that you have signed.

Data access requirement 9: All data we supply must be acknowledged in reporting

If you use narratives from the NEON Collection in a publication, any report must cite this paper:

> Slade M, Rennick-Egglestone S, Llewellyn-Beardsley J, Yeo C, Roe J, Bailey S, Smith R, Booth S, Harrison J, Bhogal A, Moran P, Hui A, Quadri D, Robinson C, Smuk M, Farkas M, Davidson L, van der Krieke L, Slade E, Bond C, Nicholson J, Grundy A, Charles A, Hare-Duke L, Pollock K, Ng F (2021) Recorded Mental Health Recovery Narratives as a Resource for People Affected by Mental Health Problems: Development of the Narrative Experiences Online (NEON) Intervention, JMIR Formative Research, 5, e24417.

and, if allowed by the journal, include this statement in the Acknowledgements:

> This [document|report|publication] draws on narratives contained in the NEON Collection, as described at: https://www.researchintorecovery.com/research/neon/neoncollection, which was developed in research funded by the NIHR under its Programme Grants for Applied Research Programme (Programme Grants for Applied Research, Personal experience as a recovery resource in psychosis: Narrative Experiences Online (NEON) Programme, RP-PG-0615-20016). Details of how to donate your narrative to NEON can be found on the NEON Collection web-page, and also at https://www.researchintorecovery.com/donateastory/.

If you use INCRESE characteristics in a publication, your report must cite this paper:

> Llewellyn-Beardsley J, Barbic S, Rennick-Egglestone S, Ng F, Roe J, Hui A, Franklin D, Deakin E, Hare-Duke L, Slade M (2020) INCRESE: Development of an Inventory to Characterize Recorded Mental Health Recovery Narratives, Journal of Recovery in Mental Health, 3, 25-44.

Data access requirement 10: NEON study researchers involved in the development of the NEON Collection should be acknowledged in resulting publications.

This is in keeping with recommendations on authorship published by the ICJME here, as NEON study researchers have made a substantial contribution to the acquisition of narratives. When the publication is being developed, please liaise with the NEON team to discuss the appropriate balance of co-authorship and acknowledgements of NEON study researchers to include.

Data access requirement 11: Limitations in the diversity of the NEON Collection should be acknowledged in reports using NEON Collection narratives and/or INCRESE characteristics.

Whilst we have tried to create a collection that is diverse (for example by identifying areas in earlier versions of the collection lacked diversity, and actively seeking the donation of narratives to increase diversity), researchers working with the collection should be aware that there may be groups of narrators who are not

represented in the collection, and should acknowledge this constraint in their reports, for example by including a statement or a table summarising INCRESE characteristics.

Signatures

The NEON Chief Investigator confirms these Special Conditions are appropriate for the dataset described.

Signature: Date: 4.8.22

I am requesting access to the data described, and confirm that I agree to these Special Conditions.

Name:	Email address:
Organisation:	Role in organisation
Signature:	Date: