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Extended Research Article

Recorded mental health recovery narratives for people with mental health problems and informal carers: the NEON research programme including 3 RCTs

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Abstract

Background: Personal narratives describing recovery from mental health problems are widely available to the public. We developed theory on the characteristics and impact of recovery narratives, developed curation procedures for the NEON Collection of 659 recovery narratives and developed and evaluated the NEON Intervention, a theory-informed web application providing access to the NEON Collection.

Objectives: To evaluate the effectiveness and cost-effectiveness of the NEON Intervention as compared to usual care and whether this varies by prior health service usage.

Design: Three pragmatic parallel-group randomised controlled trials of the NEON Intervention. Intervention arm participants received immediate access. Control arm participants received access after a 52-week follow-up. The effectiveness analysis was a linear regression model of outcome at 52 weeks. The cost-effectiveness analysis compared the incremental cost-effectiveness ratio to the £20,000–30,000 threshold defined in the National Institute for Health and Care Excellence reference case. All analyses were intention-to-treat and baseline-adjusted, with multiple imputation for missing data.

Setting: England.

Participants: All trials recruited people who were aged 18+ years, resident in England, capable of accessing or being supported to access the internet, able to understand written and spoken English and capable of providing online informed consent. NEON Trial participants also had experience of mental health-related distress in the last 6 months, and psychosis in the previous 5 years. NEON-O (i.e. non-psychosis) Trial participants also had experience of mental health-related distress in the last 6 months, but with no psychosis in the previous 5 years. People identifying as informal carers for people affected by mental health problems but not eligible for the NEON Trial or NEON-O Trial were recruited to the NEON-C feasibility trial. All inclusion criteria were self-rated. Recruitment was from March 2020 to March 2021, through public communications by the central study team, and the work of clinical support officers at 11 secondary care research sites.

Interventions: The NEON Intervention has four narrative access mechanisms: theory-informed algorithmic recommendation, random selection, self-selection by narrative category and return to impactful narratives. Participants used the NEON Intervention as much as they wished.

Main outcome measures: Primary outcome: quality of life (Manchester Short Assessment). Secondary outcomes: distress, hope, self-efficacy, meaning in life and health status.

Results: For the NEON-O (i.e. non-psychosis) Trial, we found a significant baseline-adjusted difference of 0.13 (95% confidence interval 0.01 to 0.26, $p = 0.041$) in the Manchester Short Assessment score between intervention and control, and a significant baseline-adjusted difference of 0.22 (95% confidence interval 0.05 to 0.40, $p = 0.014$) in the presence subscale of the Meaning in Life Questionnaire. The incremental cost-effectiveness ratio was £12,526 per quality-adjusted life-year, lower than a threshold of £30,000 per quality-adjusted life-year used for health service commissioning in England. For participants who had used specialist mental health services at baseline, the intervention appeared to reduce cost, although confidence intervals were wide and results were not statistically significant (–£98, 95% credible interval –£606 to £309). It also improved quality-adjusted life-years (0.0165, 95% credible interval 0.0057 to 0.0273) per participant. Hence, for this subgroup of participants, it dominated usual care.

For the NEON Trial, no significant baseline-adjusted differences in outcome were found. An incremental cost-effectiveness ratio of £110,501 was found for the NEON Intervention. A subgroup analysis provided preliminary evidence for greater cost-effectiveness for current mental health service users, with an incremental cost-effectiveness ratio of £35,013. The NEON-C Trial showed acceptability and feasibility for informal carers. It recommended integration of carer narratives and creation of an online carer community.

Limitations: Participants were recruited during a period in which movement and social interaction were widely affected by the COVID-19 pandemic, with the potential to influence generalisability. For the NEON-O Trial, we had an unrepresentative proportion of female-gendered participants (79.3%). Therefore, our NEON-O Trial findings cannot be generalised.

Conclusions: This research programme has shown promising findings from the testing of the NEON Intervention. There is further research to do before implementation can be suggested.

Future work: The NEON Intervention should be evaluated through a randomised controlled trial with people experiencing psychosis and using mental health services. The NEON Intervention should be refined to suit the needs of carers and then evaluated through a randomised controlled trial. The NEON-O Trial should be repeated with narrower mental health populations (e.g. mood disorders, eating disorders) to refine knowledge on effectiveness and cost-effectiveness. This may include refining the narrative collection used with these populations. If the NEON Intervention is implemented on a larger scale for people with non-psychosis mental health problems, then studies should be conducted to monitor benefits, continuously assess safety and documentation implementation processes. Future studies should consider alternative forms for presenting recovery narratives, including through multilanguage or multiculture support, and addressing digital exclusion by providing access through widely available technologies, such as smartphones and text messaging. Longitudinal designs are needed to document the short-term, medium-term and long-term impacts of recovery narratives.

Trial registration: This trial is registered as NEON Trial ISRCTN11152837, NEON-O Trial ISRCTN63197153 and NEON-C Trial ISRCTN76355273.

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List of abbreviations

CHIME	Connectedness, Hope, Identity, Meaning and Empowerment
CORE-10	Clinical Outcomes in Routine Evaluation 10
CrI	credible interval
CRN	Clinical Research Network
CSG	Collection Steering Group
CSRI	Client Service Receipt Inventory
ENMESH	European Network for Mental Health Service Evaluation
EQ-5D-3L	EuroQol-5 Dimensions, three-level version
EQ-5D-5L	EuroQol-5 Dimensions, five-level version
HRA	Health Research Authority
ICC	intraclass correlation coefficient
ICER	incremental cost-effectiveness ratio
INCRESE	Inventory of the Characteristics of Recovery Stories
ITT	intention to treat
LEAP	Lived Experience Advisory Panel
MANSA	Manchester Short Assessment
MAR	missing at random
MICE	multiple imputation by chained equations
NEON	Narrative Experiences Online
NEON-C	NEON for Carers
NEON-O	NEON for Other (i.e. non-psychosis mental health)
NIHR	National Institute for Health and Care Research
PCTU	Pragmatic Clinical Trials Unit
PIS	participant information sheet
PMC	PubMed Central
PPI	patient and public involvement
PSC	Programme Steering Committee
QALY	quality-adjusted life-year
QoL	quality of life
RCT	randomised controlled trial
REC	Research Ethics Committee
RNCF	Recovery Narratives Conceptual Framework
TMG	Trial Management Group
UC	usual care
VOICES	Values and motivations; Organisation; Inclusion and exclusion; Control and collaboration; Ethics and legal; Safety and well-being
WP	work package

Plain language summary

People often share their experiences of mental health problems and recovery, for example, by publishing autobiographies or online videos. Personal accounts of mental health recovery are therefore widely available. We call these accounts 'recovery narratives'.

Individuals living with mental health problems have described how recovery narratives from others can be helpful. Similarly, healthcare professionals have described how people using mental health services can benefit from recovery narratives. However, we do not know enough about how recovery narratives have an impact on people with mental health problems.

In the NEON study, we created a database of 659 recovery narratives. This included working with international collections of recovery narratives to gain consent to use these narratives, including OC87 Recovery Diaries (United States of America), Here to Help (Canada) and with a broad range of United Kingdom-based individuals and collections. We then created the NEON Intervention, an online web application to give access to these narratives. The design of the NEON Intervention was based on studies we conducted to find out how recovery narratives make an impact. We included safety features, such as warnings about potentially distressing forms of content.

We then evaluated the NEON Intervention in two studies involving 1762 people with mental health problems. The NEON Trial included only people who had experienced psychosis in the previous 5 years, and the NEON-O (i.e. non-psychosis) Trial included people with any other type of mental health problem, such as depression or anxiety.

In the NEON-O Trial, we found that the NEON Intervention improved people's quality of life and their perception that their life has meaning. In the NEON Trial, we did not find a benefit for everyone, but we did find some evidence that people with psychosis who are currently using mental health services may benefit.

Scientific summary

Background

Personal narratives describing recovery from mental health problems are widely available to the public, even for the most stigmatised mental health problems. The Narrative Experiences Online (NEON) study was funded by the National Institute for Health and Care Research (NIHR) from 2017 to 2023. It used a mixed-methods approach to evaluate whether having online access to recorded recovery narratives is helpful for people affected by mental health problems.

Objectives

1. To describe the characteristics of recovery narratives.
2. To describe the benefits and harms of receiving recovery narratives.
3. To describe the role of curators in creating collections of recovery narratives.
4. To develop a curated collection of recovery narratives.
5. To develop a web-based intervention providing access to this collection.
6. To evaluate the intervention with people experiencing mental health problems.
7. To evaluate the feasibility and acceptability of a trial with informal carers.
8. To evaluate opportunities and challenge for clinical implementation.

Objective 1: characteristics of recovery narratives

Methods

We developed the Recovery Narratives Conceptual Framework (RNCF). Our work began with a systematic review of empirical research studies (PROSPERO CRD42018090188). Recovery narratives were defined as first-person lived experience accounts of recovery from mental health problems, which refer to events or actions over a period of time, and which include elements of both adversity/struggle and of self-defined strengths/successes/survival. Recovery narrative characteristics described in included papers were synthesised.

We conducted 80 narrative interviews with participants under-represented in recovery narratives research. Our topic guide invited participants to share their recovery narrative, with questions on factors influencing its telling. We validated and extended the RNCF by conducting a structural narrative analysis. We then documented influences on the telling of narratives through a reflexive thematic analysis and a performative narrative analysis.

Results

The RNCF was organised into nine dimensions: genre, positioning relative to mental health services, emotional tone, relationship with recovery, trajectory, use of turning points, narrative sections, protagonists and use of metaphors. Our reflexive thematic analysis found questions of power were central to how collected narratives were told. Our performative narrative analysis documented the influence of the research process on participant narratives.

Objective 2: benefits and harms of receiving recovery narratives

Methods

We developed the NEON Impact Model. Our work began with a systematic review (PROSPERO CRD42018090923) to identify forms and processes of impact. Searches used electronic databases (n = 9), reference tracking, hand-searching of selected journals (n = 2), grey literature searching and expert consultation (n = 7). Findings were validated and extended through thematic analysis of our narrative interviews. In an experimental study, mental health service users (SUs) were shown recovery narratives, quantified immediate impact and described how it occurred. We modelled the

causal chain through a qualitative interview analysis and integrated all findings to produce the NEON Impact Model. In a clinical study, mental health SUs accessed narratives through an intervention prototype for a month and quantified immediate impact. We identified predictors of immediate impact in the experimental and clinical studies using a multilevel mixed-effects model.

Results

The NEON Impact Model characterises the positive impact of receiving recorded mental health recovery narratives on health-related quality of life (QoL) through improved hope, connectedness, empowerment, greater meaning in life, positive emotional release, emulation of helpful narrative behaviours, initiation of help-seeking behaviours. The model also describes harmful outcomes which reduce QoL: inadequacy, disconnection, pessimism, burden, negative emotional release, emulation of harmful narrator behaviours and despair. Mechanisms of connection were (1) comparison with the narrative/narrator, (2) learning about other's experiences and (3) experiencing empathy. Recovery status, gender and ethnicity were moderating narrative characteristics; gender and ethnicity were moderating recipient characteristics; and matches between characteristics were shown to have significant effects.

Objective 3: the role of curators in creating collections of recovery narratives

Methods

We developed a typology of curatorial decisions for recovery narrative collections. Our work began with a systematic review (PROSPERO CRD42018086997). Empirical studies were identified from bibliographic databases (n = 13), journals indexes (n = 3) and grey literature repositories (n = 4). Documents describing decisions were identified from book prefaces (n = 53) and web-based narrative collections (n = 50). We conducted a qualitative evidence synthesis, extended through an interview study with curators. These studies raised concerns about recovery narratives misuse, so we conducted a further systematic review (PROSPERO CRD42021229458). Documents were identified from bibliographic databases (n = 11), from subject-specific websites and activist literature, and through citation tracking and expert consultation. Uses and misuses of recovery narratives were synthesised.

Results

Our VOICES (Values and motivations; Organisation; Inclusion and exclusion; Control and collaboration; Ethics and legal; Safety and well-being) typology identifies six categories of curatorial decision: values and motivations, organisation, inclusion and exclusion, control and collaboration, ethics and legal and safety and well-being. Collection organiser motivations included fighting stigma, educating about recovery, critiquing psychiatry, influencing narrative inclusion, content editing, withdrawal rights and anonymisation.

Twenty-seven narrative uses were identified in five categories: political, societal, community, service level and individual. Misuses included co-option of narratives, unethical editing practises, coercion of narrators and triggering of distress in recipients.

Objective 4: to develop a curated collection of recovery narratives

Methods

We developed the 77-item *Inventory of the Characteristics of Recovery Stories* (INCRESE). Four coders rated 95 narratives using INCRESE, to investigate feasibility and acceptability, intercoder reliability using Fleiss's kappa coefficient (κ) and test–retest reliability using intraclass correlation coefficients (ICCs).

We developed a protocol describing principles and procedures for the NEON Collection, with professional and lived experience advice on critical issues, such as inclusion criteria, approaches to anonymisation and narrator withdrawal rights. Procedures were initially iterated through assembling a collection of 100 recovery narratives. As changes ceased, we analysed process documentation to enumerate decisions and rationales.

Results

The INCRESE items spanned five sections: narrative eligibility, narrative mode, narrator characteristics, narrative characteristics and narrative content. In the reliability assessment, no floor or ceiling effects were found, intercoder reliability ranged from moderate (κ = 0.58) to perfect agreement (κ = 1.00) and test–retest reliability ranged from moderate (ICC = 0.57) to complete agreement (ICC = 1.00). Coder well-being was identified as a support need.

We adopted decisions setting a distinctive direction for the NEON Collection, including never editing or anonymising narratives, and allowing narrator updates. Reasons for exclusion included hate speech, graphic descriptions of harmful behaviours or sharing sensitive third-party unpublished personal information. We assembled 659 narratives from existing collections and through donations, all with narrator/curator consent and characterised using INCRESE.

Objective 5: to develop a web-based intervention using the Narrative Experiences Online Collection

Methods

The NEON proposal specified a web-based intervention with four narrative access routes: algorithmic recommendation, random selection, category-based browsing and return to previous narratives. To operationalise this, we selected a hybrid recommendation approach that combined narrative predictions from one content-based filtering algorithm [k-Nearest Neighbour (kNN)] and two collaborative filtering algorithms [Singular Value Decomposition (SVD), SVD++], used INCRESE items as categories and identified harm-minimisation strategies with lived experience and academic advice. In our feasibility evaluation, mental health SUs received access to the NEON Intervention for 1 month, with entry and exit interviews. Candidate improvements were organised by NEON Intervention feature and implementation decisions made.

Results

We adopted seven harm minimisation strategies: (1) describing known harms on the participant information sheet; (2) asking participants for preferred distress management strategies; (3) providing a distress page integrating reminders of preferred strategies, self-management resources and signposting to services; (4) the inclusion of researcher-rated content warnings for narratives; (5) enabling the proactive blocking of narratives by content warning category; (6) enabling the reactive blocking of individual narratives; and (7) a button for rapid exit.

Feasibility study feedback was broadly positive. Small changes were made, for example, providing clarity that trial outcome data were not used by the recommender system. Response rates to five online questions on immediate narrative impact were low, so they were adjusted, with only one question on hopefulness remaining mandatory. Mean number of narratives accessed was 9.2, lower than anticipated, so we added strategies to enhance engagement.

Objective 6: to evaluate the intervention with people experiencing mental health problems

Methods

We conducted two definitive trials of the NEON Intervention to evaluate effectiveness and cost-effectiveness for people with self-identified mental health problems. The NEON Trial (n = 739, ISRCTN11152837) included people with recent psychosis experience. The NEON for Other (i.e. non-psychosis mental health) (NEON-O) Trial (n = 1023, ISRCTN63197153) included people with mental health problems but no recent psychosis experience. All trial procedures were conducted online. Recruitment opened in March 2020 and closed in March 2021. Participants were recruited nationally in England by the central study team and 11 research sites. Participants completed baseline online questionnaires, to collect demographic, clinical outcome and health service use data, and were randomised to receive immediate or 52-week delayed access to the NEON Intervention. All participants completed the same online questionnaires at 52-week follow-up. The primary outcome was QoL measured using the Manchester Short Assessment (MANSA). Secondary outcomes were distress, hope, self-efficacy, meaning in life and health status. The primary analysis of effectiveness was a linear regression model of outcome at a 52-week follow-up adjusting for baseline score, with

multiple imputation for missing data. Cost-effectiveness was investigated from the perspective of the NHS in England, rather than the 'NHS and personal social services' perspective as recommended by National Institute for Health and Care Excellence reference case. We estimated an incremental cost-effectiveness ratio (ICER), which was compared to established thresholds of £20,000 and £30,000. UK-based unit costs were used to estimate health services resource allocation, NEON Intervention delivery costs were estimated from study records and quality-adjusted life-years (QALYs) were calculated from health status data. Baseline data analysis found significant demographic and clinical differences between participants who had used and not used specialist mental health services, so we examined effectiveness and cost-effectiveness for subgroups defined on service use history. Process evaluation interviews were conducted with participants in the NEON Trial (n = 30) and the NEON-O Trial (n = 24) and thematically analysed. To evaluate our algorithmic recommendation approach system, we used narrative request and feedback data to compare the accuracy, precision, diversity, coverage and unfairness of the three filtering algorithms.

Results

For the NEON-O Trial, we found a significant baseline-adjusted difference of 0.13 [95% confidence interval (CI) 0.01 to 0.26, p = 0.041] in the MANSA score between intervention and control, and a significant baseline-adjusted difference of 0.22 (95% CI 0.05 to 0.40, p = 0.014) on the 'presence of meaning' subscale of the Meaning in Life Questionnaire. We found an incremental gain of 0.0142 QALYs [95% credible interval (CrI) 0.0059 to 0.0226] and a £178 incremental increase in cost (95% CrI −£154 to £455) per participant, generating an ICER of £12,526 per QALY. For participants who had used specialist mental health services at baseline, the intervention reduced cost (−£98, 95% CrI −£606 to £309) and improved QALYs (0.0165, 95% CrI 0.0057 to 0.0273) per participant, and hence dominated usual care (UC).

For the NEON Trial, no significant baseline-adjusted differences in outcome were found, and the ICER (£110,501) was above the threshold for cost-effectiveness. Our findings do not support the use of the NEON Intervention as a population-level intervention for all people with psychosis experience. A subgroup analysis provided preliminary evidence that the NEON Intervention was more cost-effective for current mental health SUs, with an estimated ICER of £35,013. Further evaluation of the NEON Intervention with people experiencing psychosis and using mental health services is indicated.

Our process evaluation documented how the NEON Intervention was integrated into daily life, and perceptions of the NEON Intervention influenced usage. Our selected algorithms performed better than random choice of narrative, and our analysis provided preliminary evidence for an association between clinical population and recommendation performance.

Objective 7: to evaluate the feasibility and acceptability of a trial with informal carers

Methods

The NEON for Carers (NEON-C) feasibility trial (n = 54, ISRCTN76355273) used the same integrated web application as our definitive trials to evaluate the feasibility of a definitive trial with informal carers for people experiencing mental health problems. Procedures were as for our definitive trials. We conducted process evaluation interviews. Our analysis identified parameters relevant to definitive trial planning and identified necessary NEON Intervention modifications for carer relevance.

Results

We found a small effect on hope (Cohen's d = 0.14), a moderate effect on the presence of meaning in life (Cohen's d = 0.31) and a moderate effect on the search for meaning in life (Cohen's d = −0.33). These are candidate primary outcomes for a definitive trial. Modifications included the inclusion of carer perspective narratives, signposting to carer support services and consideration of privacy issues, for example, around the identifiability of carers in narratives accessed by people they care for.

Objective 8: to evaluate opportunities and challenges for clinical implementation

Methods

We conducted three phases of focus groups with mental health clinicians, investigating current and possible uses of recorded recovery narratives in clinical practice (n = 25), specific clinical perspectives on the NEON Intervention (n = 15) and clinical education uses of recovery narrative (n = 12). Thematic analysis was conducted.

Results

Recorded recovery narratives can reinforce the effectiveness of clinical practices, including by reducing communication barriers. They might extend clinical practice, including as an alternative when clients have become 'stuck'. Potential barriers included patient capacity to use online resources, accessibility of language, risk considerations (content triggering distress, staff skills to respond), trust in the intervention, the cost of provision and the capability of NHS information and technology systems to enable access. There were educational opportunities to enable access to lived experience perspectives, to train non-clinical staff and to facilitate attitudinal change.

Recommendations for research

1. The benefits of deploying the NEON Intervention on a larger scale as a population-level low-intensity self-management intervention for people with non-psychosis mental health problems should be evaluated.
2. An evaluation of the NEON Intervention with current mental health SUs with psychosis is justified by the evidence.
3. The NEON-O Trial should be repeated with narrower populations, to develop more specific knowledge on impact.
4. Future studies should consider alternative forms for presenting recovery narratives, including through multilanguage or multiculture support, and addressing digital exclusion by providing access through widely available technologies, such as smartphones and text messaging.
5. Longitudinal designs are needed to document the short-term, medium-term and long-term impacts of recovery narratives.

Implications for health care

This research programme has shown promising findings from the testing of the NEON Intervention. However, in our economic analysis, differences in QALYs were either small or not statistically significant. There is further research to do before implementation can be suggested.

Trial registration

This trial is registered as NEON Trial ISRCTN11152837, NEON-O Trial ISRCTN63197153 and NEON-C Trial ISRCTN76355273.

Funding

This award was funded by the National Institute for Health and Care Research (NIHR) Programme Grants for Applied Research programme (NIHR award ref.: RP-PG-0615-20016) and is published in full in Programme Grants for Applied Research; Vol. 13, No. 9. See the NIHR Funding and Awards website for further award information.

Synopsis

Overview of the programme

Introduction

Mental health recovery narratives (henceforth recovery narratives) have been defined as first-person lived experience accounts of recovery from mental health problems, which refer to events or actions over a period of time, and which include elements of adversity or struggle, and also self-defined strengths, successes or survival.[1] They are widely available to the public,[2] even for the most stigmatised of mental health problems, such as schizophrenia.[3] Some recovery narratives are published individually, for example, in the form of autobiographies[4] or online videos.[5] Others are published in collections of narratives curated around a common theme, such as in a book intended to create hope by presenting a collection of narratives describing difference experiences of psychosis recovery,[6] or in a booklet of service user (SU) recovery narratives published by an NHS trust in England.[7] Many are available in substantial online collections, such as through videos published by the Time to Change anti-stigma campaign.[8]

Mental health recovery narratives have been used to create patient benefit in healthcare settings on a broad scale,[9] including as a resource to enable discussions in psychotherapy sessions,[10] and to provide access to experiential knowledge for participants in healthcare professional training.[11] They have been widely used to promote mental health recovery, for example, through national campaigns.[12] They have also been used as a central component of national campaigns to reduce mental health stigma,[13] where they have been used a scalable mechanism for creating a perception of social contact with people who have experienced mental health problems, informed by a theory base on stigma reduction through social contact.[14]

The Narrative Experiences Online (NEON) study was a Programme Grant for Applied Research, funded by the National Institute for Health and Care Research (NIHR) from 2017 to 2023. NEON evaluated whether having online access to recovery narratives is helpful for people affected by mental health problems. Through this work, we developed the NEON Intervention, a novel web application delivering access to the NEON Collection of mental health recovery narratives. The NEON Collection contained 659 narratives by the end of the NEON study.

Users of the NEON Intervention access these recovery narratives through four routes:

- Through requesting that an algorithm generates an automated narrative recommendation.
- Through requesting a randomly selected narrative.
- By browsing narratives based on combinations of selected characteristics.
- By returning to previously accessed narratives.

After each narrative access, users were asked to quantify the immediate impact of the narrative on themselves, by responding to a set of narrative feedback questions validated by the NEON study, with one mandatory item on how hope-inspiring the narrative was. The design of these narrative feedback questions was informed by our work to develop a theory describing how recovery narratives make an impact on recipients. Responses to narrative feedback questions inform the processing conducted by the algorithm. They also enable the user to return to narratives that have made hopeful.

The NEON Intervention was evaluated in:

- the NEON Trial, a definitive randomised controlled trial (RCT) for people experiencing mental health problems and with experience of psychosis www.isrctn.com/ISRCTN11152837
- the NEON for Other (i.e. non-psychosis mental health) (NEON-O) Trial, a definitive RCT for people experiencing mental health problems, but with no experience of psychosis www.isrctn.com/ISRCTN63197153

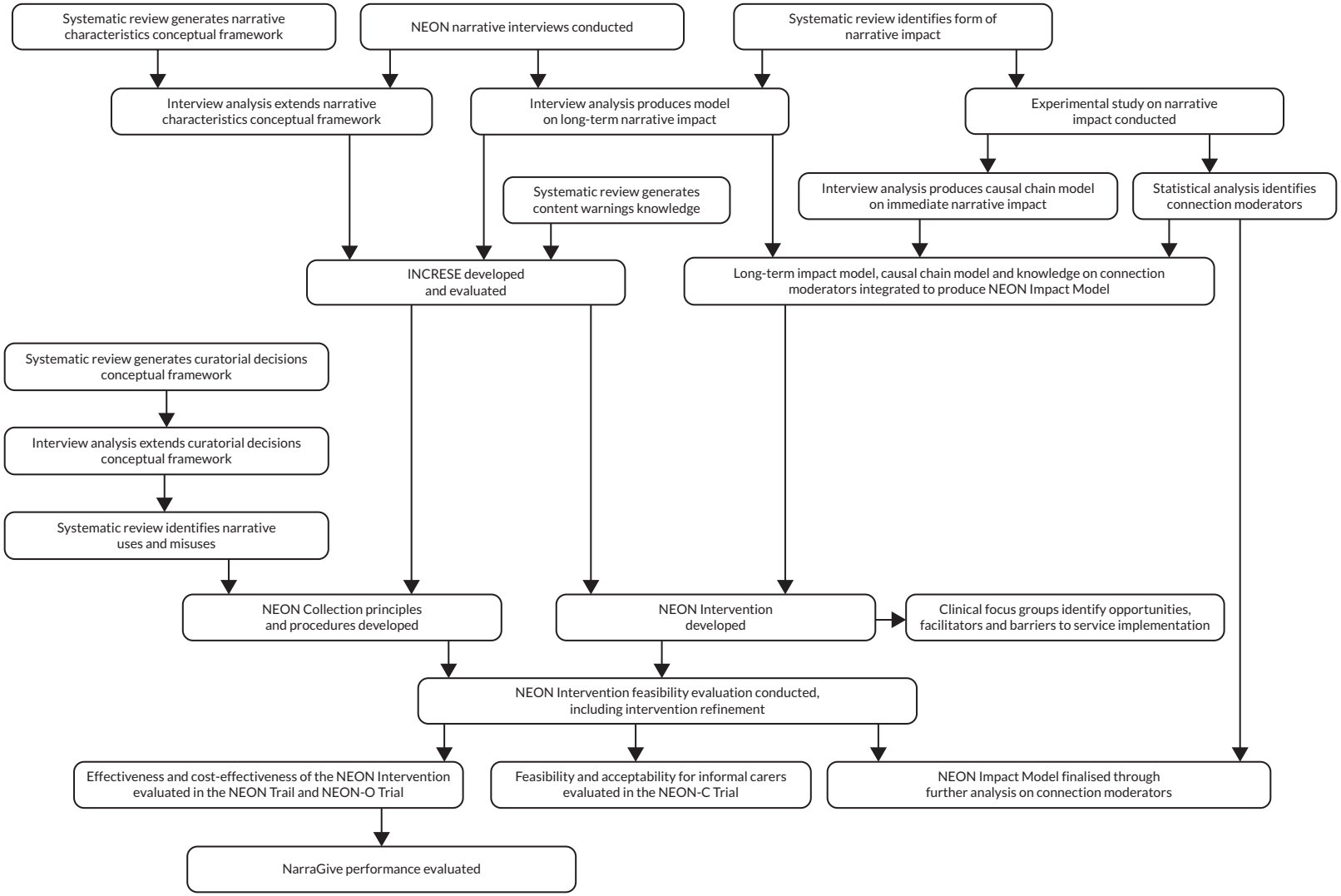

FIGURE 1 Research pathways diagram.

- the NEON for Carers (NEON-C) Trial, a feasibility RCT for people acting as informal carers for people affected by mental health problems, conducted to identify needed changes to the NEON Intervention to make it relevant to carers.

These three trials were delivered in parallel. There was no planned contact with researchers, as all trial procedures, including eligibility assessment, randomisation and outcome data collection, were delivered through an integrated web application. The randomisation system integrated into this web application was validated by the Blizard Pragmatic Clinical Trials Unit (PCTU).

Structure of the Narrative Experiences Online study

The NEON study was structured around five research themes:

- The characteristics of recovery narratives (theme 1)
- The impact of recovery narratives on recipients (theme 2)
- The curation of lived experience narrative collections (theme 3)
- Development of the NEON Intervention (theme 4)
- Evaluation of the NEON Intervention (theme 5)

Within each theme, we conducted a range of individual substudies. Findings from all planned substudies have been communicated through peer-reviewed journal publications complying with the NIHR open access policy. In this synopsis, we provide a summary of the work presented in these publications, organised by these five themes, linking to our published journal papers for those who wish to access additional detail. Substudies are illustrated in our research pathways diagram (*Figure 1*).

The NEON findings have also been communicated through presentations, posters, press releases and panel discussions and in a PhD thesis. A record of these knowledge mobilisation activities is provided at the end of this synopsis. How to effectively manage health service research is rarely discussed as a topic but is useful knowledge for future research studies. To share knowledge on our approach to research management, the NEON study Chief Investigator (CI) published an account of management procedures and principles for the Recovery Research Team which hosted the NEON study, in which NEON featured as a case study of effective management.[15]

Research team

The NEON study was led from the University of Nottingham, by CI Mike Slade. The study co-ordinator was Stefan Rennick-Egglestone.

The NEON study investigators were: Felicity Callard, Rachel Elliott, Chris Hollis, Jeroen Keppens, Vanessa Pinfold, Kristian Pollock, Stefan Priebe, Julie Repper, Justine Schneider, Graham Thornicroft and Lian van der Krieke. Responsibility for statistical analyses related to the NEON trials was delegated to a PCTU senior statistician. This role was first held by Melanie Smuk, who oversaw development of the NEON trials protocol and feasibility study statistical analysis, and then subsequently by Clare Robinson, who oversaw statistical analysis of the NEON trials.

The individual research studies composing the NEON programme were delivered by Yasmin Ali, Ashleigh Charles, Sean P Gavan, Laurie Hare-Duke, Hannah Hussain, Yasuhiro Kotera, Ada Hui, Joy Llewellyn-Beardsley, Rose McGranahan, Kate Morgan, Chris Newby, Fiona Ng, Luke Paterson, James Roe and Caroline Yeo.

The NEON study group is defined in the *Acknowledgements*. It is composed of people who have contributed to the NEON study and who given permission to be publicly identified as NEON study group members. Some NEON study contributors have chosen not to join the NEON study group.

NEON was supported by an International Advisory Board, who met at critical time points in the programme, for consultation on the most important decisions, such as harm minimisation strategies. International Advisory Board members were Dror Ben-Zeev, Simon Bradstreet, Pim Cuijpers, Larry Davidson, Marianne Farkas, Steve Gillard and Tony Morrison.

Governance arrangements

The lead organisation for the NEON study was Nottinghamshire Healthcare NHS Foundation Trust, who was the study sponsor. Independent oversight was by a Programme Steering Committee (PSC), consisting of Professor Sonia Johnson (chair, professor of Social and Community Psychiatry, UCL), Terry Harper [independent patient and public involvement (PPI) representative], Stephen Bremner (senior lecturer in Medical Statistics, Brighton & Sussex Medical School), Tom Barker (clinical psychologist, Oxford Health NHS Foundation Trust) and Paul Stevens (Peer Support Worker, Worcestershire Health and Care NHS Foundation Trust). A funder and sponsor representative were invited to all PSC meetings. Health Research Authority (HRA) approval was sought for all NEON research with human participants, which included seeking approval for NEON Collection curation procedures.[16] Details of approval applications are provided in *Additional information*.

Operational oversight of the NEON trials was by a Trial Management Group (TMG), chaired by the NEON study co-ordinator. It was composed of a PPI representative, representatives of the PCTU (roles in trial management, quality assurance, statistics, data management), representatives of the study sponsor, and NEON study research team representatives [typically Chief Investigator (CI), health economist, study co-ordinator, study team statistician]. The TMG met 24 times, from 9 October 2019 to 11 January 2022. The study co-ordinator acted as the trial manager for the NEON trials. He received a special commendation in the 2021 UK Trial Manager Network Trial Manager of the Year Competition to recognise the work of the TMG (two special commendations from 38 entries).

Lived experience involvement in the Narrative Experiences Online study

The funded proposal for NEON included applicants with self-identified lived experience of mental health problems and of caring for others with mental health problems. In the proposal, people with lived experience of mental health problems were allocated leadership responsibility for critical NEON work packages (WPs), such as intervention development, to enable their experiential knowledge to shape the programme.

People with lived experience who were not applicants were also consulted as the NEON proposal was developed, and the proposal was revised through their recommendations. Consultation was through (1) peer reviews commissioned through the McPin Foundation and (2) review by the Lived Experience Advisory Panel (LEAP) advising the REFOCUS study www.researchintorecovery.com/research/refocus/. Working with an existing LEAP allowed for a consultation which benefited from established trusting relationships and experience of working together and also enabled REFOCUS LEAP members to make a wider contribution.

Once the NEON study began, it was actively supported by a NEON LEAP chaired by Dan Robotham of the McPin Foundation. This consisted of 10 members with personal lived experience of mental health problems. Some also brought lived experience of having published or shared a recovery narrative. The NEON LEAP first met in May 2017, before the work of the study began in August 2017. It typically met as a full panel three times per year for group input, with a total of 17 meetings held. LEAP members were paid a day rate for attendance and preparation.

Agendas for meetings were coproduced between the study co-ordinator and two LEAP members, meeting at least 2 weeks before each meeting. The study co-ordinator brought knowledge about the study need, and LEAP members often worked to highlight LEAP member needs, such as aspects of proposed agenda items requiring more detailed explication. The study co-ordinator and CI attended all LEAP meetings to maximise the impact of deliberations on the study. Other researchers attended where needed, which acted to raise expectations in early career researchers about meaningful involvement. In some agenda items, LEAP members were asked for formal recommendations on study issues that were difficult to resolve, such as our approach to narrator anonymity in narratives in the NEON Collection.[16] Decisions were reached by consensus where possible, but occasionally by vote. LEAP members regularly discussed and provided feedback on issues raised by the study team, for example, to maximise the inclusivity of the opening page of the NEON Intervention.

Some LEAP members formed into subgroups to engage with specific parts of the study. Some subgroups worked together for more than a year, allowing members to develop deeper expertise on the specialist topics that these subgroups considered. In some cases, those subgroups were given decision-making powers in the study. For example, a Collection Steering Group (CSG) was formed, comprising four LEAP members and two researchers with personal lived

experience. It made binding decisions about the NEON Collection, for example, on inclusion criteria, and on inclusion of individual narratives against those criteria. CSG members regularly reviewed the diversity of the NEON Collection. It took decisions on how to correct imbalances, such as a lack of recovery narratives from people with intellectual disabilities.[16] Another example is the intervention development group, which included two LEAP members and two researchers. LEAP members also led some dissemination activities. For example, a subgroup of LEAP members who had shared their own recovery narratives published a guide targeted at people interested in sharing their own recovery narrative,[17] which was integrated into donation processes for the NEON Collection.

Involvement work on the NEON study was well resourced, enabling a substantial and productive engagement. £80,000 of NEON funding was available for involvement work. LEAP members were paid an hourly rate for meeting preparation and attendance, the production of non-academic documents and feedback on academic documents.

In keeping with other studies,[18] LEAP members were routinely offered authorship on research publications. In total, 18 journal articles included LEAP authors, and LEAP members presented in three study symposia, as a reflection of their meaningful contributions to the conception or design of the work; or the acquisition, analysis or interpretation of data for the work.[19] Throughout the study, we experimented with research methods for enabling involvement in study publications, including through LEAP members acting as a source of discrepant or informative items in a systematic review synthesis,[20] and the publication of an involvement plan mapping out a process for LEAP member to engage in a study publication, to support the negotiating of knowledge differences between LEAP members and professional researchers.[21]

Some LEAP members conceptualised their membership as a source of personal growth. Two LEAP members secured research employment during their time with the study, enabled in part by their LEAP experience. This was an unanticipated form of impact from the study.

In addition to lived experience influence due to LEAP, all NEON research and administration roles were advertised as requiring or benefiting from lived experience of mental health problems, either as experienced by the applicant ('personal lived experience') or as experienced by others they were close to or cared for. One NEON role was reserved for a 'peer researcher', who was required to have a dual identity as a researcher and individual with personal lived experience. As a result, a majority of the NEON study team comprised people with lived experience of mental health problems. This expertise had a broad influence on the conduct of the study. One study team researcher was a founding member of the association of peer researchers, which provided a more supportive environment for peer researchers across the university, enhancing peer research capacity at the University of Nottingham. One study member adopted an identity as a peer researcher during the NEON study. Whether to present as a peer researcher was an active topic of discussion within the central study team, with influences including expected impact on the relationship with participants, and the possible workplace consequences of mental health stigma.

The work to incorporate the influence of lived experience throughout the NEON study was recognised when NEON was awarded the NIHR Clinical Research Network (CRN), McPin and MQ: Mental Health Research Service User and Carer Involvement in Mental Health Research Award 2022.

Significant change to the Narrative Experiences Online study structure

The study was initially structured as five WPs:

WP1: interviews to collect recovery narratives from groups under-represented in research.
WP2: development of conceptual frameworks describing recovery narrative characteristics and how they make an impact, through systematic reviews and validation studies.
WP3: development and evaluation of the NEON Intervention.
WP4: development of a narrative-based online learning intervention for mental health professionals.
WP5: knowledge mobilisation.

WPs 1–4 were planned to start sequentially, with WP5 conducted in parallel to the other WPs.

A substantial portion of the NEON study coincided with the COVID-19 pandemic which began to significantly affect the UK from January 2020 onwards. WP4 was removed from the programme, as the planned WP4 research activities required substantial investment of time from healthcare professionals, which was not feasible given the demands on healthcare staff caused by the COVID-19 pandemic. A WP5 50-person event to consult on NHS implementation was reconfigured as a series of smaller events due to the emerging challenging of holding large events caused by COVID-19, including an ongoing decrease in willingness to meet and travel for much of the remainder of the programme.

Ethical approval for research with participants was not in place at the start of the NEON study. Hence, WP1 could not start as planned. To enable research work to begin rapidly, WP1 and WP2 were reordered and restructured. Through this change, WP2 systematic reviews on the characteristics and impact of recovery narratives began immediately at the start of the NEON programme. They were configured to produce preliminary conceptual frameworks[22] on the characteristics[1] and impact[20] of mental health recovery narratives. This change enabled the early production of knowledge on recovery narratives, which then informed the remainder of our work. To develop knowledge on the properties of influential conceptual frameworks, and hence to guide the production of our own conceptual frameworks, we conducted an unplanned citation content analysis of the Connectedness, Hope, Identity, Meaning and Empowerment (CHIME),[23] an influential framework describing mental health recovery processes, to determine factors that had made it influential.[24]

Work package 1 interviews to collect spoken mental health recovery narratives began once approved by the HRA. We conducted 80 semistructured interviews, each inviting the participant to share their recovery narrative, and then questioning the participant on factors that influenced how it was told. Our initial analyses validated and extended our preliminary conceptual frameworks, enabling the production of richer and more thorough frameworks to underpin our intervention development work. We have since conducted a range of secondary analyses, and to date, seven study publications present analyses of NEON narrative interviews. A thorough account of our data collection method has been presented.[25] Interviewees had one or more of the following characteristics: (1) lifetime experience of psychosis and no use of secondary mental health services for 5 years, (2) a Black or minority ethnicity, (3) experience of mental health problems and either no or difficult experiences with mental health services (4) statutory or voluntary experience as a peer worker in roles where lived experience is used as a tool for engagement with mental health SUs.

The changes to the NEON programme described above were initially proposed to PSC, who supported them. They were proposed to the funder, and only enacted once funder support was received. In one significant addition to the programme, we realised that the people who lead the work of creating collections of recovery narratives have a substantial amount of power over how issues around mental health and recovery are seen and understood by the population. We have opportunistically chosen to explore the work of narrative collection curators (our term) through research theme 3 as an unplanned but important element of the NEON programme.

One substantial change to the NEON programme required a more extensive governance process. Our funded proposal included one definitive RCT, which included adults experiencing mental health problems, and with psychosis experience. We operationalised this in our application for HRA approval as the NEON Trial (target n = 684). The NEON proposal also informally described the separate randomisation of people with non-psychosis mental health problems and informal carers, enabling data collection to establish the feasibility of future definitive trials with these populations. We initially operationalised this process as the NEON-O feasibility trial and the NEON-C feasibility trial. We published a protocol describing one definitive trial and two feasibility trials.[26] All three trials had a planned 60-week recruitment period.

The NEON Trial incorporated an internal pilot. PSC recommended that participants randomised during the internal pilot should be carried through into the full trial, due to analyses demonstrating that trial procedures were functioning appropriately, and assumptions on missingness were appropriate for this trial. Given that our trial procedure implementation was shared between all three trials, this provided evidence that those procedures were functioning effectively for all three trials. The NEON-O feasibility trial recruited its recruitment target of 100 participants in 10 weeks. This demonstrated substantial demand for participation in this trial and indicated that there was the potential to deliver a second definitive trial within the same funding envelope. Therefore, we sought approval (sequentially) from PSC, sponsor, funder and HRA to reconfigure this as the definitive NEON-O Trial, with a target sample of n = 994. The

higher target sample reflected greater heterogeneity in the study population, and a greater attrition rate, as estimated from completion rates for interim (1-week and 12-week) NEON-O Trial outcome data.

All approvals were received, and the NEON-O Trial returned a definitive result.[27] The details of this reconfiguration process have been published.[28]

Knowledge transfer events

The NEON proposal included three planned knowledge transfer events. These were delivered as planned, but at different month numbers for later events due to the impact of the COVID-19 pandemic on the scheduling of public conferences, which were planned target for these events. Knowledge transfer event 1 was delivered through symposia presented at the 13th International Conference of the European Network for Mental Health Service Evaluation (ENMESH 2019) conference, and the Refocus on Recovery 2019 conference. Knowledge transfer event 2 was delivered through a symposium at ENMESH 2022. Knowledge transfer event 3 was delivered through a presentation and a set of posters produced for Refocus on Recovery 2023. The content of these knowledge transfer events is defined in *Knowledge transfer events*.

Research theme 1: characteristics of mental health recovery narratives

Narratives describing experiences of a range of health problems are regularly analysed by researchers, using a methodology known as narrative inquiry.[29] To enable recovery narratives to be integrated into the NEON Intervention, it was critical for us as a study to understand how they have been characterised by researchers to date, and what may be missing from their characterisation thus far. Having a thorough conceptualisation of the characteristics of recovery narratives was necessary to guide the process of assembling the NEON Collection and for developing user interface functionality to all trial participants to search the collection.

In research theme 1, we developed a preliminary version of the Recovery Narratives Conceptual Framework (RNCF) through a systematic review.[1] We validated and extended this framework by assessing its fit to transcripts of the NEON narrative interviews.[30] We developed and evaluated the 77-item *Inventory of the Characteristics of Recovery Stories* (INCRESE),[31] which incorporated RNCF concepts. INCRESE has since been used to characterise all NEON Collection narratives, and INCRESE items are used in NEON Intervention functionality to enable browsing of the NEON Collection. We concluded by analysing selected transcripts to document how contextual factors influenced how narratives were told.[32,33]

Through examining the NEON narrative interviews, we realised that they contained content on a range of personal experiences relevant to mental health service provision. To document these, we produced unplanned papers on forms and processes of institutional injustice experienced by participants with experience of marginalisation,[34] and on the experiences of people with psychosis but no recent statutory service contact.[35] The latter paper informed NEON trials recruitment strategies, which were a priori planned to include non-SUs.

We also realised that many of the narrative interviews provided insights into growth after trauma. Hence, we published a thematic analysis describing the forms of growth that we observed in these interviews,[36] and then a systematic review on post-traumatic growth in psychosis.[37] Through this work, the NEON team consolidated our focus on post-traumatic growth in psychosis, evidenced by publication of an overview article in the highest impact factor journal in psychiatry.[38] Follow-on work has included collaborations with research groups in Canada[39] and Egypt,[40] and the acquisition of two research awards (NIHR Advanced Fellowship reference NIHR302218; University of Nottingham Anne McLaren Fellowship reference RIS6676056) worth UK£1.3M, led by NEON researcher Fiona Ng, to develop a digital health intervention to support post-traumatic growth in psychosis.

Characteristics of mental health recovery narratives: systematic review and narrative synthesis

Published by Llewellyn-Beardsley *et al*.[1]

Objectives: To review research publications describing typologies or characteristics of mental health recovery narratives and to develop a preliminary version of the RNCF.

Methods: A systematic review of empirical research studies was conducted. A novel recovery narratives definition was developed, as 'first-person lived experience accounts of recovery from mental health problems, which refer to events or actions over a period of time, and which include elements of both adversity/struggle and of self-defined strengths/successes/survival'. A review protocol was prospectively registered (PROSPERO 2018:CRD42018090188). Fourteen bibliographic databases were searched from inception to 27 July 2018. Documents were also identified through mechanisms such as forwards citations, backwards citation and expert consultation. Typologies and characteristics described in included papers were synthesised into an overarching typology. Subgroups of included documents presenting analyses of narratives describing (1) psychosis and (2) experience of trauma were examined.

Results: Eight thousand nine hundred and fifty-one titles, 366 abstracts and 121 full-text articles published between January 2000 and July 2018 were screened. 45 studies analysing 629 recovery narratives were included. A conceptual framework describing characteristics of mental health recovery narratives was developed, comprising nine dimensions: genre, positioning of narrator in relation to services, emotional tone, relationship with recovery, trajectory, use of turning points, narrative sequence, protagonists and use of metaphors. Each dimension contains between two and six types. Subgroup analysis of psychosis and of trauma studies found no important differences in their characterisation compared with those narrating other mental health experiences.

Contribution to the programme: The inclusive recovery narrative definition adopted by this systematic review has been used throughout the remainder of the NEON study. The systematic review demonstrated that recovery narratives are diverse and multidimensional, and that simplistic definitions should be avoided. Our subgroup analysis contributed to our decision-making on whether NEON Collection narratives should be segregated by mental health experience.

Not the story you want? Assessing the fit of a conceptual framework characterising mental health recovery narratives

Published by Llewellyn-Beardsley *et al*.[30]

Objectives: To assess the overall fit of the preliminary RNCF to the NEON narrative interviews and to identify necessary extensions to this framework.

Methods: A structural narrative analysis of 77 narrative interviews was undertaken to assess the relevance and comprehensiveness of the dimensions and types described in the preliminary RNCF. This represented all narrative interviews that had been collected at this point in the programme.

Results: Five or more RNCF dimensions were identifiable within 97% of the narratives, validating the choice of dimensions used in the RNCF. A range of RNCF refinements were identified. The most significant was the addition of a 'cyclical' type to the 'trajectory' dimension. This addition positioned narratives describing cycling through sequences of distress and recovery as a form of recovery narrative. The refined RNCF is presented in *Table 1*. The RNCF was found not to be relevant to two narratives, whose narrators expressed a preference for non-verbal communication.

Contribution to the programme: The addition of cyclical recovery narratives to the RNCF reaffirmed a programmatic orientation towards a broad and inclusive recovery narratives definition. A lack of fit to two narratives, and our analysis of the underlying reasons for this, raised a concern that text or spoken word narratives may not be an appropriate form for some narrators, leading to the inclusion of more diverse narratives in the NEON Collection.

Inventory of Characteristics of Recovery Stories: an instrument to characterise recorded mental health recovery narratives

Published by Llewellyn-Beardsley *et al*.[31]

TABLE 1 Final version of the RNCF

#	Dimension/type	Definition	Description
Narrative form (what kind of story is this?)			
1	Genre	A literary kind, type or class of story	
1.1	Escape	Narratives of escape from and resistance to abuse, threat, stigma and persecution	Escape from oppressive beliefs, systems, services, treatments or negative identity as a result of maltreatment or stigma. May contain images of entrapment and/or of a fight for survival
1.2	Endurance	Narratives of loss, trauma, difficult circumstances and/or seemingly insurmountable odds	Endurance of losses, weathering storms or battening down the hatches. May contain haunting or chaotic elements or be in the midst of traumatic events. Successes may be expressed in terms of having survived, or kept going. Narrator's priority may be salvaging over restoring or transforming themselves
1.3	Endeavour	Narratives of coping strategies and plans, with some continued difficulties and positive aspects	Endeavouring to make changes and incorporate positive aspects, while accepting difficulties as an ongoing factor of recovery. Narrators may feel they are active agents of change, or may focus on doing things or keeping busy. Priority may be managing rather than transforming themselves
1.4	Enlightenment	Narratives of transformation and inspiration, with experience of illness/trauma viewed as positive, as new perspective has been gained	A journey of exploration or discovery leading to empowerment. May contain aspects of redemption or having been saved by something greater than themselves, either by spiritual or humanistic means
2	Positioning	Ways in which narratives are situated in relation to mental health services (defined as the dominant clinical mental health provision of the country involved)	
2.1	Recovery within services	Narratives incorporating positive experiences of the mental health system, either through using services or through delivering services (e.g. peer support)	Diagnosis or experience of being a member of staff or volunteer within mental health services may be experienced as empowering; and treatment, services or relationships with practitioners and/or colleagues and SUs as enabling, positive or a salvation. 'Within services' may include either or both of using and delivering services
2.2	Recovery despite services	Narratives of protest in opposition to the biomedical model of mental illness or associated myths (e.g. recovery is not possible) and/or in opposition to mental health services and systems	Experiences of oppression. May include experience of maltreatment by mental health services, resistance to concepts, for example, 'myth of incurability', or recovering of voice/ agency
2.3	Recovery outside of services	Narratives of recovery in which mental health services do not feature, or feature only very minimally (e.g. visits general practitioner). May not engage with psychiatric definitions and psychological concepts of individual personal growth	Experiences of living a 'good life' beyond services. May incorporate social, political, spiritual and economic elements, often with a focus on specific areas, such as activism, adventure, relationships or spirituality. May contain elements of having a greater purpose: 'helping others in the same boat', or a changed understanding of what is most important in life
3	Emotional tone	The overall mood or feeling of the narrative	
3.1	Upbeat	Positive tones	For example, buoyant, content, hopeful, proud, optimistic, reflective
3.2	Downbeat	Negative tones	For example, agitated, apologetic, frenetic, pessimistic, sad, shaken
3.3	Challenging	Provocative or stimulating tones	For example, angry, critical, defiant, protesting
3.4	Neutral	Flat tones	For example, matter of fact, monotone, disenfranchised
4	Relationship with recovery	How the narrator relates to the concept of recovery at the time of narration	
4.1	Recovered	Recovery as an outcome which has been achieved	Period of illness or distress seen as being in the past. May be a clear split between past and present selves
4.2	Living well	Recovery as a process within which narrator is well established	Narrator is living well in either the presence or absence of mental illness and sees any continuing difficulties as things which they can overcome

continued

TABLE 1 Final version of the RNCF (*continued*)

#	Dimension/type	Definition	Description
4.3	Making progress	Recovery as an ongoing process within which narrator is beginning to see progress	Narrator is confident in the ability to cope, despite feeling relatively close to the disruptions of a mental health crisis
4.4	Surviving day to day	Recovery as an ongoing process in which the narrator is tentatively engaging	Narrator may be in a new or difficult or ongoing situation where it may be difficult to realise their hopes, but they still express experiences in terms of recovery
Narrative structure (what shape of story is this?)			
5	Trajectory	The direction of a narrative towards its destination	
5.1	Upward	An overall ascending progression towards recovery	Narratives of revelation or purposeful suffering, or of evolution from darkness to light towards a better future, or of overall improvement
5.2	Up and down	Continuing upturns towards health/well-being and downturns towards illness/struggle	May challenge the progressive trajectory of spiralling upward. May be experienced as dramatic, 'roller-coaster' narratives or more drawn-out 'progressive and regressive' stories
5.3	Horizontal	An even narrative without significant upturns or downturns	Narrator may feel that they are currently stagnating or taking one day at a time
5.4	Interrupted	A narrative interrupted by an unexpected crisis or difficulty before resuming its former shape and direction	Narrator sees the crisis or difficulty as a blip, after which their life has returned to its prior state
5.5	Cyclical	A narrative cycling through sequences of distress, gradual recovery, a period of well-being and then distress again	Narrators describe a process of going back to the beginning, with no benefits from previous periods of recovery/well-being being retained during periods of distress. Narrators may describe cycle as frustrating (a continuous battle) and/or a source of strength (pride at the ability to move through difficult periods)
6	Use of turning points	Pivotal moment(s) within the narrative which affects its overall shape	
6.1	Restorying	Turning point is the moment in which a narrator gains a new understanding of their experience	May be the moment a narrator resists being defined by a dominant discourse and takes over the authorship of their own stories
6.2	Change for the better	Turning points described as moments of transition followed by sequences where things improve	Positive events in themselves, such as a moment of self-acceptance or intervention from others, or difficult moments which prove to be a catalyst for positive change, such as realising that others couldn't help them
6.3	Change for the better or worse	Turning points described as moments of transition followed by sequences where things either improve or get worse	Narrator identifies both positive events and turns for the worse as turning points in their narrative
7	Narrative sections	The components of a mental health recovery narrative	
7.1	Origins	Possible roots or causes of later mental health distress, or description of life before illness	
7.2	Problems begin	Onset of difficulties, or a sense of going downhill	
7.3	Problems worsen	The central experience of illness or distress	
7.4	Impact of illness	Effect on narrator's life, relationships, etc.	
7.5	Glimpses of recovery	Positive changes which may lay the foundation for turning points	
7.6	Turning point	Getting involved in an activity, a new relationship, contact with services, a change of perception, hitting rock bottom	
7.7	Roads to recovery	A recovering period, or a sequence describing personal benefits, connections made, etc.	
7.8	Life afterwards	Reflections, hope for a better future, inclusion of hopeful elements/triumphs to inspire others	

TABLE 1 Final version of the RNCF (*continued*)

#	Dimension/type	Definition	Description
Narrative content (what resources have been deployed in the telling of this story?)			
8	Protagonists	The major characters and/or forces at work within a narrative.	
8.1	Personal factors	The force(s) working at micro-level or inter/intrapersonal level within a recovery narrative	Most commonly, the narrator himself or herself: the strong conqueror, the scarred survivor, the enlightened explorer. May also be a helping person or factor, such as a helpful treatment or medication
8.2	Sociocultural factors	Meso-level factors within a recovery narrative. Family, friends, groups or local organisations, mental health staff and services	These may be 'supporters or villains', exerting positive or negative effects on the narrative
8.3	Systemic factors	Macro-level factors within a recovery narrative. Wider community or sociopolitical systems, including legal, healthcare, policy, political, religious and international factors	These may affect the narrative either positively or negatively
9	Use of metaphors	Imagery employed by the narrator to depict states of being, relating to distress and recovery	
9.1	Distress metaphors	Focused on past distress or a future return to the experience of distress	May depict descent, spiralling out of control, disconnection, alienation, chaos
9.2	Recovery metaphors	Focused on past, present or future experience of recovery	May depict connection, bonding and integration: regaining control of life, partnership with others, victory in fight against illness

Objectives: To develop and evaluate INCRESE.

Methods: A theory-based inventory was developed from existing evidence, including the RNCF. It was designed to be applicable to recovery narratives presented in a range of forms (including in video, audio and text and through static imagery). Feasibility and acceptability of use were evaluated qualitatively, by three coders rating 30 purposively selected narratives. Reliability was assessed by four coders rating 95 purposively selected narratives. Intercoder reliability was assessed using Fleiss's kappa coefficients (κ), and test–retest reliability using intraclass correlation coefficients (ICCs).

Results: In the reliability assessment, data completeness was high, and no floor or ceiling effects were found. Intercoder reliability ranged from moderate (κ = 0.58) to almost perfect agreement (κ = 1.00). Test–retest ranged from moderate (ICC = 0.57) to almost complete agreement (ICC = 1.00). Coder well-being emerged as an important support need. The final INCRESE instrument consists of 76 items spanning five sections: narrative eligibility, narrative mode, narrator characteristics, narrative characteristics and narrative content.

Contributions to the programme: INCRESE was used to characterise all narratives in the NEON Collection. It has enabled international collaborations, including the development of translations and funded collaborative research studies in the Netherlands and Norway. Due to the finding on coder well-being, we developed approaches to support well-being. This included the right to refuse to work with a narrative containing personally distressing content, without need for explanation.[16]

Influences on the telling of recovery narratives

Theme 1 concluded with two publications examining the influences on how recovery narratives are told.

In publication 1,[32] a reflexive thematic analysis was conducted within a critical constructivist approach. This considered 71 of the NEON narrative interviews, comprising all participants who answered a topic guide question on how context factors influenced how they told their stories. The overarching finding was that questions of power were central to

how all 71 accounts were told. Four themes were identified that described the relationship of individual narratives to participant experiences of power: (1) using their narrative to challenge the status quo, (2) risky consequences of sharing narratives, (3) pressure to produce 'acceptable' stories and (4) forms of experience that are untellable in narratives.

In publication 2,[33] a performative narrative analysis was conducted of two NEON narrative interviews with participants with multiple and complex needs. This analysis explored the kinds of recovery stories people with multiple and complex needs tell, how micro- and macro-level contextual factors may have shaped their accounts and what ethical and other issues may arise when eliciting recovery stories for research purposes from people facing multiple sociostructural inequalities. Our paper included a detailed analysis of how the practices of the NEON study team influenced the ways in which the selected participants told their narratives, relevant to others conducting narrative enquiry research.

Contributions to the programme: Collectively, these two works argue against a simplistic treatment of narrative as a form of truth-telling, by demonstrating how contextual factors can substantially influence how narratives are told. Both make a contribution to narrative enquiry as a research approach.

Research theme 2: impact of recovery narratives

To inform our intervention development work, we developed a theory describing how recovery narratives make an impact on participants, which we published as the NEON Impact Model.[16] Work began with a systematic review to develop a preliminary conceptual framework describing forms of impact of recovery narratives on recipients.[20] A model describing long-term change due to recovery narratives was identified through an analysis of NEON narrative interviews,[25] and then a causal change model describing short-term change was developed,[41] through interviews with participants taking part in an experimental study looking at the predictors of impact.[42] Our models describing short-term and long-term change were synthesised to create the NEON Impact Model.[16] Throughout, 'receiving a narrative' was defined as viewing, reading or listening to someone else's recovery narrative. 'Impact' was defined as the processes by which receiving recovery narratives cause benefits or harms to the recipient and the outcomes generated by these.

Mental health recovery narratives and their impact on recipients: systematic review and narrative synthesis

Published by Rennick-Egglestone *et al*.[20]

Objectives: To develop a conceptual framework describing forms of impact of recovery narratives on recipients, including both benefits and harm.

Method: A systematic review on the impact of mental health recovery narratives was conducted using the inclusive NEON study definition of a recovery narrative. A review protocol was prospectively registered (PROSPERO 2018, CRD42018090923). Searches used electronic databases (n = 9), reference tracking, hand-searching of selected journals (n = 2), grey literature searching and expert consultation (n = 7). Searches included terms that might uncover papers on recovery narratives, including memoirs and autobiographies, with relevant papers manually inspected for recovery narrative content if identified. Forms of impact described in included papers were synthesised into an overarching framework.

Results: Five articles were included. Forms of impact were connectedness, understanding of recovery, reduction in stigma, validation of personal experience, affective responses and behavioural responses. Processes producing these outcomes were documented. Impact was moderated by characteristics of the recipient, context and narrative. Increases in eating disorder behaviours were identified as a harmful response specific to recipients with eating disorders.

Contributions to the programme: Our review indicated that existing research evidence on recovery narrative impact was limited, and hence confirmed that further empirical studies were needed. It provided initial evidence that recovery narratives can create harms as well as benefits, which led to a strand of work focused on harm reduction and management in recovery narrative interventions.

The impact of mental health recovery narratives on recipients experiencing mental health problems: qualitative analysis and change model

Published by Rennick-Egglestone *et al.*[25]

Objectives: To produce a model describing the long-term impact of receiving recovery narratives.

Method: Seventy-seven narrative interview transcripts colllected by the NEON study were analysed thematically. Our analysis was of reflective content describing naturalistic impact of recovery narratives on our participants. Analysis was initially deductive using the systematic review conceptual framework. Content describing impact but not fitting systematic review concepts was then analysed thematically, extending the framework. The NEON study team examined coded content to produce a change model.

Results: In the model, change is initiated when a recipient develops a connection to a narrator or to the events descripted in their narrative. Change is mediated by the recipient recognising experiences shared with the narrator, noticing the achievements or difficulties of the narrator, learning how recovery happens or experiencing emotional release. Helpful outcomes of receiving recovery narratives are connectedness, validation, hope, empowerment, appreciation, reference shift and stigma reduction. Harmful outcomes are a sense of inadequacy, disconnection, pessimism and burden. Impact is positively moderated by the perceived authenticity of the narrative, and can be reduced if the recipient is experiencing a crisis.

Contributions to the programme: Our work identified a comprehensive set of outcomes, informing the selection of standardised measures used in the NEON trials. It extended our list of known harms and hence supported the design of harm management strategies. It provided an initial understanding that connection to a narrator or narrative was an important element in the causal chain by which impact occurs, which informed our narrative feedback strategy. By establishing that authenticity enhances impact, it enabled a discussion of NEON Collection curation procedures and provided a rationale for processes preserving authenticity.

How do recorded mental health recovery narratives create connection and improve hopefulness?

Published by Ng *et al.*[42]

Objectives: To identify characteristics of the narrator, narrative content and participant which predict the short-term impact of recovery narratives on participants.

Method: Two independent studies were conducted. The experimental study took place in a controlled setting. Participants were mental health SUs (n = 40). The clinical study involved naturalistic access to recovery narratives through a prototype of the NEON Intervention, as described in the feasibility study in research theme 4. Participants from the experimental study were excluded from the clinical study.

In both studies, participants with mental health problems were shown recorded mental health recovery narratives from different modalities (text, video and audio). Narratives were characterised using the INCRESE inventory, and predictor variables were drawn from these characterisations. Subjective levels of hope were measured using the Herth Hope Index. In the experimental study, participants were asked to provide quantitative feedback on narrative impact using a preliminary set of narrative feedback questions, and in the clinical study, a validated set of questions were used.[16] Both sets of questions asked for feedback on participant connection to the narrative, connection to the narrator and hopefulness created.

Predictive characteristics were identified using multilevel (participant and narrative), mixed-effects statistical model and was implemented in R software (www.r-project.org/). Significant predictors from the univariate multilevel model from the experimental and clinical study was compared for significance. Maximum Likelihood (www.analyticsvidhya.com/blog/2018/07/introductory-guide-maximum-likelihood-estimation-case-study-r/) was used to test the fit of the model, and analysis of variance for the fit of the univariable predictor model was used to compare the fit of the intercept model to obtain a p-value. Random-effects maximum likelihood was used to test each predictor variable for significance.

Results: In the experimental study, participants received an average of seven narratives. Findings indicate that narratives portraying a narrator as living well with mental health problems (e.g. part-way between *no recovery* and *full recovery*) generated higher self-rated levels of hopefulness. Connection with the narrator was higher when there was a match between narrator gender and participant preference for narrator gender. Participants from ethnic minority backgrounds had lower levels of connection with narrators compared to participants from a White background, potentially due to reduced visibility of a narrator's diversity characteristics.

In the clinical study, participants on average received six narratives. Participants reported feeling less hopeful when the narrator was male. In general, participants who were younger females felt more connection with a narrator. Less connection was felt by participants with narrators from an ethnically diverse background, compared to narrators from a White background. A match in ethnicity between a participant and a narrator led to significantly higher levels of hopefulness.

Contributions to the programme: Our study provided first-in-field preliminary evidence that narrator ethnicity, gender and recovery status influenced narrative connection and outcome. The novel method developed for this study has enabled international collaboration to replicate the study, for example, in the NEON Young Norway study. We concluded from this study that the NEON Collection needed to include narratives with diverse narrator characteristics. This led to unplanned work to develop a range of theoretically informed approaches for assessing diversity in narrative collections.[43] We planned and conducted diversity audits of the NEON Collection, which then directly influenced our work to further develop the NEON Collection.

The mechanisms and processes of connection: developing a causal chain model capturing impacts of receiving recorded mental health recovery narratives

Published by Ng *et al*.[41]

Objectives: To characterise the immediate effects of receiving recovery narratives presented in a range of modalities (text, video and audio), by establishing the mechanisms of connection and the processes by which connection leads to outcomes.

Method: In the experimental study described above, participants were asked three questions after providing quantitative narrative feedback scores: (1) How connected to the story did you feel? (2) How connected to the narrator did you feel? (3) How hopeful did the story make you feel? Thematic analysis of responses was used to identify the mechanisms of connection and how connection leads to outcome.

Results: Receiving a recovery narrative led participants to reflect upon their own experiences or those of others, which then led to connection through three mechanisms: (1) comparing oneself with the narrative and narrator (through shared experiences, stages of recovery, narrator characteristics), (2) learning about others' experiences (perspective taking, developing new techniques) and (3) experiencing empathy (narrator struggles, narrator successes, narrative presentation). However, the three mechanisms of connection is moderated by two factors: (1) recipient characteristics (clinical and personality factors, personal beliefs and values) and (2) narrative characteristics (perceived authenticity, narrative modality). The mechanism led to outcomes through three processes: the identification of change (through attending to narrative structure), the interpretation of change (through attending to narrative content) and the internalisation of interpretations.

Contributions to the study: This was the first comprehensive study on how recovery narratives make a short-term impact on recipients. When synthesised with our prior work, it allowed us to produce the NEON Impact Model[16] illustrated in *Figure 2*, with moderators of impact described in *Table 2* and forms of learning due to recovery narratives described in *Table 3*.

Research theme 3: the curation of lived experience narrative collections

Research theme 3 began with work to document the work of curating recovery narrative collections. Our usage of the term 'curation' draws on existing usage within the discipline of museum studies, where the work of curators has been

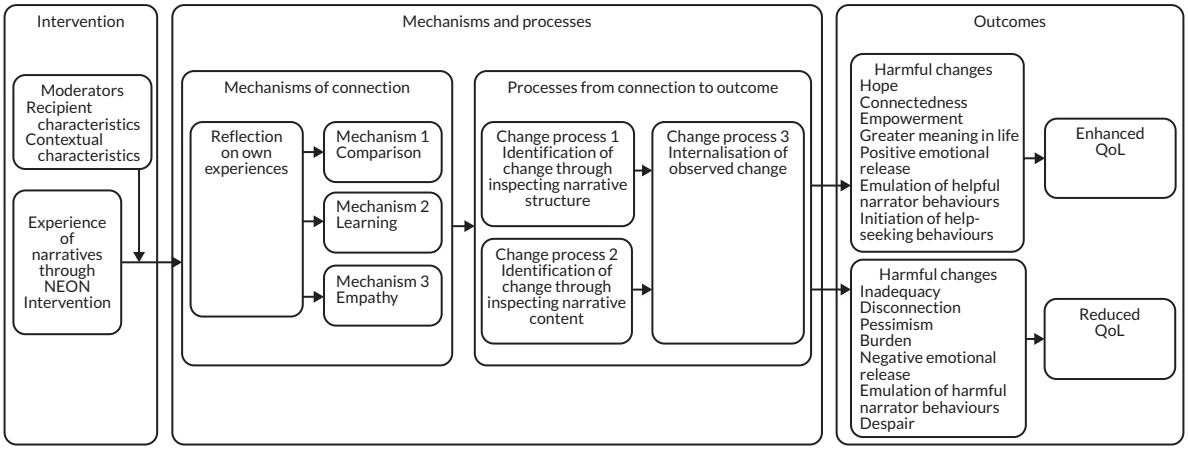

FIGURE 2 NEON Impact Model. Reproduced from Slade *et al.*[16] This is an Open Access article distributed in accordance with the terms of the Creative Commons Attribution (CC BY 4.0) licence, which permits others to distribute, remix, adapt and build upon this work, for commercial use, provided the original work is properly cited. See: https://creativecommons.org/licenses/by/4.0/ The figure includes minor additions and formatting changes to the original text.

TABLE 2 Moderators of impact described in the NEON Impact Model

Moderator	Direction of influence
Recipient characteristics	
Recipient reports a long-term inability to connect with others	Reduced impact
Recipient has experienced a recent event perceived as distressing	Reduced impact
Recipient is experiencing a mental health crisis	Reduced impact
Recipient has beliefs, values, or attitudes contradicting those of the narrator	Reduced impact
Recipient is experiencing mental health problems that disrupts information processing (such as hearing voices)	Reduced impact
Recipient perceives the content of the narrative to be emotionally challenging	Reduced impact
Recipient experiences difficulties in comprehending the form of the narrative (e.g. if the narrative is presented as a poem)	Reduced impact
Recipient perceives the narrative or narrator to be inauthentic	Reduced impact
Recipient perceives the narrative or narrator to be authentic	Increased impact
Contextual characteristics	
Recipient has access to a private space to access challenging narratives	Increased impact
Recipient has access to a mental health worker who supports processing	Increased impact

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studied and taught for several centuries, and hence where knowledge on curation processes is seen as an important target for research.

We first conducted a systematic review producing a preliminary typology describing the choices made by collection curators.[2] This review included only one empirical study, hence highlighting a lack of research knowledge on this topic. We, therefore, chose to extend our typology through an interview study with a diverse set of curators of mental health lived experience narrative collections.[44,45] These interviews provided access to details and perspectives on curation that were not necessarily available in public documents.

TABLE 3 Types of learning due to recovery narratives

Learning about mental health
How others experience a mental health condition
Alternative conceptualisations of mental health problems
The impact of mental health problems on others (e.g. carers)
New coping strategies to enhance daily living
Learning about recovery
Recovery is possible
Specific recovery strategies that have helped others
Barriers to recovery that others have experienced
Differing beliefs and values that have supported recovery
How to manage treatment and make best use of services

Through these works, and through the personal experiences of the NEON study team, we understood that there are concerns about the misuse of narratives presenting lived experiences of mental health problems, so we conducted a systematic review to document all known uses and to formulate a categorisation of misuses.[46] We then used the knowledge developed during this theme as a whole to publish an unplanned guide presenting recommendations for avoiding misuses and adopting good practices in relation to lived experience narratives.[47]

The curation of mental health recovery narrative collections: systematic review and qualitative synthesis

Published by McGranahan *et al.*[2]

Objectives: To produce a typology identifying and categorising decisions made in the curation of recorded recovery narrative (RRN) collections.

Methods: A typology was produced through a systematic review of empirical research studies, and a qualitative evidence synthesis of public documents describing the work of collection curators. A protocol was prospectively registered (PROSPERO 2018:CRD42018086997). Research articles were identified through searching bibliographic databases (n = 13), indexes of specific journals (n = 3) and grey literature repositories (n = 4). Informal documents presenting knowledge about curation were identified from editorial chapters of electronically available books (n = 50), public documents provided by web-based collections (n = 50) and prefaces of health service booklets identified through expert consultation (n = 3). Narrative summaries of included research articles were produced. A qualitative evidence synthesis was conducted on all included documents through an inductive thematic analysis. Subgroup analyses were conducted to identify differences in curatorial concerns between web-based and printed collections.

Results: A total of 5410 documents were screened, and 23 documents were included. These comprised 1 research publication and 22 informal documents. Moreover, nine higher-level themes were identified, which considered: the intended purpose and audience of the collection; how to support safety of narrators, recipients, and third parties; the processes of collecting, selecting, organising and presenting recovery narratives; ethical and legal issues around collections; and the societal positioning of the collection. Web-based collections placed more emphasis on providing benefits for narrators and providing safety for recipients. Printed collections placed more emphasis on the ordering of narrative within printed material and the political context.

Contribution to the programme: Only one research article was identified despite extensive searches, hence this review revealed a lack of peer-reviewed empirical research. The most strongly evidenced theme in our synthesis was narrator

identity, where our work identified a range of existing approaches, highlighting this as a critical issue to consider in NEON Collection curation processes.

Interview study with curators of mental health lived experience narrative collections

Published by Yeo *et al.*[44,45]

Objectives: To develop a typology of curatorial decisions involved in curating collections of lived experience narratives; to understand curator goals for collections, and the influence of these goals on the working practices they select.

Methods: The typology produced by the systematic review was iteratively developed through consultation with an experienced curator of multiple recovery narrative collections to produce a more thorough preliminary typology of curatorial decision. This informed the topic guide for semistructured interviews with a maximum variation sample of 30 curators from seven different countries. In a first analysis, a refined typology was produced through thematic analysis with constant comparison. In a second analysis, material relating to curator goals and their influence on the curation processes was identified and inductively organised.

Results: Curators interviewed were from seven countries (Brazil, Canada, Hong Kong, India, Italy, UK and USA), and 60% had lived experience of mental health service usage. The final typology identified six categories of decision, collectively referred to as VOICES, which stands for values and motivations, organisation, inclusion and exclusion, control and collaboration, ethics and legal, and safety and well-being. A total of 26 subthemes relating to specific forms of decision were identified. Themes and subthemes are presented in *Table 4*. Participants discussed eight goals that inspired their work: fighting stigma, campaigning for change in service provision, educating about mental health and recovery, supporting others in their recovery journey, critiquing psychiatry, influencing policy, marketing health services and reframing mental illness. These goals influenced how decisions were made about inclusion of narratives, editing of narrative content, withdrawal rights and anonymisation.

TABLE 4 The VOICES framework describing curatorial decision-making

Themes	Subthemes
1. Values and motivation	1.1 Guiding values
	1.2 Purpose
	1.3 Audience
	1.4 Context
2. Organisation	2.1 Identification
	2.2 Collection process
	2.3 Presentation
	2.4 Impact and evaluation
3. Inclusion and exclusion	3.1 Selection and inclusion
	3.2 Exclusion
	3.3 Editing
	3.4 Language
4. Control and collaboration	4.1 Role of curator
	4.2 Curatorial team
	4.3 Power dynamics
	4.4 Working together

continued

TABLE 4 The VOICES framework describing curatorial decision-making (*continued*)

Themes	Subthemes
5. Ethics and legal	5.1 Anonymisation
	5.2 Consent process
	5.3 Data security
	5.4 Funding
	5.5 Payments
	5.6 Copyright and ownership
	5.7 Withdrawal process
6. Safety and well-being	6.1 Safety and well-being
	6.2 Distress
	6.3 Trigger warnings

Contribution to the programme: This work identified key decisions to consider when curating narrative collections, and informed decisions made about the curation of the NEON Collection. It reaffirmed our understanding of the power of curators in influencing the collections that they produce.

Uses and misuses of recorded mental health lived experience narratives in healthcare and community settings: systematic review

Published by Yeo *et al.*[46]

Objectives: To identify all known uses and misuses of mental health lived experience narratives in healthcare settings and in community groupings relevant to mental health.

Methods: A four-language systematic review was conducted of published literature characterising uses and misuses of mental health lived experience narratives within healthcare and community settings. A review protocol was prospectively registered (PROSPERO 2021:CRD42021229458). Documents were identified from international publication databases in English (n = 7) and from subject-specific Scandinavian databases in English, Danish, Swedish and Norwegian. Documents were also identified through inspection of subject-specific websites, from activist literature, through citation tracking and through expert consultation. Uses and misuses described in included documents were synthesised into categories.

Results: Twenty-seven uses were identified in five categories: political, societal, community, service level and individual. Eleven misuses were found, categorised as relating to the narrative (narratives may be co-opted, narratives may be used against the author, narratives may be used for different purpose than authorial intent, narratives may be reinterpreted by others, narratives may become patient porn, narratives may lack diversity), relating to the narrator (narrator may be subject to unethical editing practises, narrator may be subject to coercion, narrator may be harmed) and relating to the audience (audience may be triggered, audience may misunderstand). Four open questions were identified: does including a researcher's personal mental health narrative reduce the credibility of their research? Should the confidentiality of narrators be protected? Who should profit from narratives? How reliable are narratives as evidence?

Contribution to the programme: Good practice recommendations presented in the discussion section of this review provided a starting point for our published good practice guidelines.[47] The understanding of narrative misuses that we developed through this work directly contributed to NEON Collection curation principles and procedures.

Research theme 4: development of the Narrative Experiences Online Intervention

The NEON Intervention, and the NEON Collection that underpins it, was developed through a series of interlinked research activities. This began with a systematic review developing a typology of intersectoral content warnings,[48] important when uncertainty remains about whether content warnings are helpful or harmful for different populations[49,50] and when there are no standardised content warning frameworks. We then identified curation principles for the NEON Collection[16] and identified NEON Intervention harm minimisation strategies (including selecting specific categories of content warning).[16] We worked internationally to secure consent for inclusion of 659 narratives in the NEON Collection and developed a working prototype of the NEON Intervention. We selected and implemented an approach for generating algorithmic recommendations of recovery narratives, in which a hybrid recommender system integrated pre-existing collaborative and content-based algorithms.[51] Finally, we evaluated and improved the NEON Intervention prototype through a feasibility study.[16]

Typology of content warnings and trigger warnings: systematic review

Published by Charles *et al*.[48]

Objectives: To develop a typology of content warnings and to identify the contexts in which content warnings are used, comprising sector, format and target audience.

Methods: A systematic review was conducted. The review was pre-registered (PROSPERO 2021:CRD42020197687). It used five sources: electronic databases covering multiple sectors (*n* = 19); table of contents from multisectoral journals (*n* = 5), traditional and social media websites (*n* = 53 spanning 36 countries); forward and backward citation tracking; and expert consultation (*n* = 15).

Results: About 6254 documents were reviewed for eligibility, and 136 documents from 32 countries were included. These were synthesised to develop the NEON content warning typology. This comprises 14 domains: violence, sex, stigma, disturbing content, language, risky behaviours, mental health, death, parental guidance, crime, abuse, sociopolitics, flashing lights and objects. Ten sectors were identified: education, audio-visual industries, games and apps, media studies, social sciences, comic books, social media, music, mental health, and science and technology. Presentation formats (*n* = 15) comprised: education materials, film, games, websites, television, books, social media, verbally, print media, apps, radio, music, research, digital versatile disc/video and policy document.

Contribution to the programme: This review provided a broad understanding of content warning types which contributed to the selection of content warnings for the NEON Collection.

Identification of curation principles for the Narrative Experiences Online Collection

Published by Slade *et al*.[14]

Objectives: To develop curation principles for the NEON Collection, to ensure that the NEON Collection addresses all safeguarding, ethical, legal, clinical and technological challenges associated with storing and using recovery narratives.

Methods: All elements of the design of the NEON Collection were explored. The research team sought advice on specialist issues from relevant experts, for example, legal advice was obtained on intellectual property and third-party references in RRNs. Three LEAP meetings considered the most complex ethical challenges: inclusion and exclusion criteria, approaches to anonymisation, withdrawal of narratives and procedures for processing third-party requests for withdrawal. Initial principles and inclusion and exclusion criteria were described in a protocol, which was submitted for NHS Research Ethics Committee (REC) and HRA approval. Once approved, a preliminary collection of 100 recovery narratives was assembled from publicly accessible resources. Each narrative was assessed against the proposed inclusion and exclusion criteria, and narratives with uncertain inclusion were referred to the CSG for a final decision. CSG identified necessary clarifications regarding the wording and interpretation of the inclusion criteria. The process of assessing narratives and reviewing criteria was repeated as the NEON Collection expanded. Once changes to inclusion criteria and collection principles and procedures had ceased, a document analysis was conducted on all

documents produced through this process. Text describing a decision or the rationale for the decision was identified and summarised. Decisions were organised into the six predefined VOICES categories for presentation.

Results: *Table 5* presents principles adopted for the NEON Collection. This included decisions that set a distinctive direction for the NEON Collection, including never to edit or anonymise narratives that have been submitted, and to allow narrators to make updates to their narrative.

TABLE 5 Principles underpinning the NEON Collection of RRNs

VOICES domain 1: values and motivations of the NEON Collection
Purpose: the primary purpose of the NEON Collection is to provide benefits to recipients Mission: the NEON Collection will seek for heterogeneity of narrative content, form and narrator demographics and to be as large as possible. Greater heterogeneity and size increase the chance of a recipient finding someone like them or a story like theirs and hence experiencing helpful outcomes. Insufficient heterogeneity and size risk a recipient failing to find someone like them and hence feeling more disconnected from others Less-hopeful narratives: the NEON Collection will include some narratives where adversity and struggle are the dominant themes. Although these narratives are less regularly used by health services, recipients experiencing profound distress may find it easier to connect with such narratives
VOICES domain 2: organisation of the NEON Collection
Donation from existing collections: narratives can be donated to the NEON Collection by organisers of existing collections, but only if the collection organiser confirms that appropriate consent has been obtained and only if the narrative is already public. Appropriate consent means either the collection organiser has previously collected consent to enable reuse or has obtained consent from individual narrators to donate their narrative to the NEON Collection. Details of the source collection will be retained and may be displayed to recipients to help them understand the context of the narrative. Donations from individuals: narratives can also be offered to the NEON Collection by individual narrators, even if they have not been published Role of the curator: NEON researchers will assess inclusion of narratives, with involvement of the CSG, the NEON CI or a legal expert where uncertainty exists around specific exclusion criteria. Diversity in the NEON Collection will be monitored to identify under-represented groups to be targeted for narrative donation. Curators of the NEON Collection will not edit narratives, which will be displayed as close as possible to their original form
VOICES domain 3: inclusion and exclusion of narratives in the NEON Collection
Decision-making process: decisions on inclusion will be made with reference to formal current inclusion and exclusion criteria. These criteria will be publicly available to ensure transparency. Numbers of narratives considered, included and excluded will be published for transparency. If stories link to external material, then the contents of this material should not be considered when deciding inclusion, as it may change. Donors (either individual narrators or collection organisers) will be informed if their narrative is not included, and there will be an appeal process Inclusion criteria: a narrative is includable in the NEON Collection if all of the following criteria are met: (1) it includes elements of adversity or struggle that relate to mental health problems, broadly defined; (2) it includes descriptions of strength, success or survival, as defined by the narrator or identifiable by a third party; (3) it refers to events or actions over a period (including either external events or internal mental events); (4) it is told by an individual with experience of mental health problems and recovery; (5) where language is used, the narrative is mainly in English or, if translated, the translation needs to be provided or approved by the narrator; (6) the story is provided in a digital file, the story is provided in a format that can easily be converted into a digital file or the story is hosted on an existing web page, the URL to the web page is permanent and the page does not contain links that would enable navigation to another page; or (7) consent to use the narrative in perpetuity (other than if the narrative is withdrawn) has been obtained from the narrator, from the owners of an existing collection who have previously collected consent from their donors that is broad enough to allow for reuse, or from the owners of an existing collection who have collected individual consent from their donors for usage in the NEON Collection Exclusion criteria: a narrative is excluded from the NEON Collection if any of the following criteria are met: (1) it is presented as fictional; (2) it is told by anyone other than the individual experiencing mental health problems and recovery (such as a carer or journalist); (3) (for video and audio stories) the quality of recording is so low that the story is very difficult or not possible to understand; (4) it is split across multiple files or modalities or uses a multimedia approach that cannot easily be integrated into a single file; (5) it contains descriptions of potentially harmful behaviours in sufficient detail as to be likely to encourage imitation; (6) it indicates that the narrator has engaged in an undisclosed, serious criminal activity; (7) the narrator is a child or appears to be a child, unless it has been confirmed that the narrator is now an adult and has provided consent for a childhood story to be shared; (8) it contains hate speech; (9) it provides information about a third party that might reasonably lead to harm being caused to the third party, such as providing directly identifying information about someone accused of abuse; (10) it includes sensitive personal information about individual third parties, unless the third party has already made this information public, for example, by publishing their own recovery story, or unless the third party is no longer alive. A story includes sensitive information about a third party if it clearly reveals their political or religious beliefs, mental or physical health conditions, sexual orientation or behaviours, or any offences committed or alleged to have been committed by them; (11) it reveals the adoption status of a third party, unless the third party has already made this information public; or (12) it raises any other unforeseen concerns, in which case this list of reasons for exclusion may be updated. Exclusion criterion 9 is included for predominantly legal reasons: the NEON Collection is hosted in the European Union (EU) and hence subject to the EU General Data Protection Regulations on personal information

TABLE 5 Principles underpinning the NEON Collection of RRNs (*continued*)

VOICES domain 4: control and collaboration around the NEON Collection
Resolution of uncertainty: when making an assessment, there will be a bias towards the inclusion of a narrative. For example, inclusion criterion 2 is met if any rater can see strengths, successes or survival in a narrative. If NEON researchers are uncertain whether a narrative meets all the inclusion criteria or exclusion criterion 1, 2 or 3, a final decision will be made by CSG. If the uncertainty is about exclusion criterion 4, 5, 7, 11 or 12, a final decision will be made by the NEON CI. If the uncertainty is about exclusion criterion 6, 8, 9 or 10, an opinion will be sought from a legal representative approved by the study sponsor. Some forms of uncertainty can be resolved by asking the narrator for a short addendum to contextualise the narrative, but narrators are not required to submit this or may not be contactable, and hence final decisions may need to be made without it Oversight: for the duration of the NEON programme, the study sponsor will act as an auditor and may examine records relating to narrative consent. If use of the NEON Collection continues beyond the end of the study, an equivalent authority needs to be in place and approved by the study sponsor Archiving and reinstatement: the NEON Collection can be temporarily archived (e.g. at the end of the NEON programme), and withdrawal requests cannot be met while it is archived. It can only be reinstated from the archive if a body with an equivalent status to a study sponsor is identified Information about approvals: details of legal and ethical approvals for the NEON programme and the NEON Collection will be displayed whenever narratives from the NEON Collection are used
VOICES domain 5: ethical and legal considerations for the NEON Collection
Documentation of consent: if a collection organiser wishes to offer narratives to the NEON Collection, they must confirm in writing that consent has been provided. This confirmation will be stored for audit purposes Rights of collections: collection organisers have the right to withdraw any narratives that they have donated Rights of the narrator: accepted narrators have a right to inclusion and publication of a short addendum. They might use this to illustrate how their life has changed since they created their narrative or to contextualise what was happening in their life at the time they wrote their narrative. All narrators have a right to withdraw a narrative. They can request withdrawal through a collection organiser if the narrative was donated from an existing collection or directly through the NEON Collection in all cases Rights of third parties: third parties can request withdrawal, for example, if they assert that a narrator did not have capacity when they submitted a narrative, and each request will be individually assessed by the NEON CSG. To protect the right of narrators to have their story told, third parties do not have an automatic right to withdrawal Processing of withdrawal requests: all narratives will be given a unique identity document to aid withdrawal requests. Since some withdrawal requests may be malicious, such as an attempt by someone who is not the narrator to withdraw the narrative without due cause, in order to protect the rights of narrators and the existence of the NEON Collection, proof of identity may be required. Low-burden mechanisms will be provided to establish identity Assertion of copyright breach: individuals can assert that a narrative has breached their copyright, and assertions of copyright theft will be processed in accordance with the European e-Commerce Directive 2000/31/EC (81) Expectations on recipients: to access narratives in the NEON Collection, a user must register an account and commit to not copying any material. This is because some individuals have donated narratives that are not published elsewhere
VOICES domain 6: safety and well-being
Safety of narrators: the NEON Collection will not edit or anonymise narratives that have been submitted because stories can be an economic and social resource for some narrators and because this may have intellectual property implications for the NEON programme. If an individual donates their narrative to NEON, they will be provided with information about how the narrative will be used and encouraged to think about consequences of revealing their identity in a narrative, allowing them to make an informed choice about whether to be identifiable. They can submit identifying metadata (such as a story title that includes their name) if they wish Safety of curators: when assessing narratives for inclusion, curators have the right to disengage from a narrative that distresses them, either temporarily or permanently, without providing a reason

Contribution to the programme: These principles were adopted for work to develop the NEON Collection throughout the remainder of the programme. They have enabled international collaboration work, for example, in the NEON Young Norway study funded by the Norwegian Research Council, and hence should be seen as an important output of the programme.

Identification of harm minimisation strategies for the Narrative Experiences Online Intervention

https://doi.org/10.2196/24417 (JMIR Formative Research, 2021).

Objectives: To identify appropriate strategies for minimising harm from the NEON Intervention.

Methods: Harm minimisation strategies were developed through consultation with advisers. An initial set of harm minimisation strategies was developed by the NEON research team, responding to harms identified in the NEON Impact Model. This included a decision to display a content warning before access to relevant recovery narratives. A draft of a protocol describing these strategies was discussed with NEON International Advisory Board members, and an early prototype of the NEON Intervention incorporating those strategies was discussed by the NEON Intervention development group comprising of two LEAP members and two researchers. The harm minimisation approach embodied in the protocol and prototype were enhanced. The updated prototype was considered at a NEON LEAP meeting, and further enhancements were made, including renaming of content warning categories to be less distressing to users.

Results: Seven harm minimisation strategies were adopted in the design of the NEON Intervention and the procedures for the NEON trials: (1) describing all known harms on the participant information sheet (PIS); (2) asking participants to document preferred distress management strategies at first contact with the NEON Intervention; (3) providing a NEON Intervention distress page, which reminded participants of their preferred distress management strategies, recommended online self-management resources and signposted to relevant services; (4) the inclusion of researcher-rated warnings for narratives containing any of abuse or sexual violence, loss of life or endangerment to life, self-harm (including eating disorders), violence or aggression and injustice, and prejudice and discrimination; (5) enabling the proactive blocking of narratives based upon these content warning categories; (6) enabling the reactive blocking of individual narratives causing distress; and (7) a button allowing rapid exit from the NEON Intervention.

Contribution to the programme: These harm minimisation strategies were adopted for the NEON trials.

Narrative Experiences Online Intervention feasibility evaluation

Published by Slade *et al.*[14]

Objectives: To evaluate the feasibility of using the NEON Intervention and associated trial procedures with people with experience of mental health problems.

Methods: Participants who were mental health SUs (n = 24) were given access to a prototype web application integrating a simplified set of automated online trial procedures (e.g. online eligibility assessment, outcome collection) with the NEON Intervention. Participants attended an interview session, where they were asked to walk through selected features by a researcher, and verbalised their responses to these features. They were then given the NEON Intervention to use for a month, and their usage was logged. Finally, they were interviewed about their NEON Intervention use. Acceptable, unacceptable, more usable and less usable features were identified. Summary statistics on usage were collected.

Results: Feedback on the NEON Intervention was broadly positive, and a wide range of small changes were made, as documented in our intervention development paper.[16] These included updating outcome data collection forms, to provide clarity that collected data were not used by the NEON Intervention, and including a larger number of more precise ethnicity categories, so that participants could directly recognise their own ethnicity in the categories that we presented. Response rates to the five narrative feedback questions provided were lower than anticipated, and hence to increase response rates, we adjusted our interface to present a question on hopefulness as mandatory, and four as optional, following the NEON Impact Model. Mean number of unique narratives accessed per participant was 9.2 [standard deviation (SD) 6.3], which was lower than anticipated, and hence the NEON trials incorporated strategies to enhance engagement, such as the sending of messages to remind participants of the NEON Intervention.

Contribution to the programme: Insights from our feasibility study were used to refine the NEON Intervention for use in the NEON trials.

Research theme 5: evaluation of the Narrative Experiences Online Intervention

In research theme 5, we published a protocol for the NEON trials,[26] which defined all data items collected in our trials. This was followed by an update which described our approach to reconfiguring the NEON-O Trial into a definitive trial.[28]

We separately published our approach to ethical trial recruitment work,[52] important given that emerging evidence that some mental health recruitment practices can cause harm.[53] We opened all three NEON trials across 11 research sites in March 2020 and closed to recruitment in March 2021, with follow-up data collected by September 2021. All harm minimisation strategies developed in research theme 4 were implemented.

We analysed NEON Trial and NEON-O Trial data in parallel. In a preliminary analysis, we compared baseline participant characteristics, and found statistically significant differences in demographic characteristics between people who had and had not used specialist mental health services, in both trials.[21] This informed the development of our statistical analysis plan[54] and our health economics analysis plan. We estimated development and delivery costs for the NEON Intervention through an analysis of study records.[55] We then conducted our pre-planned clinical and economic analyses.[56] We also conducted 54 interviews with trial participants for our process evaluation.[57] We evaluated the performance of NarraGive, the hybrid recommender system used in the NEON Intervention.[51] We conducted focus groups with healthcare staff as a preliminary investigation of implementation issues around interventions incorporating recovery narratives.[56]

For the NEON-C Trial, we conducted a mixed-methods analysis which generated knowledge to inform a future definitive trial.[58]

Differences between online trial participants who have used statutory mental health services and those who have not: analysis of baseline data from two pragmatic trials of a digital health intervention

Published by Rennick-Egglestone *et al.*[21]

Objectives: To identify differences in baseline sociodemographic and clinical characteristics associated with specialist mental health service use for NEON Trial and NEON-O Trial participants.

Methods: For both trials, hypothesis testing was used to compare baseline sociodemographic and clinical characteristics of participants in the intention-to-treat (ITT) sample who had used specialist mental health services and those who had not. Bonferroni correction was applied to significance thresholds to account for multiple testing.

Results: Significant differences in characteristics were identified in both trials. Compared with non-SUs (124/739, 16.8%), NEON Trial specialist SUs (609/739, 82.4%) were more likely to be female ($p < 0.001$), older ($p < 0.001$) and White British ($p < 0.001$), with lower quality of life (QoL) ($p < 0.001$) and lower health status ($p = 0.002$). There were differences in geographical distribution ($p < 0.001$), employment ($p < 0.001$; more unemployment), current mental health problems ($p < 0.001$; more psychosis and personality disorders) and recovery status ($p < 0.001$; more recovered). Current SUs were more likely to be experiencing psychosis than prior SUs. Compared with non-SUs (399/1023, 39%), NEON-O Trial specialist SUs (614/1023, 60.02%) had differences in employment ($p < 0.001$; more unemployment) and current mental health problems ($p < 0.001$; more personality disorders), with lower QoL ($p < 0.001$), more distress ($p < 0.001$), less hope ($p < 0.001$), less empowerment ($p < 0.001$), less meaning in life ($p < 0.001$) and lower health status ($p < 0.001$).

Contribution to the programme: Our analysis found that mental health service use history was associated with numerous differences in baseline characteristics. We concluded that investigators should account for service use when developing and evaluating interventions for populations with mixed service use histories. This informed our decision to include subgroup analyses on service use history in our statistical[54] and health economic analysis plans.

Development and delivery cost of digital health technologies for mental health: application to the Narrative Experiences Online Intervention

Published by Paterson *et al.*[55]

Objectives: To describe and estimate the cost components and total cost of developing and delivering the NEON Intervention.

Method: Total costs for the NEON Trial (739 participants) and NEON-O Trial (1024 participants) were estimated by: identifying resource use categories involved in intervention development and delivery; accurate measurement or estimation of resource use; and a valuation of resource use to generate overall costs, using relevant unit costs. Resource use categories were identified through consultation with literature, costing reporting standards and iterative consultation with health researchers involved in NEON Intervention development and delivery. Sensitivity analysis was used to test assumptions made.

Results: The total cost of developing the NEON Intervention was £182,851. The largest cost components were software development (27%), LEAP workshops (23%), coding the narratives (9%) and researchers' time to source narratives (9%). The total cost of NEON Intervention delivery during the NEON Trial was £118,663 (£349 per NEON Intervention user). In the NEON-O Trial, the total delivery cost of the NEON Intervention was £123,444 (£241 per NEON Intervention user). The largest cost components include updating the narrative collection (50%), advertising (19%), administration (14%) and software maintenance (11%). Uncertainty in the cost of administration had the largest effect on delivery cost estimates.

Contribution to the programme: Per-participant delivery costs were used in the economic evaluation of the NEON Trial and NEON-O Trial.

Methodological procedures used in the Narrative Experiences Online trials

Protocol published by Rennick-Egglestone *et al*.[26]

Update published by Rennick-Egglestone *et al*.[28]

Ethical recruitment principles published by Rennick-Egglestone.[52]

Statistical analysis plan published by Robinson *et al*.[54]

Economic analysis plan: https://ars.els-cdn.com/content/image/1-s2.0-S2666776224002680-mmc1.docx (published as an appendix of our report on the NEON Trial[59]).

Effectiveness and cost-effectiveness of the Narrative Experiences Online Intervention for psychosis: the NEON Trial

Published by Slade *et al*.[59]

Consolidated Standards of Reporting Trials and Consolidated Health Economic Evaluation Reporting Standards checklists have been published: https://ars.els-cdn.com/content/image/1-s2.0-S2666776224002680-mmc1.docx

Objectives: The aim of the NEON Trial[59] was to understand whether receiving online RRNs benefits people with experience of psychosis. The primary objective was to evaluate the effectiveness of the NEON Intervention in improving QoL at 1-year follow-up, as compared to usual care (UC). Secondary objectives were: (1) to evaluate the effectiveness of the NEON Intervention in improving hope, empowerment and meaning in life, and in reducing psychological distress, as compared to UC; (2) to assess the cost-effectiveness of the NEON Intervention compared to UC, from a health and social care provider perspective; (3) to determine whether effectiveness and cost-effectiveness varied according to prior health service usage and (4) to understand how the intervention was used.

Methods: The NEON Trial included people (1) who had experienced psychosis in the last 5 years, (2) who had experienced mental health-related distress in the previous 6 months, (3) resident in England, (4) aged 18 years or older, (5) capable of accessing or being supported to access the internet, (6) able to understand written and spoken English and (7) capable of providing online informed consent.

Eligibility was confirmed through an online self-report questionnaire. Participants were recruited through a mixed online and offline approach to participant recruitment. To enable planning by future studies, we have published details of resources allocated to different forms of recruitment activity.[21] Participants providing online informed consent were

asked to provide baseline demographic and clinical outcomes data, and were randomised. Intervention group users were given immediate access to the NEON Intervention. Control group users gained access after primary end-point questionnaires were completed. All participants continued with UC. Intervention group users were told that they could use the NEON Intervention as little or as much as they wanted to encourage self-management of interaction with distressing narratives.

The primary outcome was QoL as assessed using the 12 items in section 3 of the Manchester Short Assessment (MANSA).[60] MANSA was collected at baseline, week 1, week 12 and (primary end point) week 52. Five secondary outcomes were assessed at baseline and primary end point. *Psychological distress* was assessed using Clinical Outcomes in Routine Evaluation 10 (CORE-10). *Hope* was assessed using the Herth Hope Index. *Self-efficacy* was assessed through the Mental Health Confidence Scale. The *presence* and *search* for meaning in life were assessed through the Meaning in Life Questionnaire. For the secondary outcomes, hope, meaning in life and self-efficacy were selected due to their match to the NEON Impact Model, with self-efficacy selected as a measurable component of empowerment. Psychological distress was selected for its important in a mental health content. For the economic analysis, *health status* was assessed through the EuroQol-5 Dimensions, five-level version (EQ-5D-5L).[61,62] An abridged Client Service Receipt Inventory (CSRI) was used to capture service use data for primary care, secondary mental and physical care, social care, and time away from usual activity or employment.[63] Collection forms, psychometric properties and calculation details have been described.[21]

The NEON Trial was powered on MANSA. The primary end point was a minimally clinically important difference in the index value, defined as an improvement of 0.25 at 52-week follow-up in the intervention group relative to the control group. For the NEON Trial, a target sample size of 684 was selected to provide 90% power allowing for 20% attrition (SD = 0.9,[64] power= 0.9, p = 0.05). The analysable sample required was 546.[26]

The economic analysis was conducted in Stata version 16.1 (StataCorp LP, College Station, TX, USA). All other analyses were conducted in R 64 version 4.1.2 (The R Foundation for statistical Computing, Vienna, Austria). The statistical significance level was 5%. Analysis was by a prospectively planned modified ITT principle which excluded accounts suspended due to repeat registration.[54] Repeat registrations by the same person are a known issue in health studies recruiting online.[65] A study-specific procedure was developed to manage repeat registration accounts, and was approved by PSC and TMG.

The primary analysis of primary and secondary outcomes was a linear regression model of outcome at 52-week follow-up adjusting for baseline score. Multiple imputation by chained equations (MICE)[66] was performed once to impute all missing baseline and clinical outcomes using the MI package, with the assumption that missing data are missing at random (MAR). Fifty data sets were generated and combined using Rubin's rules. Diagnostic checks were performed to evaluate the MICE procedure. A prospectively planned cost-effectiveness analysis compared the cost and quality-adjusted life-years (QALYs) gained for both arms from the perspective of the NHS in England (price year: 2020/21). UC was assumed to have zero upfront cost because the NEON Intervention was an addition to participants' current levels of care. Downstream healthcare resource use was calculated for both arms using the CSRI and combined with UK-based unit costs. EQ-5D-5L data collected at baseline and 52-week follow-up were used to estimate health status. EQ-5D-5L responses were converted to EuroQol-5 Dimensions, three-level version (EQ-5D-3L) utility values (UK tariff),[67] using the mapping method by Hernández Alava *et al.*[68] QALYs were calculated from the utility values for each participant, assuming a linear relationship between the time points (area under the curve method).[69] Mean total cost (log-link and Gamma family) and QALYs (identity-link and Gaussian family) were estimated for each arm using generalised linear models and recycled predictions adjusting for trial allocation and baseline characteristics (age, gender, MANSA total score), baseline EQ-5D-3L utility value and baseline cost (cost regression only).[69] Missing data were handled with MICE assuming MAR.[70] The main outcome was the incremental cost-effectiveness ratio (ICER), calculated as the ratio of incremental costs to incremental QALYs. Subgroups were examined by specialist service usage.

Results: Between 9 March 2020 and 1 March 2021, we recruited 739 participants, with 370 allocated to the intervention arm (immediate intervention access) and 369 allocated to the control arm (52-week delayed access). Mean age was 34.8 years (SD 12), 561 (75.9%) were White British, 443 (59.9%) were female, 609 (82.4%) had accessed specialist care mental health services and 698 (94.5%) had accessed primary care mental health services. The most

common mental health problems experienced in the last month were mood disorders (265, 35.9%) and psychosis (154, 20.8%). About 70.9% lived with others, and 48.2% were unemployed. About 84 (11.4%) identified as living beyond disability. Including imputed data for the primary analysis, we found no evidence of a difference in QoL between the two groups (baseline-adjusted difference 0.07, 95% CI −0.07 to 0.21, $p = 0.346$), or in any secondary outcomes. The NEON Intervention increased costs by £1177 per participant [95% credible interval (CrI) £438 to £1969], and increased QALYs by 0.0107 per participant (95% CrI 0.0041 to 0.0258). The estimated ICER was £110,501 per QALY gained, which exceeded the threshold to determine cost-effectiveness in England (£20,000–30,000 per QALY). There were no serious adverse events related to trial procedures or NEON Intervention access. Our findings do not support the use of the NEON Intervention to improve QoL for all people with psychosis experience, but an unplanned subgroup analysis provided preliminary evidence that the NEON Intervention may be more cost-effective for current mental health SUs (estimated ICER £35,013). More generally, broad variation in narrative usage during our trial indicates the need for future work to identify subgroups who might benefit from narrative access.

Contribution to the study: This definitive trial does not support the roll-out of the NEON Intervention at population level for psychosis but does support the continued exploration of effectiveness and cost-effectiveness for people with psychosis who currently use mental health services.

Effectiveness and cost-effectiveness of the Narrative Experiences Online Intervention for non-psychosis mental health problems: the Narrative Experiences Online – Others Trial

Published by Slade *et al*.[32]

Objectives: The aim of the NEON-O Trial was to understand whether receiving online RRNs benefits people with mental health problems other than psychosis. The primary objective was to evaluate the effectiveness of the NEON Intervention in improving QoL at 1-year follow-up as compared to UC. Secondary objectives were: (1) to evaluate the effectiveness of the NEON Intervention in improving hope, empowerment and meaning in life, and in reducing psychological distress, as compared to UC; (2) to assess the cost-effectiveness of the NEON Intervention compared to UC, from a health and social care provider perspective; (3) to determine whether effectiveness and cost-effectiveness varied according to prior health service usage; and (4) to understand how the intervention was used.

Methods: The NEON-O Trial included people (1) who had experienced non-psychosis mental health problems in the last 5 years, (2) who had experienced mental health-related distress in the previous 6 months, (3) resident in England, (4) aged 18 years or older, (5) capable of accessing or being supported to access the internet, (6) able to understand written and spoken English and (7) capable of providing online informed consent.

Eligibility was confirmed through an online self-report questionnaire. Participants were recruited through a mixed online and offline approach to participant recruitment. To enable planning by future studies, we have published details of resources allocated to different forms of recruitment activity.[21] Participants providing online informed consent were asked to provide baseline demographic and clinical outcomes data, and were randomised. Intervention group users were given immediate access to the NEON Intervention. Control group users gained access after primary end-point questionnaires were completed. All participants continued with UC. Intervention group users were told that they could use the NEON Intervention as little or as much as they wanted, to encourage self-management of interaction with distressing narratives.

The primary outcome was QoL as assessed using the 12 items in section 3 of MANSA.[60] MANSA was collected at baseline, week 1, week 12 and (primary end point) week 52. Five secondary outcomes were assessed at baseline and primary end point. *Psychological distress* was assessed using CORE-10. *Hope* was assessed using the Herth Hope Index. *Self-efficacy* was assessed through the Mental Health Confidence Scale. The *presence* and *search* for meaning in life were assessed through the Meaning in Life Questionnaire. For the secondary outcomes, hope, meaning in life, and self-efficacy were selected due to their match to the NEON Impact Model, with self-efficacy selected as a measurable component of empowerment. Psychological distress was selected for its important in a mental health content. For the economic analysis, *health status* was assessed through the EQ-5D-5L.[61,62] An abridged CSRI was used to capture

service use data for primary care, secondary mental and physical care, social care, and time away from usual activity or employment.[63] Collection forms, psychometric properties and calculation details have been described.[21]

The NEON-O Trial was powered on MANSA. The primary end point was a minimally clinically important difference in the index value, defined as an improvement of 0.25 at 52-week follow-up in the intervention group relative to the control group. For the NEON-O Trial, a target sample size of 994, was selected to provide 90% power to detect a difference in the MANSA score of 0.25 between intervention and control (SD = 0.94, power= 0.9, $p = 0.05$). This allowed for 40% attrition, which was estimated from inspection of week 1 and 12 attrition. The analysable sample was 596. The population deviation was estimated from the first 350 baseline responses.[28]

The economic analysis was conducted in Stata version 16.1 (StataCorp LP, College Station, TX, USA). All other analyses were conducted in R 64 version 4.1.2 (The R Foundation for Statistical Computing, Vienna, Austria). The statistical significance level was 5%. Analysis was by a prospectively planned modified ITT principle which excluded accounts suspended due to repeat registration.[54] Repeat registrations by the same person are a known issue in health studies recruiting online.[65] A study-specific procedure was developed to manage repeat registration accounts, and was approved by PSC and TMG.

The primary analysis of primary and secondary outcomes was a linear regression model of outcome at 52-week follow-up adjusting for baseline score. MICE[66] was performed once to impute all missing baseline and clinical outcomes using the MI package, with an assumption of MAR. Fifty data sets were generated, and combined using Rubin's rules. Diagnostic checks were performed to evaluate the MICE procedure. A prospectively planned cost-effectiveness analysis compared the QALYs gained for both arms from the perspective of the NHS in England (price year: 2020–21). UC was assumed to have zero upfront cost because the NEON Intervention was an addition to participants' current levels of care. Downstream healthcare resource use was calculated for both arms using the CSRI and combined with UK-based unit costs. EQ-5D-5L data collected at baseline and 52-week follow-up were used to estimate health status. EQ-5D-5L responses were converted to EQ-5D-3L utility values (UK tariff),[67] using the mapping method by Hernández Alava *et al.*[68] QALYs were calculated from the utility values for each participant, assuming a linear relationship between the time points (area under the curve method).[69] Mean total cost (log-link and Gamma family) and QALYs (identity-link and Gaussian family) were estimated for each arm using generalised linear models and recycled predictions adjusting for trial allocation and baseline characteristics (age, gender, MANSA total score), baseline EQ-5D-3L utility value, and baseline cost (cost regression only).[69] Missing data were handled with MICE assuming MAR.[70] The main outcome was the ICER, calculated as the ratio of incremental costs to incremental QALYs. Subgroups were examined by specialist service usage.

Results of the NEON-O Trial: Between 9 March 2020 and 26 March 2021, we recruited 1023 participants from across England (target: 994). 827 (80.8%) identified as White British, 811 (79.3%) as female, 586 (57.3%) were employed, 272 (26.6%) were unemployed, and the mean age was 38.4 years (SD 13.6). Mood disorders ($n = 626$, 61.2%) and stress-related disorders (152, 14.9%) were the most common mental health problems. At 52 weeks, our ITT analysis found a baseline-adjusted increase in the MANSA score of 0.13 (95% CI 0.01 to 0.26, $p = 0.041$), a baseline-adjusted increase in the Meaning in Life Questionnaire (presence subscale) of 0.22 (95% CI 0.05 to 0.4, $p = 0.014$), and no significant change in any other secondary outcomes. There was an incremental gain of 0.0142 QALYs (95% CrI 0.0059 to 0.0226) per participant and a £178 incremental increase in cost (95% CrI £154 to £455), generating an ICER of £12,526 per QALY compared with usual treatment, which was sufficiently cost-effective against a £20,000 per QALY threshold used by the National Health Service in England. There was one related serious adverse event, due to a known harm identified in the PIS, which the participant managed through disengaging from the NEON Intervention. We conclude that the NEON Intervention is a sufficiently cost-effective new intervention for people experiencing non-psychosis mental health problems, and that its safety should be monitored as larger-scale deployments are conducted.

Contribution to the study: This definitive trial supports the implementation of the NEON Intervention for people living with mental health problems other than psychosis, both as a widely available population intervention and as an evidence-based intervention within mental health services.

Perception and appropriation of a web-based recovery narratives intervention: qualitative interview study

Published by Ali *et al*.[57]

Objectives: The aim was to understand the experiences of NEON Trial and NEON-O Trial participants in registering for the NEON Trial and NEON-O Trial, and in using the NEON Intervention. The objectives were: (1) to identify motivations for trial participation and intervention usage; (2) to document how the NEON Intervention was appropriated; and (3) to document perceptions of the NEON Collection that influenced usage.

Methods: Inductive thematic analysis of interviews with a purposive sample of intervention arm participants from both trials who had completed trial participation. Maximum variation samples were sought on (a) intervention use level and (b) mental health service use history.

Results: We interviewed 34 NEON Trial and 20 NEON-O Trial participants (mean age 40.4 years). Some users accessed narratives through the NEON Intervention almost daily, while others used it infrequently or not at all. Motivations for trial participation included: exploring the NEON Intervention as an alternative or addition to existing mental health provision; searching for answers about mental health experiences; developing their practice as a mental health professional (for a subset who were mental health professionals); claiming payment vouchers. High users (10 + narrative accesses) described three forms of appropriation: distracting from difficult mental health experiences; providing an emotional boost; sustaining a sense of having a social support network. Most participants valued the scale of the NEON Collection (n = 659 narratives), but some found it overwhelming. Many felt they could describe the characteristics of a desired narrative that would benefit their mental health. Finding a narrative meeting their desires enhanced engagement, but not finding one reduced engagement. Narratives in the NEON Collection were perceived as authentic if they acknowledged the difficult reality of mental health experiences, appeared to describe real world experiences, and described mental health experiences similar to those of the participant.

Contribution to the study: This process evaluation will support the implementation of the NEON Intervention, for example, by enabling providers to plan how to support their SUs in successfully appropriating the NEON Intervention.

The use of recommender systems for mental health recovery narratives: a novel evaluation

Published by Slade *et al*.[51]

Objectives: To evaluate NarraGive by describing how participants used it and by comparing the performance of the content-based filtering algorithm with the two collaborative filtering algorithms.

Methods: Using a recently published framework for evaluating recommender systems to structure the analysis, we compared the content-based filtering algorithm and collaborative filtering algorithms used by NarraGive, by evaluating their accuracy (how close the predicted ratings are to the true ratings), precision (the proportion of the recommended narratives that are relevant), diversity (how diverse the recommended narratives are), coverage (the proportion of all available narratives that can be recommended), and unfairness (whether the algorithms produce less accurate predictions for disadvantaged participants) across gender and ethnicity. We used baseline demographic data, and narrative request and feedback data, from all participants in the NEON Trial and NEON-O Trial.

Results: Participants from the NEON Trial and NEON-O Trial provided 2288 and 1896 narrative ratings, respectively. Each rated narrative had a median of 3 ratings and 2 ratings respectively. For the NEON Trial, the content-based filtering algorithm performed better for coverage, the collaborative filtering algorithms performed better for accuracy, diversity and unfairness across both gender and ethnicity, and neither algorithm performed better for precision. For the NEON-O Trial, the content-based filtering algorithm did not perform better on any metric, the collaborative filtering algorithms performed better on accuracy and unfairness across both gender and ethnicity, and neither algorithm performed better for precision, diversity or coverage.

Contribution to the programme: This analysis demonstrated that the recommender system incorporated in the NEON Intervention consistently performed better than random choice of narrative, providing some validation for the incorporation of recommender systems into narrative-based interventions. It provides preliminary evidence that there may be an association between clinical population and recommender system performance.

Pragmatic, feasibility randomised controlled trial of a recorded mental health recovery narrative intervention: Narrative Experiences Online Intervention for informal carers (NEON-C)

Published by Ng *et al*.[58]

Objectives: To examine the feasibility and acceptability of the NEON Intervention on informal carers.

Method: Two-arm feasibility RCT. Carers were randomly assigned to receiving versus not receiving the NEON Intervention. Feasibility aspects investigated included: the acceptability of the intervention and of randomisation, trial processes, engagement rates, recruitment procedures, attrition, sample size estimation, identification of candidate primary and secondary outcomes, and the feasibility to conduct a definitive trial. Qualitative process evaluation was conducted.

Results: 121 carers were eligible, 54 carers were randomised (intervention: 27, control: 27). Twelve-month follow-up data were available for 36 carers. Carers accessed a mean of 25 narratives over a 12-month period and the intervention group, compared with the control group, reported a small effect on hope (Cohen's $d = 0.14$), a moderate effect on the presence of meaning in life (Cohen's $d = 0.31$), and a moderate effect on the search for meaning in life (Cohen's $d = -0.33$). Five modifications were recommended to improve the user experience, applicability and trial processes. These were: the inclusion of carer perspective narratives; the inclusion of signposting information to carer support services; user interface clarifications on whether data collection forms should be answered from a carer or lived experience perspective; development of an interactive carer community around the NEON Intervention; consideration of specific privacy issues, for example, if carers are identifiable in narratives accessed by people they care for.

Contribution to the programme: The study demonstrated that the NEON Intervention is feasible and acceptable in principle for use by informal carers, but that significant refinement of the NEON Intervention and trial processes is required to personalise and ensure applicability to carers.

Opportunities, enablers and barriers to the use of recorded recovery narratives in clinical settings

Published by Roe *et al*.[56]

Objectives: To enable implementation planning for interventions incorporating RRNs, by documenting a range of clinical perspectives on determinants of uptake in clinical and clinical education settings.

Method: Three phases of focus groups were conducted with multiprofessional mental health clinicians. Phase 1 (4 groups, $n = 25$) investigated current and possible uses of RRNs. Phase 2 (2 groups, $n = 15$) investigated clinical perspectives on the NEON Intervention. Phase 3 (2 groups, $n = 12$) investigated clinical education uses. Thematic analysis was conducted.

Results: Focus group participants felt that RRNs can reinforce the effectiveness of existing clinical practices, by reducing communication barriers and normalising mental health problems. They can also extend clinical practice (through increasing hope and connection, and providing help when clients have become 'stuck' in a therapeutic process). Clinical considerations are the relationship with care pathways, choice of staff and stage of recovery. In educational use there were opportunities to access lived experience perspectives, train non-clinical staff and facilitate attitudinal change. Barriers and enablers related to design (ability to use online resources, accessibility of language, ability to individualise choice of narrative), risk (triggering content, staff skills to respond to negative effects), trust in online resource (evidence base, maintenance), and technology (cost of use, technology requirements).

Contribution to the programme: This preliminary study will inform the future clinical implementation of the NEON Intervention.

Discussion

Overall achievements

The work plan changed from that submitted, partly due to changed circumstances such as the COVID-19 pandemic, and partly due to a deepening understanding of the central issues as the study progressed. We restructured WPs 1 and 2 to respond to the immediate needs of the programme at the time. Our new structure, in which systematic reviews were used to develop preliminary conceptual frameworks, which were subsequently extended through empirical research work, was a success. Findings from our systematic review on the impact of recovery narratives were particularly limited, due to the small number of included papers, and hence empirical work was particularly important to create thorough conceptual frameworks. Three new forms of harm were added through empirical work, to the one form of harm identified from systematic reviews. It is possible that research studies can under-state harms, and hence our thorough attention to these was a success, and enabled the design of appropriate harm minimisation strategies.

The capacity provided by a long and well-staffed study allowed several un-planned added-value substudies to be conducted, including secondary analysis of our qualitative data to develop novel findings in relation to institutional injustice, experience of non-SUs, and post-traumatic growth (which led to a new programme of work led by a NEON researcher), exploration of methodologies for assessing diversity in the NEON Collection, and a series of papers exploring the issues around curation of mental health recovery and lived experience narratives.

Our overall management approach, of structuring the NEON study as a series of self-contained substudies, has been a success as it has enabled the early publication of findings. In turn, this has enabled our partners to replicate or extend our published work by conducting and publishing their own studies, for example, in the development and evaluation of a recovery narrative intervention for alcohol misuse,[18,71–73] and through the translation of INCRESE to Dutch.[74]

Patient and public involvement

Our work to include diverse public members in our research was broadly successful. We maintained a panel of 10 public advisers throughout most of the programme, with new members invited in as others chose to depart. LEAP had a meaningful influence over important programmatic decisions, including our decisions to not require anonymisation of narratives, the presentation of our content warnings, and the design of user-facing elements of the NEON Intervention. Given that the original NEON proposal only had one definitive trial for people with experience of psychosis, then we contemplated including only narratives describing psychosis experiences, but LEAP persuaded us that a more diverse collection was better, and we now believe that this was the correct choice. Our CSG developed substantial expertise in thinking about the choice and rationale to include or exclude particular narratives. It was a success to create this group, and to award it decision-making powers. In turn, CSG decided that there were certain narratives, such as those including graphic descriptions of self-harm which may create harm through behavioural emulation, that it did not have competence to decide on, and recommended that the clinically qualified NEON CI should make the decision, which was a success of the processes that we had designed.

Equality, diversity and inclusion

Equality, diversity and inclusion and the Narrative Experiences Online Collection

At several points during the programme, we assessed the diversity of the recovery narratives contained in the NEON Collection by analysing the distribution of INCRESE ratings across all narratives. We then sought to increase narrative diversity by targeted engagement with relevant community organisations, to encourage narrative donation from under-represented groups. This led to an unplanned theoretically informed paper investigating the methodological challenges of assessing diversity in narrative collections and using the NEON Collection as an exemplar.[43] This will be of wider use in supporting the development of diverse and inclusive narrative collections.

Equality, diversity and inclusion and the Narrative Experiences Online trials

To maximise diversity of participants in the NEON trials, we used multiple approaches to recruitment, including:

- Paid online advertising on mental health websites and printed magazines.

- Engaging with 775 diverse mental health community groups to distribute promotional materials to diverse communities, specifically including traditionally under-represented groups.
- Engaging with 66 primary healthcare practices to distribute promotional materials to local communities.
- Distributing promotional messaging through paid (to enhance message reach) social media promotions on Facebook [Meta Platforms, Inc.(formerly Facebook) Menlo Park, CA, USA], Twitter [X Corp. (formerly Twitter) San Francisco, CA, USA] and Google (Google Inc., Mountain View, CA, USA).
- Television and radio media appearances by the central study team.
- Working with the CRNs of 11 secondary care mental health trusts.

For the NEON-O Trial, we had an unrepresentative proportion of female-gendered participants (79.3%). The proportion of participants who were White British was close to the proportion reported in the 2021 census for England (census: 81.7%; NEON-O Trial: 77.1%). We found evidence for differential effectiveness by gender in our CORE-10 finding, where women experienced a reduction in psychological distress, but men did not. We found evidence for differential effectiveness by ethnicity in our findings on the presence of meaning in life, where White British people benefited, but people who were not White British did not. The mechanisms creating these interaction effects should be explored through future research, to examine their impact on health service implementation. For the NEON Trial, the proportion of participants who were White British was close to the proportion reported in the 2021 census for England (census: 81.7%; NEON Trial: 75.9%). No interaction effects for ethnicity or gender were found.

Engagement with partners and stakeholders

Existing collections of recovery narratives were critically important partners to the success of our programme, as most of the narratives that were included in the NEON Collection, and hence used in our trials, were sourced from existing collections. We worked carefully to build relationships with existing collections, and to establish appropriate procedures for obtaining and documenting consent to include their narratives. In some cases, collection organisers obtained individual consent from narrators, and in others, collection organisers had pre-existing documentation of consent to share narratives. Engaging with collection organisers required a substantial effort from the study team. Payments to collection organisers enabled success in gaining consent for narratives, particularly where our partner was a smaller organisation, with more limited resources. For example, for some collections, we compensated collection organisers for the time required to contact narrators, inform them about the NEON study, and manage consent records for our use of their narrative. We recruited eleven NHS secondary care trusts to partner with our programme as research sites in our trials. Some trusts also acted as stakeholders, providing access to knowledge on how recovery narrative interventions might be deployed in the NHS, and insights into how clinicians viewed the NEON Intervention.

Institutional capacity building

Narratives describing lived experiences of mental health problems are widely used as a form of intervention in health and community settings,[9] and are regularly analysed to understand personal experiences of healthcare problems.[75] In our own institutions, interventional use of lived experience narratives was not a common endeavour, and research through narrative inquiry was relatively common. To succeed, we have needed to build capacity to work with lived experience narratives as a form of intervention. This has included developing protocols for managing narrative collections (which have subsequently been re-used in new NIHR-funded studies, e.g. LEND https://fundingawards.nihr.ac.uk/award/NIHR206255) and through developing research staff knowledge on ethical and legal challenges of working with lived experience narratives. Greater knowledge around narratives has in turn generated research success, including through analysis of healthcare narratives provided through patient feedback systems regularly used in England.[76]

Limitations

Our empirical work gave a thorough account of the long-term impact, as many participants in our NEON narrative interviews were found to be capable of reflecting on several years of their life, and thinking about this impact. It gave a thorough account of short-term impact. There were limitations to this work that could be addressed through future studies, in that our designs may not have catered well for people experiencing challenges with their memory, and may not have been able to capture medium-term detail on processes by which the impact of recovery narratives plays out. In our NEON-O Trial, there was no significant baseline-adjusted difference between intervention and control at 1-week and 12-week follow-up, but there was a significant baseline-adjusted difference at 52-week follow-up, suggesting that the study of how change occurs over a period of around a year could be important. Our empirical studies on the

characteristics and impact of narratives, both of which included interviews, had a bias towards participants comfortable with expressing themselves verbally, and might be extended through alternative study mechanisms catering for participants with a preference for other (e.g. non-verbal) forms of communication. This use of interviewing is a consistent bias in health research.[77]

A limitation of our trials is that they did not capture outcome data over periods longer than 1 year. In the NEON Trial, use of mental health services increased, which was a driver of increased participant cost in intervention compared to control. This is consistent with treatment seeking behaviour, a known mechanism of action for online digital health interventions.[78] Especially given current long waiting lists for mental health treatment, then it is possible that a longer follow-up period would find benefits for intervention arm participants, as treatment received once sought starts to help. A substantial challenge to the design of our trials was that mental health recovery narratives are now broadly available to the public. In the NEON Trial and the NEON-O Trial, recovery narratives were accessed by a substantial number of the control group, and the use of NEON Collection narratives predicted the use of narratives outside of the NEON Intervention. This use of recovery narratives by the control group might be conceptualised as a form of contamination, and it may mean that effect sizes are underestimated in both trials. The ICER for both trials may be overestimated if compared to a population-scale deployment, as the NEON Intervention delivery cost incorporates some fixed costs, whose per-participant value would reduce with a larger user base. Our sensitivity analysis using a pattern mixture model demonstrated that our significant finding on effectiveness in increasing QoL was sensitive to small departures from MAR, since it became insignificant if people in the intervention arm with missing data had a reduction of more than 1% in their MANSA score compared with individuals who had observed data.

We are uncertain about our use of payment vouchers for trial participants. In the NEON Trial, £80 was available to participants across four sets of questionnaires, representing a liability of £54,270, which represents a substantial commitment of study resources. In the NEON-O Trial, our amendment introduced payment vouchers for the primary end-point questionnaire only, with a liability of £19,880. The intention of this amendment was to increase completion rates for outcome data collection questionnaires. For the NEON-O Trial, completion rates at the primary end point were higher than at 12-week follow up (565 compared to 442 MANSA scores), which is consistent with voucher payments increasing completion rates. However, for the NEON Trial, 66 (17.8%) of intervention arm participants accessed no narratives, which is consistent with a process evaluation finding that some participants registered to the trial purely to obtain vouchers, thereby diluting any possible effect of the NEON Intervention. An alternative use of the committed study resources for voucher payments would have been additional recruitment effort, for example, through boosting the reach of social media posts, which were an effective route to recruitment.

Recommendations for research

1. The NEON Intervention should be evaluated through a RCT with people experiencing psychosis and using mental health services.
2. The NEON Intervention should be refined to suit the needs of carers and then evaluated through a RCT.
3. The NEON-O Trial should be repeated with narrower mental health populations (e.g. mood disorders, eating disorders) to refine knowledge on effectiveness and cost-effectiveness. This may include refining the narrative collection used with these populations.
4. If the NEON Intervention is implemented on a larger scale for people with non-psychosis mental health problems, then studies should be conducted to monitor benefits, continuously assess safety, and documentation implementation processes.
5. Future studies should consider alternative forms for presenting recovery narratives, including through multilanguage or multiculture support, and addressing digital exclusion by providing access through widely available technologies, such as smartphones and text messaging.
6. Longitudinal designs are needed to document the short-term, medium-term and long-term impacts of recovery narratives.

Implications for healthcare practice

Our NEON-O Trial provided a definitive finding that the NEON Intervention led to a very small QALY gain in a particular and non-representative population. Our economic analyses suggested that it may be cost-effective for people with

mental health problems but no experience of psychosis, with cost-effectiveness evaluated from the perspective of the NHS in England, but results lacked statistical significance. These promising findings need to be further tested in the future research programme we have specified.

Our systematic review on the uses and misuses of recovery narratives has provided evidence that recovery narratives can be misused, including through co-option by mental health services.[9] For example, we have learnt of examples of the misuse of recovery narratives within the NHS in England, such as mental health workers being asked to collect recovery narratives from SUs, and to edit these narratives to provide a more positive view on the role and actions of mental health services. Mental health service providers should create an expectation that recovery narratives are not misused within their services, perhaps through integrating our published good practice guidelines.[47]

Impact and learning

Digital health interventions can be relatively cheap to deliver, especially as user numbers grow (and hence the overall cost of providing access is amortised across a larger number of people). The greatest impact from our work may come from provision of the NEON Intervention as a national public health resource. This will require work to re-engineer the NEON Intervention to cater for much larger numbers of users. The strongest impact and learning would come from international replications of our NEON trials, perhaps with an examination of how to select narratives that were most appropriate for different national or cultural settings.

Conclusions

The NEON Programme ran from 2017 to 2023. It has synthesised existing and new evidence on the characteristics of mental health recovery narratives, provided RCT evidence that mental health recovery narratives can provide sufficiently cost-effective benefits to QoL, and demonstrated that an automated algorithm can make narrative recommendations with the capacity to help people. The available literature on the impact of recovery narratives was particularly limited at the start of our programme, and we have made a substantial contribution to this, including through the first definitive trial registered with ISRCTN demonstrating a benefit to meaning in life. Through conducting our work, we have established an inclusive recovery narratives definition, developed ethical and legal processes for curating recovery narrative collections, documented the various ways in which social factors influence narrative experience, and developed a narrative-based intervention that priorities diversity narrative form, and narrator identity. A promising next step for research would be a RCT evaluation of the NEON Intervention with current users of statutory mental services experiencing psychosis.

Additional information

CRediT contribution statement

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Data-sharing statement

Data access is controlled to protect the confidentiality of research participants in the NEON study, and in particular to avoid re-identification through combination of multiple data files. Data will be available on reasonable request, supervised by the study sponsor.

Requests can be denied if the sponsor has reason to believe that the requestor has malicious intent, and while research publications are being generated by the study team or investigators. Only anonymous and pseudonymous elements of the data sets used or analysed during the study will be available. Informed consent information has been retained for

audit but will not be shared. Some categories of demographic data will be redacted to avoid re-identification. A data dictionary will be provided when data are released.

Anonymous and pseudonymous research data will be available from the study sponsor until the end of the retention period. After the retention period, availability through the study sponsor or Chief Investigator may be provided at their discretion. Contact the study sponsor through Research@nottshc.nhs.uk, citing the funder's reference number (RP-PG-0615-20016). To obtain access, an end-user licence must be signed by an authorised representative.

Ethics statement

All research work with human research participants was approved by the HRA, including work to assemble the NEON Collection. We sought approval through three applications to the HRA, which were considered by NHS RECs. Application 1 was for the NEON narrative interviews, and interviews with narrative collection curators. It was given favourable opinion by Nottingham 2 REC (17/EM/0401, 12 December 2017). Application 2 was for all subsequent study research activities other than the evaluation of the NEON trials. It was given favourable opinion by West London and Gene Therapy Advisory Committee REC (18/LO/0991, 9 July 2018). Application 3 was for approval of the NEON trials. It was given favourable opinion by Leicester Central REC (19/EM/0326, 9 December 2019).

Information governance statement

Nottinghamshire Healthcare NHS Foundation Trust was the lead organisation for the NEON study and is committed to handling all personal information in line with the UK Data Protection Act (2018) and the General Data Protection Regulation (EU GDPR) 2016/679. Under the Data Protection legislation, Nottinghamshire Healthcare NHS Foundation Trust is the Data Controller, and you can find out more about how we handle personal data, including how to exercise your individual rights and the contact details for our Data Protection Officer here: www.nottinghamshirehealthcare.nhs.uk/your-information

Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at https://doi.org/10.3310/PPOG2281.

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Publications

Peer-reviewed journal publications

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35. Ali Y, Rennick-Egglestone S, Llewellyn-Beardsley J, Ng F, Yeo C, Franklin D, *et al*. Perception and appropriation of a web-based recovery narratives intervention: qualitative interview study. *Front Digit Health* 2024;**6**. https://doi.org/10.3389/fdgth.2024.1297935

36. Slade E, Rennick-Egglestone S, Ng F, Kotera Y, Llewellyn-Beardsley J, Newby C, *et al*. The implementation of recommender systems for mental health recovery narratives: evaluation of usage and performance. *JMIR Ment Health* 2024;**11**. https://doi.org/10.2196/45754

37. French B, Babbage C, Bird K, Marsh L, Pelton M, Patel S, *et al*. Data integrity issues with online studies, an institutional example of a widespread challenge. *JMIR Ment Health* 2024;**11**:e58432. https://doi.org/10.2196/58432

38. Slade M, Rennick-Egglestone S, Robinson C, Newby C, Elliott R, Ali Y, *et al*. Effectiveness and cost-effectiveness of online recorded recovery narratives in improving quality of life for people with psychosis experience (NEON Trial): a pragmatic randomised controlled trial. *Lancet Region Health: Europe* 2024;**47**:101101. https://doi.org/10.1016/j.lanepe.2024.101101

Editor-reviewed publications

1. Narrative Experiences Online Lived Experience Advisory Panel. *Telling a Story of Mental Health Experiences, a Guide*. London: McPin Foundation, 2020. URL: www.researchintorecovery.com/files/Telling%20a%20story%20of%20mental%20health%20experiences_McPin%20Foundation_0.pdf (accessed 28 September 2023).

2. Harrison J. *The Importance of the Storyteller's Identity in Mental Health Narratives*. London: McPin Foundation, 24 November 2022. URL: https://mcpin.org/the-importance-of-the-storytellers-identity-in-mental-health-narratives/ (accessed 28 September 2023).

3. Yeo C, Rennick-Egglestone S, Ali Y, Armstrong V, Borg M, Bradstreet S, *et al*. *Mental Health Lived Experience nNarratives: Recommendations for Avoiding Misuses and Adopting Good Practice*. Nottingham: Institute of Mental Health; 2023. URL: https://institutemh.org.uk/research/projects-and-studies/completed-studies/neon-good-practice-guidelines (accessed 28 September 2023).

4. Rennick-Egglestone S. Mental health recovery outside of statutory services – the contribution of public health. Editorial for special issue on 'Recovery outside of mental health services: what can public health contribute?'. *Perspect Publ Health* 2023;**143**. https://doi.org/10.1177/17579139231172679

5. Pomberth S. *Differences Between Online Trial Participants Who Have Used Statutory Mental Health Services and Who Have Not: My Involvement in a Research Publication*. Institute of Mental Health blog series, 3 July 2023. URL: www.institutemh.org.uk/news/blog/differences-between-online-trial-participants-who-have-used-statutory-mental-health-services-and-who-have-not-my-involvement-in-a-research-publication (accessed 28 September 2023).

6. Llewellyn-Beardsley J, Ali Y, Bailey S, Booth S, Davis P, Fox-Yeo C, *et al*. Lived experience narratives for mental health recovery: the Narrative Experiences Online (NEON) Programme. Nottingham: Institute of Mental Health; 2025. URL: https://institutemh.org.uk/research/projects-and-studies/completed-studies/neon (accessed 28 July 2025).

PhD thesis

Llewellyn-Beardsley J. *'Not the Story You Want, I'm Sure': Mental Health Recovery and the Narratives of People from Marginalised Communities*. PhD thesis. University of Nottingham. URL: https://eprints.nottingham.ac.uk/73527/ (accessed 28 September 2023).

Press releases

1. Rennick-Egglestone S, Anscombe C. *Personal Stories of Mental Illness Can Help Others on the Road to Recovery*. Press release published at www.nottingham.ac.uk/news/personal-stories-of-mental-illness on 13 May 2019

2. Rennick-Egglestone S, Abdallah H. *Content and Trigger Warnings from 32 Countries and 10 Different Sectors Analyzed to Produce a New Framework of Classification by Theme (Violence, Language, Flashing Lights, etc.) and Media Type*. Press release published at www.eurekalert.org/news-releases/950988 on 4 May 2022

3. Rennick-Egglestone S, Anscombe C. *Experts Develop a Common Language for Trigger and Content Warnings*. Press release published at www.eurekalert.org/news-releases/951278 on 4 May 2022

4. National Institute for Health and Care Research. *Mental Health Research Service User and Carer Involvement 2022 Award Winners Announced*. 16 May 2022. URL: www.nihr.ac.uk/documents/mental-health-research-service-user-and-carer-involvement-2022-award-winners-announced/30598

5. Institute of Mental Health. *NEON Study Wins 2022 Mental Health Research Service User and Care Involvement Award*. 16 May 2022. URL: www.institutemh.org.uk/news/1531-neon-trial-wins-2022-mental-health-research-service-user-and-care-involvement-award

6. Clinical Research Network. *Mental Health Research Service User and Carer Involvement Award*. 16 May 2022. URL: https://mailchi.mp/nihr/crn-connect-issue-14931973?e=c1c15f2f23

7. Anscombe C, Rennick-Egglestone S, Slade M. *Personal Stories of Overcoming Mental Illness Can Help Others on Similar Paths to Recovery*. University of Nottingham Press Office, 22 January 2024. URL: www.nottingham.ac.uk/news/neon-trial-results

8. Rennick-Egglestone S. *NEON-O Trial Research Has Been Published in the World Psychiatry*. Institute of Mental Health, 2 February 2024. URL: www.institutemh.org.uk/news/1782-neon-o-trial-research-has-been-published-in-the-world-psychiatry

9. *Mental Health Recovery Narratives Improve the Quality of Life for Others with Similar Experiences*. URL: www.nihr.ac.uk/news/mental-health-recovery-narratives-improve-the-quality-of-life-for-others-with-similar-experiences/35370

Media coverage

1. University of Nottingham. Prescribe yourself a story. *Vision Magazine*. Publication date not recorded. www.nottingham.ac.uk/vision/vision-prescribe-story

2. Study shows sharing personal mental health stories helps others recover. *Happiful.com*, 26 January 2024. https://happiful.com/study-shows-sharing-personal-mental-health-stories-helps-others-recover

3. 'This too shall pass'. World-first study proves the power of mental health recovery stories. *Positive News*, 29 January 2024. www.positive.news/society/study-proves-power-mental-health-recovery-stories/

Presentations

1. Rennick-Egglestone S. NEON: *Personal Experience as a Recovery Resource in Psychosis*. NIHR Centre for Primary Care seminar series, Manchester, UK, 5 December 2017. (Invited).

2. Slade M, Robotham D. *NEON: Machine Learning and Mental Health Recovery*. MindTech Annual Conference, London, UK, 7 December 2017. (Invited).

3. Llewellyn-Beardsley J. *Characteristics of Mental Health Recovery Narratives: A Systematic Review and Narrative Synthesis*. University of Nottingham Health Humanities Showcase, Nottingham, UK, 16 January 2018.

4. Beardsley J. *What is a Mental Health Recovery Story?* Annual IMH Research Day, Nottingham, UK, 22 May 2018.

5. Morgan K. *The Impact of Recovery Narratives on Others: A Systematic Review and Narrative Synthesis*. Annual IMH Research Day, Nottingham, UK, 22 May 2018.

6. Rennick-Egglestone S. *Narrative Experiences Online: Connecting People. 'Visions of the Future'*, NHS Wessex, 1 November 2018. (Invited).

7. Llewellyn-Beardsley J. *Nine Dimensions of Mental Health Recovery Narratives*. Image and Narrative: Illness, Recovery, Change workshop. University of Nottingham, Nottingham, UK, 29 April 2019. (Invited).

8. Yeo C. *Ethical Concerns in the Curation of Mental Health Recovery Narratives*. Annual IMH Research Day, Nottingham, UK, 21 May 2019.

9. Ng F. *Mental Health Recovery Narratives: How Do They Impact People?* Annual IMH Research Day, Nottingham, UK, 21 May 2019.

10. Ng F, Rennick-Egglestone S, Ramsay A, Morgan K, Llewellyn-Beardsley J, McGranahan R, Hui A, Booth S, Slade M. *How Do Mental Health Recovery Narratives Impact on Others?* 13th International Conference of the European Network for Mental Health Service Evaluation conference (ENMESH 2019), Lisbon, 6–8 June 2019.

11. Yeo C, McGranahan R, Rennick-Egglestone S, Hui A, Ramsay A, Llewellyn-Beardsley J, Slade M. *Ethical Concerns in the Curation of Mental Health Recovery Narratives*. 13th International Conference of the European Network for Mental Health Service Evaluation conference (ENMESH 2019), Lisbon, 6–8 June 2019.

12. Llewellyn-Beardsley J, Rennick-Egglestone S, Hui A, Pollock K, Ramsay A, McGranahan R, Smith R, Slade M. *What is a Mental Health Recovery Narrative?* 13th International Conference of the European Network for Mental Health Service Evaluation conference (ENMESH 2019), Lisbon, 6–8 June 2019.

13. Smith R, Robotham D, Rennick-Egglestone S, Slade M. *Practical Considerations for Mental Health Recovery Narrators*. 13th International Conference of the European Network for Mental Health Service Evaluation Conference (ENMESH 2019), Lisbon, 6–8 June 2019.

14. Llewellyn-Beardsley J, Hui A, Rennick-Egglestone S. *The characteristics of Mental Health Recovery Narratives*. Refocus on Recovery 2019, Nottingham, UK, 3–5 September 2019.

15. Rennick-Egglestone S, Ramsay A, Thornicroft G, Slade M. *A Change Model for the Impact of Mental Health rRecovery Narratives*. Refocus on Recovery 2019, Nottingham, UK, 3–5 September 2019.

16. Ng F, Roe J, Rennick-Egglestone S, Slade M. *How do Recovery Narratives Generate Hope and Connectedness?* Refocus on Recovery 2019, Nottingham, UK. 3–5 September 2019.

17. Yeo C, Booth S, Duncan K, Slade S. *'Whose VOICES Are They Anyway?' The Curation of Mental Health, Madness and Recovery Story Collections*. Refocus on Recovery 2019, Nottingham, UK, 3–5 September 2019.

18. Bhogal A, Robotham D, Smith R, Slade M. *Practical Considerations for Mental Health Recovery Narrators*. Refocus on Recovery 2019, Nottingham, UK, 3–5 September 2019.

19. Hui A, Llewellyn-Beardsley J, Rennick-Egglestone S, Slade M. *Institutional Injustice: Learning Through the Recovery Narratives of Marginalised Communities*. Refocus on Recovery 2019, Nottingham, UK, 3–5 September 2019.

20. Roe J, Brown S, Rennick-Egglestone S, Slade M. *How Can Recorded Recovery Narratives Find a Place in Mental Health Practice?* Refocus on Recovery 2019, Nottingham, UK, 3–5 September 2019.

21. Rennick-Egglestone S. *NEON: Narrative Experiences Online*. Devon Partnership Trustwide Weekly Clinical Education Webinars – Research and Development. Delivered online, 22 September 2020. (Invited).

22. Rennick-Egglestone S. *Peer Researchers and the 'Narrative Experiences Online' (NEON) Study*. Kick-Off Event for the University of Nottingham Association of Peer Researchers, University of Nottingham, Nottingham, UK, 10 October 2019. (Invited).

23. Slade M. Radio interview on All in the mind on BBC Radio 4, 17 November 2020. (Invited).

24. Rennick-Egglestone S. Television interview on BBC South–East Today, 14 January 2021. www.facebook.com/NeonTrials1/videos/169195207952787/ (Invited).

25. Rennick-Egglestone, S. *Online Lived Experience Narratives*. Mixed Reality Laboratory Seminar Series, Nottingham, UK, 22 January 2021. (Invited).

26. Rennick-Egglestone S. *Co-producing the NEON Collection of Recovery Stories*. Keynote at Recovery Chapter 2021, Hong Kong, 2 February 2021. (Invited).

27. Rennick-Egglestone S. *NEON: Narrative Experiences Online*. Lincoln Partnership NHS Foundation Trust Virtual Research Conference, delivered online 22 April 2021.

28. Jordan G, Ng F, Thomas R. Positive, transformational change and growth following a psychosis: Foundations. (Webinar). Mental Health Technology Transfer Center Network, United States of America, 3 November 2021. https://mhttcnetwork.org/centers/new-england-mhttc/product/overview-positive-change-and-post-traumatic-growth-following. (Invited).

29. Jordan G, Ng F, Thomas R. *How Clinicians Can Support People as They Experience Positive, Transformational Change and Growth Following a Psychosis*. (Webinar). Mental Health Technology Transfer Center Network, United States of America, 17 November 2021. https://mhttcnetwork.org/centers/new-england-mhttc/product/how-clinicians-can-facilitate-positive-change-and-post-traumatic. (Invited).

30. Rennick-Egglestone S. *The NEON (Narrative Experiences Online) Intervention*. Centre for Implementation Science (King's College London) Seminar Series, delivered online, 30 November 2021. (Invited).

31. Rennick-Egglestone S. *e-Consent in Clinical Trials*. East Midlands Clinical Research Network Principle Investigators group, delivered online, 26 January 2022. (Invited).

32. Rennick-Egglestone S. *The Narrative Experiences Online (NEON) Intervention*. Division of Pharmacy Practice and Policy Weekly Seminar Series, School of Pharmacy, University of Nottingham, delivered online 7 March 2022. (Invited).

33. Rennick-Egglestone S. *Uses and Abuses of Mental Health Narratives*. Pint of Science, Nottingham, UK, 11 May 2022. (Invited).

34. Ali Y, Rennick-Egglestone S, Franklin D, Llewellyn-Beardsley J, Pollock K, Ng F, Slade M. *Perceptions of an Online Collection of Mental Health Recovery Narratives (NEON)*. Institute of Mental Health Research Conference, Nottingham, UK, 17–18 May 2022.

35. Llewellyn-Beardsley J, Rennick-Egglestone S, Ng F, Ali Y, Slade M, Edgley A. *What Is Performative Narrative Analysis and What Can It Tell Us About Mental Health Recovery?* Institute of Mental Health Research Conference, Nottingham, UK, 17–18 May 2022.

36. Franklin D, Rennick-Egglestone S, Llewellyn-Beardsley J. *Developing an Anti-racism Agenda Within Research*. Institute of Mental Health Research Conference, Nottingham, UK, 17–18 May 2022.

37. Ng F, Rennick-Egglestone S, Hui A, Llewellyn-Beardsley J, Franklin D, Charles A, Slade M. *Using Mental Health Recovery Narratives to Create Change in Recipients*. 14 International Conference of the European Network for Mental Health Service Evaluation conference (ENMESH) 2022, Tel Aviv, Israel, 27–29 June 2022.

38. Rennick-Egglestone S, Bailey S, Booth S, Elliott R, Harrison J, Llewellyn-Beardsley J, Newby C, Ng F, Robinson C, Smith R, Walcott R, Slade M. *The Narrative Experiences Online (NEON) Intervention: Development and Clinical Trials*. 14th International Conference of the European Network for Mental Health Service Evaluation conference (ENMESH) 2022, Tel Aviv, Israel, 27–29 June 2022.

39. Franklin D, Llewellyn-Beardsley J, Rennick-Egglestone S, Slade M. *Developing an Anti-Racist Agenda from Lived Experience Involvement Within Health Research*. 14th International Conference of the European Network for Mental Health Service Evaluation conference (ENMESH) 2022, Tel Aviv, Israel, 27–29 June 2022.

40. Ali Y, Rennick-Egglestone S, Franklin D, Llewellyn-Beardsley J, Pollock K, Ng F, Slade M. *Perceptions of a Collection of Recovery Narratives from Two Clinical Trials of the NEON Intervention*. 14th International Conference of the European Network for Mental Health Service Evaluation conference (ENMESH) 2022, Tel Aviv, Israel, 27–29 June 2022.

41. Yeo C, Rennick-Egglestone S, Ali Y, Armstrong V, Borg M, Bradstreet S, Faulkner A, Franklin D, Llewellyn-Beardsley J, Mottram K, Ng F, Voronka J, Slade M. *Mental Health Lived Experience Narratives: Recommendations for Avoiding Misuses*. 14th International Conference of the European Network for Mental Health Service Evaluation Conference (ENMESH) 2022, Tel Aviv, Israel, 27–29 June 2022.

42. Ng F, Franklin D, Rennick-Egglestone S, Jordan G, Slade M. *What Facilitates Posttraumatic Growth in Experiences of Psychosis?* 14th International Conference of the European Network for Mental Health Service Evaluation Conference (ENMESH) 2022, Tel Aviv, Israel, 27–29 June 2022.

43. Llewellyn-Beardsley J. *Performative Narrative Analysis and Mental Health Recovery: Telling a Story about Collecting a Story*. School of Health Sciences Research Community of Practice Seminar Series, University of Nottingham, delivered online, 15 November 2022. (Invited).

44. Rennick-Egglestone S. *What Can We Learn from Publicly Shared Online Accounts of Mental Health Recovery?* Presentation to the Turing Institute 'Data Science for Mental Health' group, delivered online, 17 November 2022. (Invited).

45. Rennick-Egglestone S. *The NEON Study (Narrative Experiences Online): Self-Guided and Recommender System Access to an Online Collection of Mental Health Recovery Narratives – Findings from Two Clinical Trials*. NIHR MindTech MIC National Symposium 2022, London, UK, 24 November 2022. (Invited).

46. Rennick-Egglestone S. *Spotlight Study – NEON*. Lincolnshire Partnership NHS Foundation Trust Research Round Up Session, delivered online, 10 January 2023. (Invited).

47. Rennick-Egglestone S. *The NEON Study: Design and Recruitment for Two Clinical Trials of a New Online Mental Health Intervention*. School of Health Sciences Research Community of Practice seminar series, University of Nottingham, delivered online 7 February 2023. (Invited).

48. Charles A, Hare-Duke L, Egglestone-Rennick S, Slade M. *Content and Trigger Warnings – Systematic Review*, University English Conference and Annual General Meeting, London, UK, 14 April 2023. (Invited).

49. Gavan SP, Paterson L, Rennick-Egglestone S, Slade M, Newby C, Ng F, Elliott RE. *Mapping between the MANSA Quality of Life Instrument and EQ-5D-3L for Mental Health Problems*. Society for Medical Decision Making 2023 – 18th Biennial European Conference, Berlin, Germany, 21–23 May 2023.

50. Gavan SP, Paterson L, Rennick-Egglestone S, Slade M, Newby C, Ng F, Elliott RE. *Estimating EQ-5D-3L Utility Values from EQ-5D-5L for People with Mental Health Problems: A Comparison of Methods*. Society for Medical Decision Making 2023 – 18th Biennial European Conference, Berlin, Germany, 21–23 May 2023.

51. Gavan SP, Paterson L, Rennick-Egglestone S, Slade M, Newby C, Ng G, Elliott R. *Estimating EQ-5D-3L Utility Values from EQ-5D-5L for People with Mental Health Problems: A Comparison of Methods*. Society for Medical Decision Making 18th Biennial European Conference, Berlin, Germany, 21–23 May 2023.

52. Rennick-Egglestone S. *Building a Collection of Mental Health Recovery Narratives: Ethical and Legal Considerations*. Third UK and Ireland Mental Diversity Law Conference, Nottingham, UK, 6–7 June 2023.

53. Llewellyn-Beardsley J and Edgley A. *'Nothing's Changed, Baby': The Centrality of Critical Reflexivity in Decolonising Uses of Mental Health Recovery Narratives*. Narrative Matters 2023, Tamperere, Finland, 15–17 June 2023.

54. Ali Y, Rennick-Egglestone S, Llewellyn-Beardsley J, Yeo C, Franklin D, Slade M. *Utilisations of an Online Mental Health Recovery Narrative Intervention (NEON)*. Inaugural International Digital Mental Health and Wellbeing Conference, Belfast, UK, 22–23 June 2022.

55. Rennick-Egglestone S, Llewellyn-Beardsley J, Ng F, Yeo C, Ali Y, Elliott R, Slade M. *Learnings from the Narrative Experiences Online (NEON) Programme*. Refocus on Recovery 2023, Nottingham, UK, 6–7 June 2023.

56. Rennick-Egglestone S. *Building a Collection of Mental Health Recovery Narratives: Ethical and Legal Considerations*. RRT Collaboration Day, Nottingham, UK, 4 September 2023. (Invited).

57. Rennick-Egglestone S, Ng F, Llewellyn-Beardsley J, Ali Y, Kotera Y, Slade M. *The Impact of Narratives Describing Mental Health Recovery*. International Health Humanities conference, Derby, UK, 21–23 September 2023.

Posters

1. Hui, A, Ramsay, A, Rennick-Egglestone, S, Llewellyn-Beardsley, J, McGranahan, R, Pollock, K, Thornicroft, G, Slade, M. *Recovery Narratives of Marginalised Communities*. 13th ENMESH Conference, Lisbon, Portugal, 6–8 June 2019.

2. Rennick-Egglestone S. *Principles for the Ethical and Efficient Production and Dissemination of Online Recruitment Material for Health Research Studies*. Institute of Mental Health Research Conference, Nottingham, UK, 17–18 May 2022.

3. Ng F, Ibrahim N, Franklin D, Jordan G, Lewandowski F, Rennick-Egglestone S, Newby C, Llewellyn-Beardsley J, Slade M. *How Does Posttraumatic Growth Occur in Experiences of Psychosis: A Systematic Review and Narrative Synthesis*. Institute of Mental Health Research Conference, Nottingham, UK, 17–18 May 2022.

4. Rennick-Egglestone S, Robinson C, Elliott R, Newby C, Newton S, Slade M. *Managing Repeat Registrations by the Same Participant: Principles and Procedures from Two Online Trials of a Web-Based Digital Health Intervention (the NEON Intervention)*. UK Trial Managers' Network Annual Conference 2023, Birmingham, UK, 13 June 2023.

5. Ng F, Rennick-Egglestone S, Onwumere J, Newby C, Llewellyn-Beardsley J, Pomberth S, Slade M. *Narrative Experiences Online Intervention for Informal Carers (NEON-C) Trial: Is It Feasible and Acceptable?* Refocus on Recovery 2023, 6–7 June 2023, Nottingham, UK.

6. Yeo C, Rennick-Egglestone S, Borg M, Klevan T, Voronka J, Slade M. *Uses and Misuses of Recorded Mental Health Lived Experience Narratives*. Refocus on Recovery 2023, 6–7 June 2023, Nottingham, UK.

7. Roe J, Brown S, Rennick-Egglestone S, Yeo C, Ng F, Slade M. *Opportunities, Enablers and Barriers to the Use of Recorded Recovery Narratives in Clinical Settings*. Refocus on Recovery 2023, Nottingham, UK, 6–7 June 2023.

8. Ali Y, Rennick-Egglestone S, Ng F, Llewellyn-Beardsley J, Yeo C, Franklin D, Slade M. *Utilisations of an Online Mental Health Recovery Narrative Intervention (NEON)*. Refocus on Recovery 2023, Nottingham, UK, 6–7 June 2023.

9. Ali Y, Rennick-Egglestone S, Ng F, Llewellyn-Beardsley J, Yeo C, Franklin D, Slade M. *Extending the NEON Impact Model*. Refocus on Recovery 2023, Nottingham, UK, 6–7 June 2023.

10. Paterson L, Rennick-Egglestone S, Gavan S, Rennick-Egglestone S, Slade M, Llewellyn-Beardsley J, Elliott R. *Development and Delivery Cost of Digital Health Technologies for Mental Health: Application to the Narrative Experiences Online Intervention*. Refocus on Recovery 2023, Nottingham, UK, 6–7 June 2023.

11. Gavan S, Paterson L, Rennick-Egglestone S, Slade M, Newby C, Ng F, Elliott R. *Mapping between the MANSA Quality of Life Instrument and EQ-5D-3L for Mental Health Problems Using Data from an Online Randomised Controlled Trial*. Refocus on Recovery 2023, Nottingham, UK, 6–7 June 2023.

12. Gavan S, Paterson L, Rennick-Egglestone S, Slade M, Newby C, Elliott R. *Cost-Effectiveness Analysis of the NEON Intervention for People with Psychosis and Non-Psychosis Mental Health Problems*. Refocus on Recovery 2023, Nottingham, UK, 6–7 June 2023.

13. Rennick-Egglestone S, Newby C, Robinson C, Llewellyn-Beardsley J, Ng F, Gavan SP, Slade M. Differences between online trial participants who have and have not used secondary care mental health services. Refocus on Recovery 2023, Nottingham, UK, 6–7 June 2023.

14. Gavan S, Paterson L, Rennick-Egglestone S, Slade M, Newby C, Elliott R. *Cost-Effectiveness Analysis of the NEON Intervention for People with Psychosis and Non-Psychosis Mental Health Problems*. ISPOR Europe 2023, Copenhagen, Denmark, 12–15 November 2023.

Debates, panel discussions and workshops

1. Walcott R, Rennick-Egglestone S, Hui A, Robotham D. *Mental Health in Art and Research*. Instagram live event hosted by the Healthy Brains Global Initiative (HBGI), 11 October 2021. (Invited).

2. Rennick-Egglestone S. *Designing Sensitive Digital Health Interventions*. Workshop at the Refocus on Recovery 2019 Conference, Nottingham, UK, 3 September 2019. (Invited).

Knowledge transfer events

Knowledge transfer event 1

Knowledge transfer event 1 was delivered through symposia presented at the ENMESH 2019 and Refocus on Recovery 2019 conferences.

Our ENMESH 2019 symposium consisted of the following presentations:

1. Ng F, Rennick-Egglestone S, Ramsay A, Morgan K, Llewellyn-Beardsley J, McGranahan R, Hui A, Booth S, Slade M. *How do Mental Health Recovery Narratives Impact on Others?* 13th International Conference of the European Network for Mental Health Service Evaluation conference (ENMESH 2019), Lisbon, 6–8 June 2019.

2. Yeo C, McGranahan R, Rennick-Egglestone S, Hui A, Ramsay A, Llewellyn-Beardsley J, Slade M. *Ethical Concerns in the Curation of Mental Health Recovery Narratives*. 13th International Conference of the European Network for Mental Health Service Evaluation conference (ENMESH 2019), Lisbon, 6–8 June 2019.

3. Llewellyn-Beardsley J, Rennick-Egglestone S, Hui A, Pollock K, Ramsay A, McGranahan R, Smith R, Slade M. *What Is a Mental Health Recovery Narrative?* 13th International Conference of the European Network for Mental Health Service Evaluation conference (ENMESH 2019), Lisbon, 6–8 June 2019.

4. Smith R, Robotham D, Rennick-Egglestone S, Slade M. *Practical Considerations for Mental Health Recovery Narrators*. 13th International Conference of the European Network for Mental Health Service Evaluation conference (ENMESH 2019), Lisbon, 6–8 June 2019.

Our Refocus on Recovery 2019 symposium consisted of the following presentations:

1. Llewellyn-Beardsley J, Hui A, Rennick-Egglestone S. *The Characteristics of Mental Health Recovery Narratives*. Refocus on Recovery 2019, Nottingham, UK, 3–5 September 2019.

2. Rennick-Egglestone S, Ramsay A, Thornicroft G, Slade M. *A Change Model for the Impact of Mental Health Recovery Narratives*. Refocus on Recovery 2019, Nottingham, UK, 3–5 September 2019.

3. Ng F, Roe J, Rennick-Egglestone S, Slade M. *How do Recovery Narratives Generate Hope and Connectedness?* Refocus on Recovery 2019, Nottingham, UK. 3–5 September 2019.

4. Yeo C, Booth S, Duncan K, Slade S. *'Whose VOICES Are They Anyway?' The Curation of Mental Health, Madness and Recovery Story Collections*. Refocus on Recovery 2019, Nottingham, UK, 3–5 September 2019.

5. Bhogal A, Robotham D, Smith R, Slade M. *Practical Considerations for Mental Health Recovery Narrators*. Refocus on Recovery 2019, Nottingham, UK, 3–5 September 2019.

6. Hui A, Llewellyn-Beardsley J, Rennick-Egglestone S, Slade M. *Institutional injustice: Learning Through the Recovery Narratives of Marginalised Communities*. Refocus on Recovery 2019, Nottingham, UK, 3–5 September 2019.

7. Roe J, Brown S, Rennick-Egglestone S, Slade M. *How Can Recorded Recovery Narratives Find a Place in Mental Health Practice?* Refocus on Recovery 2019, Nottingham, UK, 3–5 September 2019.

Knowledge transfer event 2

Knowledge transfer event 2 was delivered through a symposium presented at the ENMESH 2022 conference. It consisted of the following presentations:

1. Ng F, Rennick-Egglestone S, Hui A, Llewellyn-Beardsley J, Franklin D, Charles A, Slade M. *Using Mental Health Recovery Narratives to Create Change in Recipients*. 14th International Conference of the European Network for Mental Health Service Evaluation conference (ENMESH2022), Tel Aviv, Israel, 27–29 June 2022.

2. Rennick-Egglestone S, Bailey S, Booth S, Elliott R, Harrison J, Llewellyn-Beardsley J, Newby C, Ng F, Robinson C, Smith R, Walcott R, Slade M. *The Narrative Experiences Online (NEON) Intervention: Development and Clinical Trials*. 14th International Conference of the European Network for Mental Health Service Evaluation conference (ENMESH2022), Tel Aviv, Israel, 27–29 June 2022.

3. Franklin D, Llewellyn-Beardsley J, Rennick-Egglestone S, Slade M. *Developing an Anti-Racist Agenda from Lived Experience Involvement Within Health Research*. 14th International Conference of the European Network for Mental Health Service Evaluation conference (ENMESH2022), Tel Aviv, Israel, 27–29 June 2022.

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6. Ng F, Franklin D, Rennick-Egglestone S, Jordan G, Slade M. *What Facilitates Posttraumatic Growth in Experiences of Psychosis?* 14th International Conference of the European Network for Mental Health Service Evaluation conference (ENMESH2022), Tel Aviv, Israel, 27–29 June 2022.

Knowledge transfer event 3

Knowledge transfer event 3 was delivered through a presentation at the Refocus on Recovery 2023 conference, and set of posters providing a retrospective of NEON work. The presentation was:

Rennick-Egglestone S, Llewellyn-Beardsley J, Ng F, Yeo C, Ali Y, Elliott R, Slade M. *Learnings from the Narrative Experiences Online (NEON) Programme*. Refocus on Recovery 2023, Nottingham, UK, 6–7 June 2023.

The posters were:

1. Ng F, Rennick-Egglestone S, Onwumere J, Newby C, Llewellyn-Beardsley J, Pomberth S, Slade M. *Narrative Experiences Online Intervention for Informal Carers (NEON-C) Trial: Is It Feasible and Acceptable?* Refocus on Recovery 2023, 6–7 June 2023, Nottingham, UK.

2. Yeo C, Rennick-Egglestone S, Borg M, Klevan T, Voronka J, Slade M. *Uses and Misuses of Recorded Mental Health Lived Experience Narratives*. Refocus on Recovery 2023, 6–7 June 2023, Nottingham, UK.

3. Roe J, Brown S, Rennick-Egglestone S, Yeo C, Ng F, Slade M. *Opportunities, Enablers and Barriers to the Use of Recorded Recovery Narratives in Clinical Settings*. Refocus on Recovery 2023, Nottingham, UK, 6–7 June 2023.

4. Ali Y, Rennick-Egglestone S, Ng F, Llewellyn-Beardsley J, Yeo C, Franklin D, Slade M. *Utilisations of an Online Mental Health Recovery Narrative Intervention (NEON)*. Refocus on Recovery 2023, Nottingham, UK, 6–7 June 2023.

5. Ali Y, Rennick-Egglestone S, Ng F, Llewellyn-Beardsley J, Yeo C, Franklin D, Slade M. *Extending the NEON Impact Model*. Refocus on Recovery 2023, Nottingham, UK, 6–7 June 2023.

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7. Gavan S, Paterson L, Rennick-Egglestone S, Slade M, Newby C, Ng F, Elliott R. *Mapping between the MANSA Quality of Life Instrument and EQ-5D-3L for Mental Health Problems Using Data from an Online Randomised Controlled Trial*. Refocus on Recovery 2023, Nottingham, UK, 6–7 June 2023.

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9. Rennick-Egglestone S, Newby C, Robinson C, Llewellyn-Beardsley J, Ng F, Gavan SP, Slade M. *Differences Between Online Trial Participants Who Have and Have Not Used Secondary Care Mental Health Services*. Refocus on Recovery 2023, Nottingham, UK, 6–7 June 2023.

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