NEON
Narrative Experiences Online

Lived experience narratives for mental health recovery

The Narrative Experiences Online (NEON) Programme

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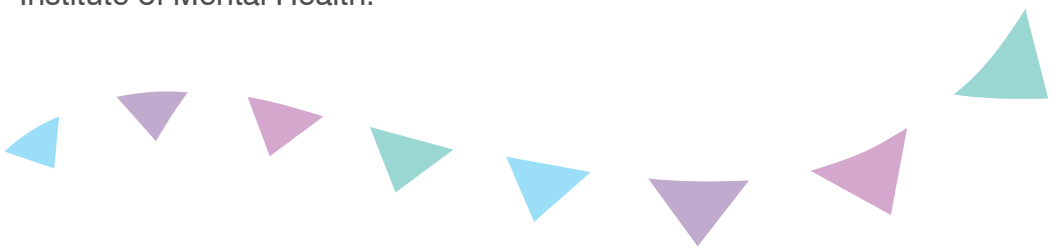

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Introducing the NEON Study

> This report is a summary of learning from the Narrative Experiences Online (NEON) programme of research that was led from England, UK from 2017-2023. We describe what our study involved, what we learned, and how people might benefit from this work in the future.

The personal stories of people who have experienced mental health problems (described here as people with 'lived experience') were at the heart of the NEON study. So in this document we present our learning in two ways:

1. through descriptions of what we did and found, and
2. through the stories of people involved in the study, as lived experience advisors, research participants, and researchers.

What is the Narrative Experiences Online (NEON) study?

NEON aimed to find out whether having online access to people's real-life stories of recovery from mental health problems could be helpful for people currently experiencing mental distress, and for people who care for them. During our programme, we have used the terms "recovery story" and "recovery narrative" interchangeably to describe these real-life stories. We mostly use recovery narrative in this document.

Stage One:

From 2017-2019 we developed our understanding of some important questions:

- **What is a recovery narrative?** (Described in Section 1)
- **How have recovery narratives been collected and presented publicly?** (Section 2)
- **What effects can recovery narratives have on people who access them?** (Section 3)

We worked with organisations, community groups and individuals to build a diverse collection of recovery narratives called the NEON Collection. We then developed the NEON Intervention, which is an interactive web-site that allowed people to find narratives that might most help them, and to provide feedback on how individual narratives had changed them. The NEON Intervention is described in Section 4.

Stage Two:

From 2019-2023 we ran three online trials which tested whether people benefitted from accessing the recovery narratives in the NEON Intervention. In Section 5 we describe the results of the trials and what participants in the trials thought of the NEON Intervention.

The NEON study was informed and undertaken by people with lived experience of recovery from mental health problems. This was achieved through appointing a Lived Experience Advisory Panel (LEAP) and by employing some professional researchers who also had lived experience of mental distress. In Section 6 we comment on what we learned about the importance of being informed by a diversity of lived experience perspectives.

Why a focus on stories?

From being surrounded by stigma and silence, stories of mental health experiences (and sometimes of recovery) are now being shared much more publicly: through social media and personal blogs, in celebrity biographies, books, art exhibitions, charity campaigns, and other ways. To the right, we've provided some examples of collections that are available to the public and which contain recovery narratives. But we haven't known much about the effects that accessing narratives of recovery can have on people currently experiencing mental distress, or on their family and friends. The NEON study aimed to find out more about this.

Examples of collections containing recovery narratives:

- Beyond the Storms and Riding the Storms, two books published by Recovery Devon: **recoverydevon.co.uk/book-shop/**
- Emerging Proud: **emergingproud.com**
- Exploring Experience: **sites.google.com/view/exploring-experience/about**
- OC87 Recovery Diaries: **oc87recoverydiaries.com/mental-health-first-person-essays**
- Scottish Recovery Network: **scottishrecovery.net/sharing-recovery/latest-stories/**
- Sheffield Flourish: **sheffieldflourish.co.uk/stories**
- The Schizophrenia Oral History project: **schizophreniaoralhistories.com**
- Psychosis: Stories of Recovery and Hope, book published by Quay Books: **www.quaybooks.co.uk/psychosis-stories-of-recovery-and-hope-3**
- The Colour of Madness, book published by Pan Macmillan: **panmacmillan.com/authors/samara-linton/the-colour-of-madness/9781035044399**

The NEON Collection

The NEON Collection includes more than 600 narratives from people who have experienced mental health problems and a sense of recovery from them. Some of these recovery narratives were collected by the NEON study team, working in partnership with organisations and community groups who had previously collected and published recovery narratives. Some were donated directly by individuals. All narrators gave their permission for their narratives to be included.

> NEON Collection narratives describe experiences of recovery in many different ways, including from people who used mental health services and people who didn't or couldn't.

The narratives are presented in various forms, including written text (prose and poetry), videos, audio recordings and images. An online account will always be needed to access the NEON Collection. This is to avoid narratives becoming publicly available in search engines, or used by Artificial Intelligence technologies.

Further information

You can find further information about the NEON study on our website here:

www.researchintorecovery.com/research/neon

All publications produced by the study can be found here:

www.researchintorecovery.com/research/neon/findings

All of the research produced by the NEON programme is freely available to the public. In section 7, we provide a numbered list of all our study publications, with details of how to find a free version of each document. In the text below, we mention a numbered publication where we think that readers might want to find out more about a piece of work.

NEON experiences:
Anonymous trial participant

> I started the NEON Trial at the height of the COVID-19 pandemic. I was one of those people who found that although there was so much tragedy in the world at that time, lockdown created a peace that is rare and, being a very introverted person, the quietness seemed a gift.

But lockdown also cut many of my usual connections. I'd been volunteering with a group of 'experts by experience' for National Health Service (NHS) mental health services before COVID, telling our stories to staff in the same way that people offer their stories in the NEON Collection. The friendships and connections that grew in that group became a needed part of my strategies for staying well. However, the NHS out of necessity focused on its response to COVID, and initiatives such as service user involvement were shelved and we lost touch with each other.

The NEON trial came into my life at that time.

I registered for the trial out of the same feelings of altruism and wanting to give something back that led to me joining the NHS service user involvement activities. I set my PC up so that when I turned it on, my browser would load NEON and I would find a story to read.

The first thing I noticed was how personal and very honest people's stories were. Although they were in written form, I still took from them that 'yes, me too!' feeling that feels so validating when you realise you're not alone in your experiences. I would search specifically for those stories which were closest to my own, and which brought that feeling of validation. This helped me feel that despite the isolation of lockdown, there were still people out there who would understand me.

As I read more stories I noticed themes coming out. How connections helped people. Connection was difficult for me in lockdown as I couldn't 'get on with' telephone or video conferencing. The technology gets in the way for me, it comes with a feeling that the person is distant, detached, unreal. I found the written word stories on NEON much more relatable and intimate, nurturing that feeling of connection with others.

There was hope too. How so many times people found hope in adversity. How they went on to achieve very meaningful things in their lives, building for themselves an identity outside of their experience of mental health difficulties. This theme was particularly helpful to me at that time as I considered applying for an NHS paid role as a peer support worker on a psychiatric intensive care unit. Having been admitted to inpatient wards myself at the end of 2018, ending my then job in 2019 and at a low ebb in terms of self-worth and self-confidence, the inspiration and encouragement I found in the NEON Collection helped me take that chance and apply for the position.

I did – and have been a part-time peer worker for a year now. As that role is part time I've also just taken up a second position as a Lived Experience Educator for the NHS, bringing the lived experience view of mental health difficulties and mental health services to the teaching of medical students. Taking up that position I'm hoping that the NEON Collection will stay open and I will be able to draw inspiration for this new work from the people whose lives are offered there, in the hope that in doing so they will be supporting others.

Democratic learning within the NEON programme

How the LEAP was organised

> The ten-person NEON Lived Experience Advisory Panel (LEAP) was recruited at the beginning of the NEON study, soon after funding was confirmed. A panel chair (Dan) was appointed from the **McPin Foundation**, a charity which specialises in involving people with relevant personal experiences in research studies.

The chair's role was to run each LEAP meeting, and to look after the wellbeing of LEAP members. Dan and the NEON Chief Investigator (Mike) circulated an Expression of Interest form to contacts in the East Midlands. The aim was to find people who could draw on their own mental health experiences to offer recommendations to our study, and who had an interest in narratives and storytelling. Some of the people who expressed an interest had told (or published) their own narrative, others had listened to the stories of others and learned from them or been inspired by them. Some people described their experiences in terms of 'recovery', others did not.

People interested in being involved attended a face-to-face introductory session with Dan and Mike at a community venue in Nottingham city centre. This meeting helped set people's expectations about what would be involved before they committed. It took place before the study started, so that LEAP was ready to be involved in the study as soon as it began.

The first full LEAP meeting happened shortly afterwards, and we met three or four times per year during the study – a total of sixteen meetings throughout the five-year period. Meetings were arranged 'in person' for the first half of the study. The COVID-19 pandemic meant that we then moved to an online format. Towards the end of the study we attempted hybrid (in-person and online) meetings. Some challenges remain in how to run hybrid meetings most effectively, but we found that these were the most inclusive kind of meeting, involving those who could not travel to physical meetings or preferred not to meet in person during the pandemic, and those who preferred to meet face-to-face.

LEAP meetings were organised at first by Dan (LEAP chair), working with Mike (Chief Investigator), Stefan (Programme Co-ordinator) and the NEON administrator. After two meetings, LEAP members suggested they should be involved in planning the agenda for future meetings. This was implemented, and subsequent meetings were planned with Stefan and members of the research

team working directly with LEAP members (approximately two researchers and two LEAP members each time). This group would then provide an agenda and materials for the Chair to review in advance of the meeting, and circulate to all LEAP members. This worked well and helped with a sense of a shared ownership of the content of the meetings.

LEAP meetings ran for four hours during the working day. They usually started at 11:00am with some informal catch-up time for members and researchers before the meeting began. There was a long lunch break which gave everyone sufficient informal time to speak to one another. Members were paid for their time through the local NHS Trust (the purse holder for the study). The administrator took minutes and arranged taxis and transport for members, to help people feel comfortable and to reduce the stresses associated with attendance and transportation. LEAP members were paid for a day of work, to recognise the personal efforts of attending a four-hour meeting, such as preparing for the meeting, or debriefing afterwards. The rate of payment was roughly equivalent to what a researcher with a PhD would earn for a day.

> Over time, some LEAP members left the group for various reasons. We recruited new members, often with diversity in mind and thinking about who could bring new perspectives into the project.

Role of the LEAP throughout the programme

The LEAP took on various roles in the NEON study. Perhaps the most obvious role was that of 'critical friend' to the research team, who brought issues and topics to the meetings for discussion. Issues included our criteria for includable recovery narratives, ethical issues around the NEON Collection, how the NEON Intervention website would look, ensuring it was easy to use, the diversity of narratives in the Collection, and many more.

Almost all NEON study publications were completed with the involvement of at least one LEAP member and usually more. Two members presented at international conferences, sharing how their lived experience impacted the study. One was able to share her narrative of experiencing race-based trauma, the result of racism in professional psychology training. Sharing her narrative was a powerful telling of the truth as a first step to the righting of an injustice. This resulted in a sense of validation, refocusing her narrative into a post-traumatic arc. The LEAP also led their own outputs, by producing a guide to telling recovery narratives, and to ways of sharing your mental health lived experiences with others (NEON document N4).

Between meetings, the research team often asked for paid LEAP involvement with specific tasks. This meant that decisions could be made much faster than relying on the meetings alone, and extended the number of involvement opportunities for people who were interested in taking on more.

LEAP members were involved, for example:

- In recruitment of new research staff (all interview panels included a LEAP member)
- Deciding what should be included in the interactive NEON Intervention website
- Finding narratives that showed less 'positive' depictions of recovery
- Supporting the research team in finding narratives from people from under-represented groups in the NEON Collection
- Working on creating content warnings and thinking around which narratives in the NEON Collection to apply them to
- Developing trials evaluation processes
- And co-writing and reviewing this programme summary.

The LEAP's role as an independent critical friend influenced the study in many other ways. For example, the amount of lived experience expertise in the study helped to create a culture where researchers felt comfortable to share their own lived experiences, and to work from that perspective. This helped break down the barriers that can exist in traditional 'Patient and Public Involvement' (PPI) structures. The Chief Investigator (Mike) was the ultimate decision maker, but his decisions were informed by the LEAP. Where LEAP suggestions were not taken forward, the Chair and research team provided updates to explain why.

Collection Steering Group processes

> As we started to assemble the NEON Collection, we realised that we needed a group of people to oversee our work, and to make the most important decisions about the Collection.

We formed a body called the Collection Steering Group (CSG), which met eight times between October 2018 and March 2022. CSG was composed of four LEAP members with experience of recounting their own stories, and two study team researchers with personal experience of mental health distress. This brought a balance of expertise, but prioritised insights from outside of the study team. We sought to make all decisions by consensus, and only very occasionally held a vote. We met in-person where we could, and then online as our work was disrupted by the COVID-19 pandemic.

CSG had a number of roles. At two critical points, it reviewed the diversity and inclusivity of the NEON Collection, made recommendations for how to increase inclusivity, and then helped the NEON study team to implement these recommendations. This led us to seek and find more recovery narratives from people with learning difficulties, for example. Sometimes, the NEON study team was uncertain about whether a narrative should be included in the NEON Collection; a CSG role was to make a decision, and sometimes to update our narrative inclusion criteria. In a small number of cases, of narratives describing self-harm, CSG decided that it did not have the competence to decide whether these could be included. These narratives were important to consider, as we believed they might trigger an episode of self-harm in others with previous experience of self-harm. For these, CSG referred the narratives to Mike as Chief Investigator, who used his clinical expertise to decide on inclusion. **You can read more about the work of the CSG in NEON paper #14.**

LEAP membership as an opportunity for personal growth

LEAP members were supported to develop in their roles, should they wish to, as the study went on. Both the Programme Co-ordinator (Stefan) and the LEAP Chair (Dan) checked in regularly with individual members, and an 'appraisal' process was offered half-way through the study. This gave members an opportunity to reflect on their individual and group achievements, and to discuss what they were interested in doing, or skills they would like to develop. In retrospect, it would have been valuable to have done this more often.

> Many LEAP members were involved for the duration of the study, and have continued to be involved after the study ends, providing advice on other research activities at the University of Nottingham and the local NHS Trust.

NEON experiences:
Susie Booth (LEAP member)

> I've learnt a lot since the inception of NEON, mostly about myself and my personal journey, but also about kindness, respect, and integrity, to do with the thoroughness of the quality of the research.

Kindness because of the sensitivity of the researchers in discussing subjects that may trigger unwelcome responses in other members of the team. Respect because of the recognised need to accept each other on an equal basis, each bringing different gifts and strengths to the table, each with our own weaknesses and frailties. And integrity because of the high and rigorous standards expected in good research such as NEON: no stone left unturned, every angle approached in a systematic and detailed manner, teasing out the nuances, finding that as one detail was uncovered, that may lead to a whole new avenue and way of looking at a problem, opening up the necessity to possibly write a new paper because the uncovered detail reveals the need to explore that detail in much further depth.

On a personal level, I could say I was bumbling along, fairly bored, fairly broke, wondering really what my life was about. I had dabbled in research with the mental health charity Rethink, finding the work interesting but very patchy. Then Rethink stopped doing research I think, and McPin took over, encouraging research opportunities for people with Lived Experience of mental health issues. I remember

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a meeting in London with the now project leader Mike Slade, and the topic seemed way over my head: I didn't grasp it at all. Then Mike moved to Nottingham and the NEON project took on a life of its own; we've had meetings upon meetings, where the language used is acceptably understood by all, engaging and stimulating.

The LEAP group are varied in every way, all bringing their knowledge, gifts, pain and suffering, joys and sorrows to the table. Staff members came and went; different sub-groups formed to examine certain ethical dimensions. I found myself curating an Art Exhibition that a friend of mine had entered work in, fascinating, a lovely sideline. All this brought joy, stimulation and a desire to study that I had not felt since teenage years, except now it was right up to date, valid and useful for our society.

> I would recommend Lived Experience Advisory Panels to anyone!

It's changed my life, given focus, empowered me to know myself, brought me confidence, and the knowledge that my issues haven't all been for nothing, of no worth, no, there was a logic to my trauma, and a peace to be found when the depths of one's being are plummeted and faced, and even come to be accepted.

NEON experiences:
Julian Harrison (LEAP member)

Though the number of opportunities to use your lived experience to guide, shape and inform research and actual practice seem almost to be legion – and growing – in healthcare and indeed in other areas of life, there are perhaps few occasions when you get the chance to make a real difference to people around you, people experiencing difficulties, people who see and view the world similarly through the lens of mental illness, people like yourself.

NEON has been one of these rare opportunities. Part of my own lived experience now for over five years, it has been a solid and progressive companion, its constituents – both content and human – self-enriching and life-enhancing. People have become friends, soulmates even. The work has been personal, relevant and forward-thinking. Challenging always, but in a meaningful and positive way.

> Now comes the time to take stock.
> What actually have I learned?
> And specifically, what have I gained?

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As an Equality and Diversity specialist as well as someone with a lifetime's experience of living with mental illness, this combination of fact and lived reality has enabled me to contribute in a way that is both professional and personal. Truth be told, it is often the case that equality, diversity and inclusion is something that people simply note. They nod their heads. They make small adjustments. They instigate procedures and practices. But often without enthusiasm and passion as an accompaniment. The head rules, but the heart is absent. And genuine equality work requires both.

> NEON has demonstrated that when you recognise and use these 'twin heads' in equal measure, the outcome can be quite stunning in terms of admission, awareness and achievement.

To be able to talk constructively and continuously about people from communities represented by the nine 'protected characteristics' identified under the Equality Act 2010, to recognise their experience, the discrimination they face, the challenges that life brings them and the need not just to be aware of them, but to involve them personally in work, current and future, has been intensely rewarding. I could see my colleagues really engaging with what I said. Listening attentively, questioning appropriately, looking always to contextualise and to fashion meaningful opportunities. To experience this fully and consistently has been so refreshing, it has helped boost my, at times, flagging mental state. It has enabled me both to inform, but just as importantly, to learn from people who share my own disability, but who are varied and unique in their own individual make-up, experience and character.

If there is one personal thing I do take from the NEON experience, it is this: when we talked on so many occasions about emotional reaction, about how we feel when we hear survivor stories. When we recognised trigger points, things that are difficult, personally, to internalise and to react to. When we acknowledged and related genuine upset, I often felt removed and remote. A lot of the time, I wasn't shocked. There wasn't anything that I didn't want to hear. There was basically nothing I couldn't stomach. Nothing that I wanted to avoid. It was as if, over the years, I had learned to switch off that internal component and attribute called emotion. This was never a conscious decision. I can't remember any specific occasion when I forced myself not to react emotionally or sentimentally. I had just shut down that side of myself. Automatically. Subconsciously. I felt robotic. Unyielding. A little artificial, even. I saw the vivid reactions of my colleagues. Their words, their faces, their temperament. I saw human reaction of a kind that I had long forgotten. And it made me realise even more that this wasn't weakness that I was witnessing, it was genuine, intense strength. It was human insight. Human resourcefulness. Human passion. Just human.

Julian has written about some of his personal learning from NEON in an online blog: **mcpin.org/the-importance-of-the-storytellers-identity-in-mental-health-narratives/**

> "It has enabled me both to inform, but just as importantly, to learn from people who share my own disability, but who are varied and unique in their own individual make-up, experience and character."

1. What is a recovery narrative?

> A ‘recovery story’ or ‘recovery narrative’ is part of the life story of people with lived experience of recovering from mental distress.

Recovery narratives have played a central role in establishing a recovery-based approach within mental health services across the world. When designing the NEON Intervention, it was important for us to understand what kinds of lived experience were considered to be “recovery narratives” by different communities, including previous researchers, community organisations and survivor/service user/activist groups. We wanted to develop a definition of recovery narratives, and a framework describing some of their characteristics. These would be used to help decide what kinds of recovery narrative could be included in the NEON Collection.

How have recovery narratives been described?

We searched for all research studies and other published literature which described characteristics of recovery narratives. We found 45 studies that fitted our inclusion criteria, containing analysis of 629 recovery narratives. Based on these studies we defined recovery narratives 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 or struggle and of self-defined strengths, successes or survival.”

We then combined the findings of the 45 studies. We found that the recovery narratives in the study had many different types of shape, structure and content. Characteristics of the narratives could be described using nine dimensions, each of which had between two and six types, summarised here in our Recovery Narratives Conceptual Framework:

Super-ordinate category	No.	Dimension	Types			
Form	1.	**Genre**	Escape	Enlightenment	Endeavour	Endurance
	2.	**Positioning**	Recovery within the system	Recovery despite the system	Recovery outside of the system	-
	3.	**Emotional tone**	Challenging Shaken	Disenfranchised Tragic	Reflective -	Buoyant -
	4.	**Relationship with recovery**	Recovered	Living well	Making progress	Surviving day-to-day
Structure	5.	**Trajectory**	Upward spiral	Up and down	Horizontal	Interrupted
	6.	**Turning points**	Restorying	Change for the better	Change for the better or worse	-
	7.	**Narrative sequence**	Experience of distress/trauma	Turning point	Experience of recovery	-
Content	8.	**Protagonists and antagonists**	Personal level	Socio-cultural level	Systemic level	-
	9.	**Use of metaphor**	Distress metaphors	Recovery metaphors	-	-

You can read more about the systematic review in NEON paper #1.

What about recovery narratives from groups that hadn't been researched?

This conceptual framework was based on the lived experience of people from groups which had already been researched. But some groups are often excluded from research and we wanted to know whether our framework was relevant to these more diverse populations. To investigate this we interviewed 77 people from four under-researched groups and asked them to tell us their recovery narratives: (A) people who had psychosis-like experiences and hadn't recently used services; (B) people from Black, Asian and minority ethnic communities; (C) people from groups not well-served by mental health services, including people from LGBTQ+ and rural communities, and people experiencing homelessness, substance use and/or the justice system; and (D) people with paid or voluntary peer support roles. We found that:

- At least five and often more of the dimensions were identifiable within 97% of narratives, so the framework was relevant
- Refinements were needed – more types of Positioning, Tone, Trajectory and Narrative Sequence were found and added to make the framework more comprehensive
- The framework was not relevant for two of the 77 narratives, whose narrators expressed a preference for communicating through art and dance rather than words.

We used these findings to create a revised typology of recovery narrative characteristics. **You can find this and read more about this study in NEON paper #5.**

In analysing narratives, we found that many described personal growth that had occurred after one or more traumas. This observation led to an unplanned strand of work on post-traumatic growth (NEON papers #3 and #19). For interview group A, we explored the reasons for non-service use in NEON paper #17. Some narratives described mental health harm that had been caused by UK institutions. We described this in NEON paper #13.

How should we characterise recovery narratives in the NEON Intervention?

We then created a tool based on the revised typology that would help us to summarise recovery narratives appearing in the NEON Intervention. Having summaries meant participants could search for recovery narratives using categories, or choose to be matched to lived experience they might find helpful using a machine-learning algorithm. The research team created a preliminary Inventory of Characteristics of Recovery Stories (INCRESE) and worked with other researchers and LEAP members to ensure that it was practical, reliable and acceptable to use. We made multiple refinements to descriptions, categories and the language we were using. The final INCRESE tool comprises 77 items spanning five sections: Narrative Eligibility; Narrative Mode; Narrator Characteristics; Narrative Characteristics; Narrative Content. **You can read more about it in NEON paper #9.** INCRESE has since been translated into Dutch (NEON paper #34).

What can go wrong when characterising recovery narratives?

Some researchers and activists with lived experience have raised concerns about creating definitions of recovery narratives. One concern is that having definitions might lead some people's lived experience to be excluded or not seen as valid by services, because they don't fit certain ideas of what a recovery narrative should look like. This is important to address because people with lived experience have often had our experiences dismissed in this way.

The three studies described above address these concerns by showing that an evidence-based definition of recovery narratives includes an enormously diverse range of people's lived experience. This includes recovery narratives from people who have recovered within, outside of, and indeed despite mental health services; recovery narratives that reject medical diagnosis and use other models to explain experiences, such as spiritual or trauma-informed approaches; recovery narratives containing social, political and rights aspects of mental health; and recovery narratives which don't unfold in a linear way or necessarily end hopefully. It also includes recovery narratives where people have found medical diagnosis helpful and those which have positive conclusions. Our key finding for mental health practice is that people designing Interventions based on people's lived experience should make sure that a wide range of narrative types is provided, to ensure that ways of recovering are represented in as diverse a way as possible.

NEON experiences:
David Paul Simon King (LEAP member)

> I first heard about the LEAP opportunity from Nature in Mind, a project for people suffering from mental health problems e.g. anxiety, that gets people into nature to improve their wellbeing.

It includes allotments where they grow crops, prepare healthy meals, and also have trips into the country and walks, learning about nature, birds, insects, plants, trees and boat trips on the canal and river.

I have Asperger's and mental health issues, I've had them all my life. When I was a child I thought too much – had panic attacks before we knew what they were. School life was a struggle for me. When born I was ill, I had a lump on my head and I had to be kept in hospital. I had my mother's milk brought to me – my mother had blood poisoning. When fathers visited they saw her connected to lots of pipes. I was sickly all my life, with very weak arms.

My parents looked after me. I was a difficult child. They did not put me into care, they were poor but did their very best for me. They loved me, sheltered me from the problems of the world. I always wanted a dog. When they could afford one they got me one, it helped me cope. I have been anorexic two times, not eating food. I lost a lot of weight each time. I had a breakdown – I was scared of open spaces (agoraphobic) for a year. I only went every three months to sign on. Each time I had a panic attack, I remember thinking things could not continue.

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I remembered reading a book as a child at school about Douglas Bader's life story. Nurses going by his room said "quiet, the man is dying". He had no pain, he was drifting away – then the pain came back and he struggled, but lived and walked again with artificial legs. He became a war hero. This encouraged me to make an effort to try and conquer my fear and recover my life. It took a very long time, with ups and downs. The first time I made the effort to go through town, the road felt like a mountainside. I had to hide in a shop for a time. I only looked at people's feet.

I got diagnosed with Asperger's very late in life. I was always different, I see the world differently. I thought my lived experience could be useful to other people – that's why I joined the NEON LEAP. At the start I did not know anything, what I was getting into, which is a good thing really. It was a learning curve! I learned loads of information; how the project created all kinds of problems like ethics and designing the study questions. I saw the project going through different stages of development, then getting everything together. I learned about mapping ideas, I met people I would not have normally have got to meet from all walks of life – college professors, people who travelled the world, people who have written their life experiences. It was stressful meeting people, because social situations cause me anxiety. Because of my Asperger's I have very bad anxiety.

> It's been nice to meet kind, friendly people who accept me even if I'm not as clever as they are. They became friends, like family.

Staff came and went, new staff started – all with their own skills to add. LEAP members came and went; new ones added their skills. I got the chance to talk to people on the study over a meal, to listen to their stories and find out about their healthy diets. Everybody looked after me, specially the ladies.

It's all been a positive experience, especially our group winning a first prize award for involving people with lived experience in research. I got to go to London for the prize-giving. I had not been for over 40 years. I had a good time, and have a photo to remind me.

The Douglas Bader experience I mentioned at the second LEAP meeting – it made the professor rethink what recovery stories were. So I have been useful to the study.

"I got diagnosed with Asperger's very late in life. I was always different, I see the world differently. I thought my lived experience could be useful to other people – that's why I joined the NEON LEAP."

NEON experiences:
Mike Slade (Chief Investigator)

> I have been hugely influenced in my understanding of mental health issues by other people with lived experience sharing their stories.

This opened my eyes to the different ways people make sense of what is going on, the impact of treatment, the damage from compulsion, and that mental health challenges are not always a fully negative thing to get rid of. On this last point, I repeatedly heard that whilst these experiences were difficult, sometimes unbearably so, they often also brought benefits, such as increased self-knowledge and awareness of limitations, better self-care skills, more compassion for others, newly-discovered creativity, and a passion to change the world to ensure others don't go through the same bad care experiences. Along with my personal mental health challenges and my clinical experience of seeing the impact of peer support workers as 'credible role models of recovery' on other people with mental health issues, I have a deep conviction that stories change us. This belief sustained me through the long journey of getting NEON funded: six tries since 2011, before it finally began in 2017!

"I have a deep conviction that stories change us. This belief sustained me through the long journey of getting NEON funded: six tries since 2011, before it finally began in 2017!"

During NEON, we have tried to maximise the impact of lived experience, for example by working with the Lived Experience Advisory Panel (LEAP) since before funding and by actively looking to employ people in NEON posts who are dually qualified with research skills and expertise-by-experience. Our LEAP has been a wellspring of innovation, support and challenge. In my role as Principal Investigator with overall responsibility for NEON, this has brought many gains. The level of involvement of LEAP members in various NEON activities has ranged from advisory to collaborating and coproducing to leading. This has improved the quality of our outputs, allowing us to extend our impact beyond the research community. LEAP and our research team have tried to meaningfully work together. This has involved engaging with embedded structural issues, such as decision-making power and resource allocation, which is an uncomfortable but necessary part of mutually respectful working relationships. Many innovations have resulted: involvement of the LEAP from the proposal-writing stage; shaping thinking about design and implementation issues; LEAP co-authors on most of our academic papers; LEAP members being part of our team presenting findings at international conferences; LEAP-led outputs extending the range and reach of our work. At a personal level, the LEAP input has for me been one of the most enjoyable parts of the study, and I really look forward to our regular meetings. Trying to hear, not just listen to, lived experience in our working together has – again – changed me.

2. Collections of Recovery Narratives

> Whilst some recovery narratives are available individually, including in YouTube videos and as published autobiographies, we found it common for narratives to be grouped together into collections.

The oldest collection we have identified is “A Plea for the Silent”, a book of accounts from anonymous individuals. This was first published in 1957 by Members of the UK Parliament Dr Donald McIntosh Johnson and Norman Dodds, to try and raise awareness of harmful psychiatric practices, and to reduce what we would now call stigma about mental health problems. More recently, the charity Time to Change has built a large collection of online recovery narratives, which it used to try and reduce stigma about mental health problems in the UK. Here to Help in Canada used narratives to help people find hope and common ground around mental health. We did a thorough review of how narratives are used to help people affected by mental health problems, which you can find in NEON paper #18.

Assembling collections of recovery narratives takes time and energy, and during the NEON study we met and worked with lots of people who had done the work of building collections, including Rianna Walcott, who co-edited the book “The Colour of Madness” which presented narratives from authors identifying with a minority ethnicity. We realised that the people who create these collections could influence how mental health is seen and understood by others. We borrowed the term “curator” from museums studies. This guided us towards doing research that helped us understand the work curators do. We started by reviewing all available research on the work of curators, and found only one research paper (reviewed in NEON paper #4, along with 22 other published documents). We then interviewed 30 people who had curated collections of recovery narratives from around the world, and analysed this data to document curators’ motivations and working practices.

> We hope that this work will help curators to thoughtfully engage with the work of building a collection, and will help the public, policymakers and healthcare commissioners to understand what underpins the narratives included in a collection.

During our work, we found that curators we interviewed were motivated to:

- Fight stigma
- Campaign for change in service provision
- Educate about mental health and recovery
- Support others in their recovery journey
- Critique psychiatry
- Influence policy change
- Market particular health services
- Reframe how people think about mental illness

Curators tried to achieve these aims through tactics such as selecting narratives with content that fitted a particular campaign, and even through editing narratives, normally with the consent of their narrator.

When we looked at the work curators do, we found that decision-making processes fitted into the following six categories (which we gave the acronym VOICES):

- Values and motivations (what the collection stands for and why it exists)
- Organization (how the team will find and present narratives, and evaluate their impact)
- Inclusion and exclusion (what narratives can and cannot be included, and how they might be edited)
- Control and collaboration (how the curatorial team will work together, and how it will manage power differences between the team and its narrators)
- Ethics and legal issues (what consent will be collected for narratives, whether narrators will be identifiable in narratives, who will own narratives, and what payments will be made)
- Safety and well-being (how narrators and people engaging with the collection will be kept safe, including whether trigger warnings will be used).

You can read about our work to understand the role of curators of narrative collections in NEON papers #10 and #15 and more about trigger warnings in NEON paper #22. NEON paper #27 describes our thinking on how to monitor the diversity of narratives included in recovery narrative collections. NEON document N4 describes guidelines for working ethically with narratives, which we developed with a range of community groups and other experts.

NEON experiences:
Rianna Walcott (LEAP member)

> I was originally invited to a conversation with one of the academics at NEON about my experiences and motivations as a curator of lived experience narratives, through the edited collection, The Colour of Madness.

This collection, first published in 2018 and republished in 2022 is an anthology of art, poetry, autobiographical writings and other creative offerings relating to Black, Asian, and Minority Ethnic (BAME) lived experience of mental health issues and access to health care in the UK. A selection of these narratives then went on to be included in the NEON Collection of lived experience narratives, and I subsequently joined the NEON LEAP in May 2019.

The LEAP was the first time I had participated in this kind of organised research, and indeed in research outside of the arts and humanities. At the time of joining, I was a PhD candidate at King's College London working in the field of Digital Humanities, so outside of my advocacy work in mental health access for BAME people, my research did not often touch on science or medical themes.

However, the technological aspect of the project that used digital affordances and algorithms to improve access to types of healthcare services appealed to me and my interest in digital technologies used by marginalised people.

Being a Black woman with lived experience of mental health difficulties, it was particularly novel and encouraging to see that the very same facets of my identity that marginalised me within academia were of particular strength and value to the LEAP. In ensuring NEON is broadly accessible and effective for a wide variety of demographics, the LEAP attempted to bring together many different types of people to advise. I did find that certain demographics were over-represented, for example white, middle-aged or older people, and people from academic backgrounds. This made my perspective feel all the more valuable and necessary in providing an alternative to the main demographic.

The ethnic demographic makeup of the LEAP was reflective of the wider racial makeup of the UK, and by including different voices in research method and output, we demonstrated the value of lived experience as data. It would have been good to see more people of colour from outside of academic backgrounds represented to ensure the inclusion of non-academic perspectives in both research methods and audience.

I found that my experience of participating in the advisory panel allowed me to think of myself as more than just a person with lived experience of poor mental health, but also as a mental health advocate and a collaborative researcher. I also appreciated how the LEAP seemed to have clear outputs in the form of papers, co-created resources about the project, and conference presentations.

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Participating in the LEAP has also lead to extra professionalisation opportunities for me beyond the project, including plenty of talks, collaborations with NEON and McPin, and my involvement with another lived experience council through the HBGI (the Healthy Brains Global Initiative). My experience with the LEAP has also found a special mention in the revised edition of The Colour of Madness, as an example of an important examples of mental health research in the UK.

> As an early-career academic from a marginalised background, my experience in the LEAP has been of great personal value to me in seeing how aspects of science, technology, engineering, and mathematics (STEM) and humanities research can go hand in hand, and in demonstrating the value of person-centred research, and lived experience as a research metric and method.

NEON experiences:
Caroline Fox-Yeo (Research team member)

> I am a peer and survivor researcher with lived experience of mental distress and found my experiential knowledge really enriched my work on the NEON project.

I had previously worked in a survivor run organization and used my contacts there to set up interviews with experts for my study in NEON about curators of lived experience narratives. My interview style was influenced by my experiential knowledge and I felt I could connect more with other service users because of my own experiences of being a service user. I could build rapport and go deeper into “challenging” or “distressing” subjects which I had personal experience of. In the analysis of the interviews where I had my own lived experience I could connect more deeply with the data I was analysing. I was first author on three peer-review journal papers published in NEON and I chose some co-authors who were peer or survivor researchers working in academia or the community. I found that lived experience was a real asset to working on NEON.

3. What impact do recovery narratives have on people accessing them?

> Engaging with a mental health recovery narrative can affect us in different ways. A narrative might leave us feeling hopeful for the future or feeling less alone. Alternatively, narratives can also have the opposite effect and may leave us feeling invalidated.

Prior to the start of the NEON study, there was no thorough model to describe how accessing a recorded mental health recovery narrative may impact someone. The NEON team did three studies to illuminate how people are affected by recorded recovery narratives.

We summarised the literature using a systematic review, which found five papers that talked about how mental health recovery narratives impact people who access them. Types of impact were: connectedness, improved understanding of recovery, stigma reduction, validation of experiences, affective response, and behavioural responses. The type of impact a narrative has can be influenced by the characteristics of the recipient, the context in which the narrative was accessed, and the narrative content itself. However, imitating harmful behaviours depicted in a narrative was also possible.

You can read more about the systematic review in NEON paper #2.

To test these findings in a real world setting and to understand the long-term effects of recovery narratives, we talked to 77 individuals with experience of mental health problems and recovery. These individuals were from four under-researched communities, described in Section 1 of this report. We developed a model to describe how narratives create change by asking the individuals to describe the impact of other people's recovery narratives on their own recovery. We found that making a connection with the narrator or narrative was required in order for change to occur. The individual having shared experience with the narrator, seeing the achievements or difficulties that the narrator experiences, learning from the narrative, or having an emotional response, all influenced change within the individual.

These changes were described as helpful or unhelpful. Helpful changes included:

- A sense of connectedness, validation, hope, empowerment, appreciation
- A shift in the individual's frame of reference
- And stigma reduction.

Unhelpful changes included:

- A sense of inadequacy, disconnection, pessimism, and emotional burden.

Change was influenced by whether an individual perceived a narrative to be authentic, or whether the individual was experiencing a crisis.

You can read more about the impact interview study in NEON paper #6.

These findings, however, could not explain how connection with a narrative was formed or how people are immediately impacted by narratives. To understand this, we ran a study where 40 mental health service users were shown up to 10 random selected mental health recovery narratives. Narratives were presented in different formats including text, audio and video. Accessing a recovery narrative led individuals to reflect upon their own experiences, which then led to connection through three mechanisms:

- comparing oneself to the narrator or narrative
- learning about the experiences of others
- and empathising with the narrator.

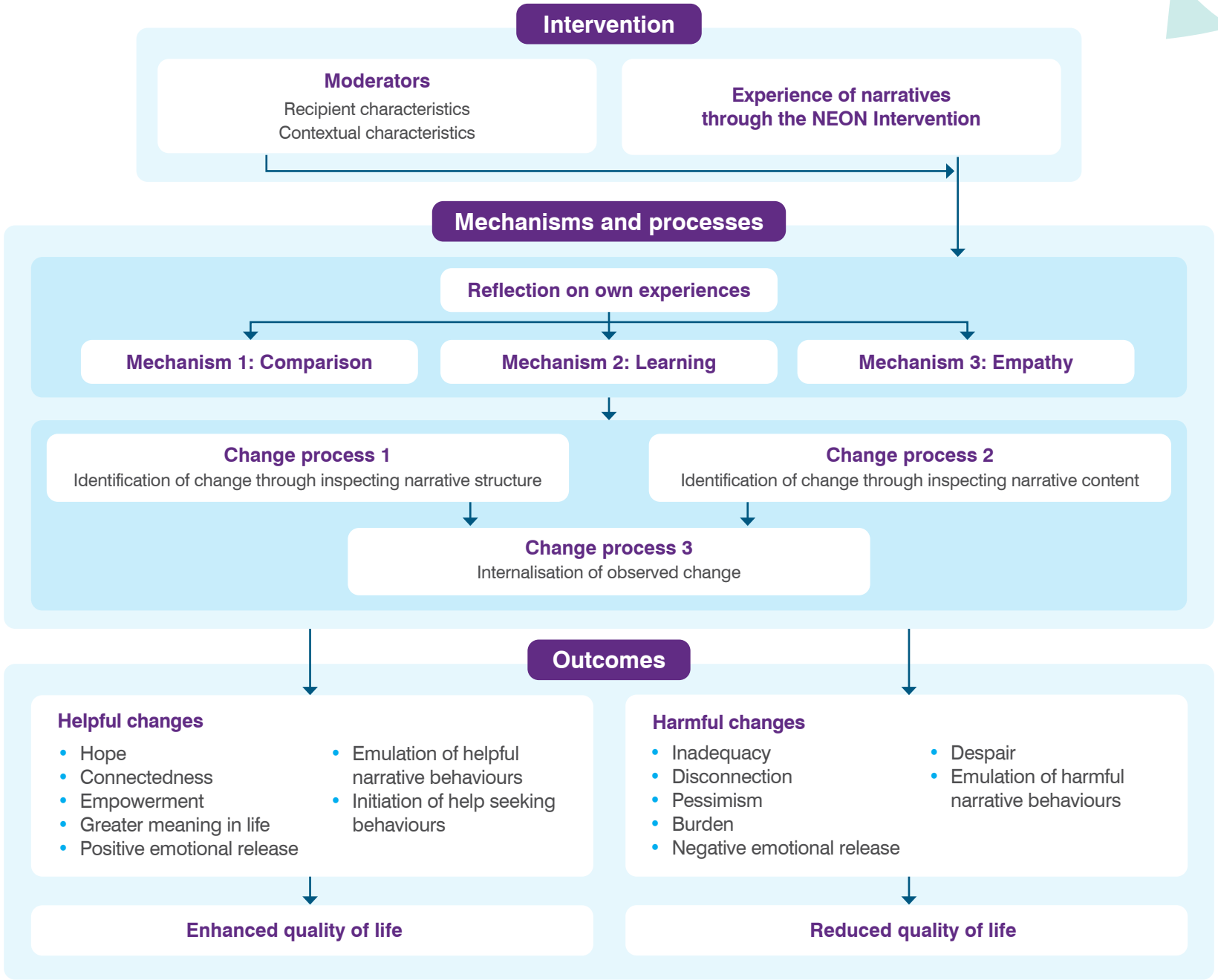
These mechanisms led to changes through three processes:

- identifying change in the narrative
- interpreting the change
- and internalising change.

Characteristics of the individual and the narrative influenced how change occurred. **You can read more about the study in NEON paper #7 and #20.**

To summarise our learning, we combined our findings to develop the NEON Impact Model. This model describes how engaging with mental health recovery narratives can lead to a number of mechanisms and processes which affects whether an outcome is experienced. **You can read more about development of the Impact Model in NEON paper #14.**

NEON Impact Model



NEON experiences:
Scott Pomberth (LEAP member)

Carer Peer Support Worker, City Crisis Resolution Home Treatment Team (CRHT)

Nottinghamshire Healthcare NHS Foundation Trust

At the time I was first involved in the LEAP, I was experiencing a high level of anxiety and a moderate level of depression. I needed something to get me thinking in a positive way, as I felt worthless and not really part of anything, but then I heard of NEON.

I first heard of NEON and LEAP about five years ago when an opportunity was given for people who have mental health experiences to participate in a research study. I have always been interested in this area and I wanted to know how people with such experiences can influence mental health services in the future. I can remember this occasion because it made me think more deeply about how people's lived experience (stories) can help others through their on-going recovery.

I found being part of the LEAP very rewarding, as it made me feel valued and that researchers were taking a genuine interest in people who have used mental health services or are still using them. It was great to meet up with like-minded people along with academics, this was a confidence booster for me as everyone involved with NEON and the LEAP were very welcoming, accommodating, and empathic.

During my time with the LEAP, I have been fortunate to have the opportunity to be involved in several research papers with different members of the NEON Team as well as taking part in numerous research projects. This was very satisfying as it gave me the opportunity to use some of my skills which I obtained during my time at university, such as researching and writing an account of my opinions and thoughts pertaining to different aspects of mental health.

I found that meeting up with the LEAP several times a year helped me with my own mental health. It gave me something to look forward to, and focus on, especially during the pandemic when I was feeling isolated working from home for a long period of time. I think that during these meetings, LEAP members influenced the NEON Team in regard to some of the approaches and the language which is used. I can remember having a good discussion with the team and fellow LEAP members about the use of the word "stories". Some people thought this was an appropriate word to use when referring to people's experiences of mental health and their lived experience. I thought the word "stories" can be misunderstood to mean a fictional story. The discussion was an excellent example of how people with mental health experiences can work collaboratively both together and with NEON Team members and arrive at a suitable outcome.

Regarding people's lived experiences ("stories"), it became apparent in my experiences of reading other people's accounts of their lived experience and their process of recovery, I didn't need to read about what I was experiencing to gain some comfort or hope. I found that reading a collection of people's "stories" about a lot of different aspects of mental health had a positive effect on me. I think it is a common misconception that only "stories" that relate directly

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to the same diagnosis as the reader will be of help and have a positive impact on them. Reading “stories” that provide hope, show opportunity, and a way of taking more control over their lives, no matter what the diagnosis can equally have a good outcome.

This is the same with Peer Support. To be able to support someone who is experiencing mental distress, you don’t need to have the same lived experiences. The “stories” I have read often have the eight core principles of Peer Support running through them like a thread.

I have gained from other people’s “stories” that often I can form a relationship based on shared experience, including authenticity and respect even without knowing the person. I have found that I have been reading accounts which are non-directive and they do not say if something has worked for them, that it should work for you. All of the “stories” are recovery focussed and gives confidence that people can grow within and beyond their experiences of mental health. In addition, most “stories” recognises people’s courage, strengths and skills and how they can use these to help themselves during their recovery. I have understood from some “stories” that it isn’t just about having mental health challenges but understanding the meaning of such experiences within the communities of which the person is a part. This can be critical among those who feel marginalised and misunderstood by traditional services.

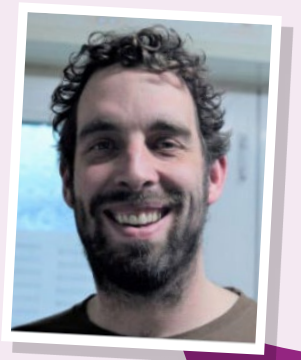
Someone who knows the language, values and nuances of those communities has an understanding of the resources and possibilities within those communities. The “stories” have provided me with hope that enables me to share a similar journey and that I have the means to move forward with my own recovery. I have felt safe when reading the accounts, as I feel the author/s are able to express themselves freely in a supportive way, where the reader also feels safe.

> In conclusion, I feel that the whole NEON Project has been a tremendous success, and this was proven with the national award the team won [the Mental Health Research Service User and Carer Involvement in Mental Health Research Awards 2022].

Going to London to be part of the team receiving the award was a very proud moment.

Scott has also written about his NEON experience in an online blog: **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**

NEON experiences: **Stefan Rennick-Egglestone (Programme Co-ordinator)**



I was the first researcher to join the NEON study, in August 2017. I'd become very interested in the possibility that some organisations publishing recovery narratives might be misusing them as a self-promotion tool. Joining a well-funded study intending to take a detailed look at recovery narratives was very appealing.

My own personal experiences of a range of mental health problems over two decades had led me to these concerns, because many of the narratives that I was encountering in the public domain felt too polished and inauthentic. They often lacked rich detail which had perhaps been edited out to suit organisational need. I worried that the overly-simplistic descriptions they provided of recovery processes might inadvertently cause harm. I wondered whether a narrative describing an easy recovery due to Cognitive Behavioural Therapy (CBT), for example, might be harmful to those for whom CBT had been ineffective.

Because of these personal concerns, I've worked to make sure that understanding the harms, as well as the benefits, of access to recovery narratives has been a central part of the NEON programme. I'm proud that we've taken care to publish our findings describing both benefits and harms, including in NEON papers #2 and #6. I'm thoroughly convinced that, for the most part, people will benefit from engaging in others' recovery narratives, but that we also need to take care, for example through sensitive use of content warnings, to enable people to protect themselves from known harms as well.

A big change for me, during the period of the study, has been an emerging identification as a peer researcher, which is defined as someone who conducts research into topics of which they have experiential knowledge. I'd previously had no exposure to that term, and have only learnt about it through working with people who do identify as peer researchers. I've learnt that peer researchers can provide many benefits to studies – for example, through an intuitive understanding of which questions are the most valuable to investigate. However, peer researchers can experience a burden of emotional labour that non-peer researchers may not experience. I've experienced that emotional labour myself during my work on the study, and an important part of my work as the study co-ordinator has been to work with other peer-researchers, and to help people stay healthy despite this emotional labour. My own experiential knowledge of profound distress has been essential in having some small understanding of how to go about this.

Of the many things that I'm proud of from the NEON study, just one example has been taking personal concerns about misuse of recovery narrative, and turning this into a strand of methodical research work. Through four papers, we have investigated the work that curators do to build collections of narratives and hence shape how mental health is seen and understood. This culminated in a large systematic review documenting existing knowledge on uses and misuses of lived experience narratives in healthcare and community settings (NEON paper #18). This strand of work has been peer led from the outset, and perhaps it would not have been as thorough and insightful if it had not deeply involved a range of people with their own personal experiences of mental health problems.

4. The NEON Intervention

> NEON has looked at how we can provide access to the NEON Collection of narratives through the web. More and more people will have a computer or smartphone with Internet access, and whilst there are some people who don't own either, computers are often available for public use in settings such as libraries.

Providing narratives on the web allows us to include hundreds of narratives, and to add new narratives as we find them. A printed book would contain far fewer stories than this and could not be changed. Accessing narratives on the Internet might be easier for people who feel anxious about mixing with others, or who live in remote places without much access to health services.

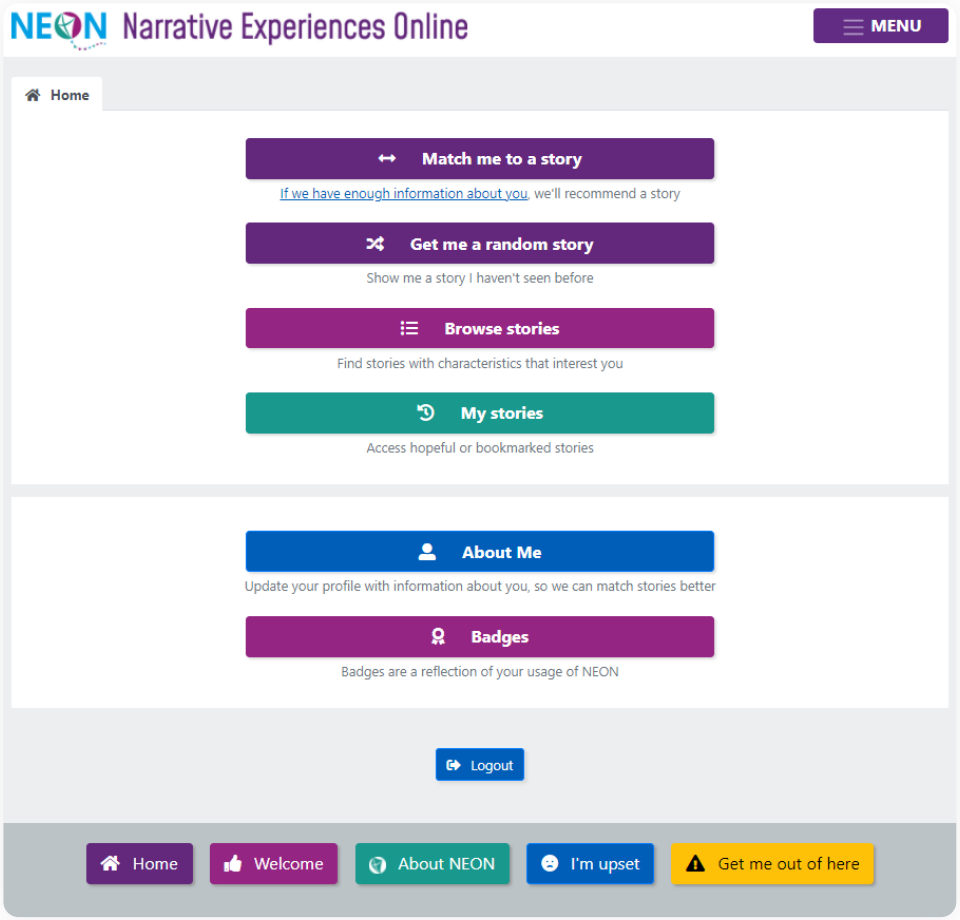
The NEON team produced a simple web-application called the NEON Intervention. The technology that we produced was carefully designed to work on most computers or smartphones, even older ones. The NEON Intervention makes it possible to watch, read, or listen to all of the narratives in our collection. We kept the design simple and bold, following guidelines on how to create technologies that are as accessible as possible to all. **You can read about how we developed it in NEON paper #14.**

Early versions of the NEON Intervention were discussed with a panel of people experienced in supporting others through mental health problems. **You can read about these focus groups in NEON paper #11.**

NEON Intervention users have to log in with a username and password. That stops NEON Collection narratives from appearing in search engines such as Google, which is important when some narratives can describe difficult experiences and events. For all of the narratives in the NEON Collection, the people who produced them have chosen how they wish to be presented. Some narratives are purely anonymous – it would be impossible to work out who the teller was after reading them. Some narratives show photographs of the teller.

> Since narratives are so personal to the people who have shared them, we decided that it was important for tellers to choose how their identity is presented.

The main screen of the NEON Intervention is shown below. “Match me to a story” uses an algorithm to select a narrative that might help someone, “Get me a random story” chooses a narrative that the user has not seen before, “Browse stories” allows users to select their own narrative from the NEON Collection, and “My stories” allows users to return to narratives that they have accessed before.



After accessing each narrative, users are asked some simple questions about how the narrative has impacted them, such as “how hopeful did this make you feel?”. Their responses are stored, and used to improve how the algorithm behind the “Match me to a story” button works.

You can read a detailed description of the NEON Intervention in NEON paper #8, and you can learn more about the algorithm that we developed, in NEON paper #36.

NEON experiences:
Anonymous trial participant

Up all night with Keanu Reeves …

I always felt like an outsider but superficially was academically competent, progressed through my career well and even temporarily owned my own home. Depression was diagnosed in my twenties but medication and counselling over the years failed to curb that sense of displacement. I also had a self-destruct button with impulsive and addictive behaviours that just didn’t feel strange at the time.

In my 40s, completely out of the blue, and thanks to an unusually perceptive GP, I was diagnosed with ADHD. If only it had been that easy. It wasn’t. I was in the middle of a work-based investigation over ‘my behaviours’ which was to conclude eventually in my losing the job I loved. In the midst of that horror I was quoted an eighteen month waiting list for specialist local NHS ADHD services. I paid for private diagnosis.

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But the silver lining of that surprise ADHD diagnosis was infinite. So much of the past and the present me made sense; from an inability to read social cues or mediate opinions in the workplace, to making reckless decisions, my inability to being anywhere on time … right down to my terror of Excel spreadsheets.

The same GP referred me onto a ten-week Art on Prescription course. Boom. Fireworks burst through that silver lining. I could paint but I also found my mindfulness fix. I entered that first painting into the University of Nottingham Institute of Mental Health (IMH)'s 2018 annual summer exhibition.

I belonged. Painting slowed my racing brain and together with medication and an adult support group I started to feel proud of the non-neurotypical brain and my super powers of uber-creativity, hyper-focus and bounce-backability.

The IMH exhibition gave me the confidence to keep challenging myself and I won an art commission, a place on a summer school and even spoke about the impact of art on my mental health at the Royal Academy of Arts.

My super nosey brain was still into everything but COVID stymied most opportunities. Luckily NEON came along around March 2020. My old career was as a storyteller so I got it. I understood the potential power of personal stories but there were some buts. If you have met one person with mental health issues … etc. The topics and range of experiences under the mental health giant golfing brolly was huge. Just as diverse was the way the stories were told or even packaged.

There were videos, audio, transcripts of interviews, art work, streams of consciousness, poetry. There were lots of different fonts and rainbow headings that set my teeth on edge. But I devoured the stories.

I was dismissive of some, shouting 'next' as I moved on. But there were some that did resonate for different reasons. Mainly because they gave me hope I guess. Sat in my little rented house with my cat and laptop I didn't feel so alone. Other people dealt with stuff. Big stuff or just some stuff that neurotypicals felt uncomfortable talking about.

Actually sometimes they couldn't deal with the stuff. I wasn't craving a happy ever after. Just sharing the story, sharing the hurt, the confusion or the fight was enough for me, regardless of the outcome.

It was mostly different stuff to my stuff. Their history of physical abuse or psychosis was not mine. Yet we were all the same really; sharing our vulnerability and being human. I was OK.

I am not much of a fan but somehow in my mind, NEON became Neo from the Matrix so it was me and Keanu against the world. Up all night meeting all these perfect imperfect people; a laptop porthole to other worlds that somehow anchored mine.

“There were videos, audio, transcripts of interviews, art work, streams of consciousness, poetry.”

NEON experiences:
Anonymous trial participant

For some time, I have appreciated the therapeutic benefits of reading autobiographies and listening to podcasts about peoples' lived experience of mental health.

The NEON study has become my go-to resource for recovery stories. When I first searched the NEON Collection, I found it difficult to uncover recovery stories which resonated with my own experience. I take most from stories written by people whose circumstances I can empathise with. I like to be able to 'walk in the shoes' of the author. I find the search function helpful when I am looking for a story which is particularly relevant to me. It is also sometimes good to read a random story. I think I have taken inspiration from many of the stories which have helped me think more deeply about my mental health.

Over time more stories which are relevant to me have been added to the collection, so I keep coming back to see what's new.

In a world where the stigma surrounding mental health conditions persists, it is wonderful to be able to access a collection of inspiring and honest recovery stories.

I found some of the stories really struck a chord with my lived experience and this convinced me of the benefits of sharing.

In 2020 I started drafting my recovery story with a view to adding it to the NEON Collection. I found this to be a cathartic exercise, as it encouraged me to reflect on my recovery journey. I wrote my recovery story during the COVID-19 pandemic when I had plenty of time to ponder my mental health. The pandemic could have led to negative emotions and unhelpful rumination, however putting my story in writing for the first time helped me to rationalise my thoughts.

Having drafted my story for NEON, I decided to share it with my partner so that she could gain a better understanding of how I experience mental health. My low moods have frequently put a strain on our relationship. At the time I thought sharing could be risky, as my story is perhaps a little self-indulgent. My partner's response was however positive and supportive. We both now find it easier to talk about our mental health.

Hearing about the stories of others has helped me come to terms with my mental health in so many ways. I am now far more open about my mental health journey and am passionate about using my experience to help others. I have obtained a qualification in mental health peer mentoring. In this role it is essential to be able to share my recovery story with mentees in order to empathise and build rapport.

I have recently joined a peer support group where we share our experiences of mental health openly and without judgement.

I also use my lived experience to help in the training of clinical psychologists and the improvement of NHS talking therapies.

My recovery journey is far from over. I have learned through sharing my story and listening to the stories of others that there are life events which have affected my mental health that I want to resolve.

> The NEON Collection is a wonderful resource, which I hope will continue to grow and be promoted so that many more people can benefit from it.

5. Findings from the NEON trials

> We collected evidence on the benefits of using the NEON Intervention through three clinical trials, which collected data from March 2020 to September 2022.

Two of these trials were very large. The **NEON Trial** was for people experiencing recent distress, and who had experienced psychosis in the last five years. 739 people took part. The **NEON-O Trial** was for people who had experience of other (non-psychosis) types of mental health distress, with 1,023 people taking part. NEON papers #8 and #21 describe how we ran our trials. NEON paper #16 describes our approach to recruiting trial participants without causing harm. For example, our researchers never posted trial information in social media groups offering mental health support, because we know that researchers' presence in these groups can be off-putting. Both trials included people who had and had not used UK mental health services. **We found that there were some differences between these two groups, which we explored in NEON paper #31.**

In all of our trials, half of those who registered received the NEON Intervention immediately, and half received it after a year. Everyone, in all trials, was asked to complete some questionnaires about their life, their wellbeing, and their use of mental health services.

Splitting people into two groups allows us to compare the changes experienced by people with immediate access and people with one-year delayed access. This allows us to make clear statements about the impact of receiving the NEON Intervention during the one-year period in which people took part in the trial. **You can read about how we analysed trial data in NEON papers #24 and #28.**

For the NEON-O Trial (involving people with experience of non-psychosis types of mental distress), we found some substantial benefits. Access to the NEON Intervention improved the quality of people's lives and their perception that their life had meaning. These benefits were provided at a cost that would be acceptable to the NHS. Female participants also experienced a reduction in psychological distress, but there was no evidence for a reduction for other participants. **The full findings of our NEON-O Trial are described in NEON paper #32.**

For the NEON Trial (involving people with psychosis-like experiences), no immediate benefit was found, but our analysis shows that no harm was caused. People who received immediate access used the NHS more in the following year, and it is possible to conclude that those people had been encouraged by narratives to seek help, and that these people might experience benefits through seeking help.

People who found at least one narrative that made them feel more hopeful, experienced an increase in their quality of life. We don't know whether this was caused by the NEON Intervention or not; it's possible that having a better quality of life led to them obtaining more hope from engaging with a narrative. The full findings of our NEON Trial are in NEON paper #38. From the NEON-O Trial and NEON Trial, we concluded that the NEON Intervention should be available to all, because it benefited people with non-psychosis mental health distress, and did not harm people with psychosis-like experiences.

We also recruited people who care for others affected by mental health problems, in the **NEON-C Trial**. This was smaller, with 54 participants; our aim was to see whether the NEON Intervention might be useful to carers, to help us run a larger trial in the future. We found that the NEON Intervention had promise for this group, but needed to be extended with narratives from carers themselves, as well as people experiencing mental health problems. An online community was also needed, to allow carers to discuss what they had found. **Findings of our NEON-C Trial are described in NEON paper #33.**

Interviews with NEON Intervention users

> To understand what people thought of the NEON Intervention we carried out 54 one-to-one interviews with people from the NEON and NEON-O trials who had used the NEON Intervention over the course of a year.

We wanted to explore any positive impacts the intervention may have had on their daily lives, and to capture when NEON may have had negative impacts or no impact. This would help us understand who the Intervention might be most useful for. We were also interested in people's feedback on their practical use of the Intervention.

We found that the NEON Intervention was described as a "safe place" for users to access and interact with recovery narratives. It was seen as most useful by people who used it as an alternative resource that helped in their recovery, for example when they wanted to opt for non-pharmaceutical options. Some people reported that they actively used the NEON Intervention more during periods of distress, to improve their mental well-being. Others reported that it was least useful for them during periods of distress. When the NEON Intervention was found to be useful by people, there was a pattern of these individuals integrating it into their lives as a part of their daily routine.

The ways in which people used the NEON Intervention differed. Some used the narratives as a tool to distract from negative thoughts and emotions. Some accessed them when they wanted to experience positive feelings like hope. Some used them for reassurance that what they were experiencing was "normal", and for inspiration, that feeling better, even if not fully "recovered", was possible.

Many people felt connected to the narrators of the stories, leading to a feeling that the NEON Collection was a type of large support network. We found this interesting, as the NEON Intervention did not include ways for users to communicate with the narrators, or with other trial participants. Despite this, some users felt part of a supportive community through the narratives, which helped them feel less alone with their experiences. Some people also reported using the NEON Intervention out of necessity, as the only resource readily available to them when they couldn't access mental health services due to high demand and long waiting lists.

Many individuals also identified what they would ideally want from a collection of recovery narratives. This was often described as having relatable, "brave", and authentic narratives. The authenticity of narratives was judged on whether they were seen to be engaging with the complex realities of mental health difficulties, rather than presenting simplified versions. Being presented with a large and diverse collection of recovery narratives made it easier for some individuals to compare their own story with others, to find a variety of experiences, and to access minority perspectives. On the other hand, others found it overwhelming to have access to such a large collection of narratives.

You can read more about what people thought of the NEON Intervention in NEON paper #35.

NEON experiences:
Anonymous trial participant

> I'm really grateful to have had the opportunity to participate in the NEON trials, as it's encouraged me to reflect on my mental health and think of some positive coping mechanisms for dealing with stress, depression and anxiety.

NEON also provides a kind of community reinforcing that none of us are alone in our low points and struggles, as depicted in the beautiful and poignant stories and art submitted to the site. I know that I will always experience mental health struggles throughout my life, but it's comforting to know that I'm not alone, that it's a part of being human, and that by getting the right help, it's manageable; whether that be through medication, therapy or expressing and processing those painful or negative feelings with art and creativity. Nobody can provide a quick fix or a permanent cure for mental health problems, but NEON offers a wonderful platform for expression and a safe space for people to access stories full of wisdom, hope and candour.

The emails reminding me to log in to NEON and letting me know that new stories have been added have been really useful, as they encouraged (and reminded!) me to focus on my mental health and build a positive habit; something I've always struggled with. I often forget to look at the site, but I definitely log in more thanks to the reminders sent to me. I quickly realised that I preferred the short and more creative posts, such as the poems and drawings/pictures, over the longer, more involved stories. I tended to find them more

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hopeful and inspiring, and they often evoked a stronger emotion from me, as they allowed me to interpret them according to my own thoughts and feelings and apply them to my own life. I think maybe I would have preferred to read shorter stories, summed up in one paragraph, as the longer stories didn't hold my attention for long enough, and some of them made me feel less hopeful and more down, whereas the art and poems usually gave me a positive boost, made me feel a strong emotion or gave me something to reflect on, so I identified more with them.

This is why I found that being able to save the stories that have really impacted me positively or that I want to be able to look back at again in the future is an extremely useful feature – it's also great that you can make notes on your saved stories, as it encourages self-expression and reflection, and enables you to note down the parts of a story that you found the most helpful or inspiring. Personally, I would really enjoy seeing a section where participants can share quotes from books or lines from songs that have positively impacted them or helped them overcome a hard time, as this could make people feel more hopeful but also allow them to discover new music and literature, which can be extremely therapeutic!

The best thing about NEON is undoubtedly the people who are working on it – I spoke to an absolutely lovely member of the team called Yasmin, who interviewed me, and she was so engaging, kind and patient. Just from my brief time talking to her, it was very clear to me that NEON is run by compassionate and caring individuals who are striving to support vulnerable people and make a difference in this world. Thank you for making a difference in mine.

“Personally, I would really enjoy seeing a section where participants can share quotes from books or lines from songs that have positively impacted them or helped them overcome a hard time...”

NEON experiences:
Anonymous trial participant

An episode of All In The Mind on Radio 4 introduced me to the NEON trials. It was November 2020 so social life was being affected by COVID. In many ways the lockdown had been a positive experience for me, as it took the pressure off finding belonging and purpose in the wider world while dealing with recovery from anorexia nervosa and anxiety. In fact I always felt I got the message it was essential for me to keep working through these challenges at the same time as the eating difficulties. I felt like finding community and purpose were crucial to my recovery but the lockdown removed the stress for a bit. I was very fortunate I had a home with my partner with easy access to public green spaces and no money worries.

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It feels difficult to disentangle the influence of NEON from everything else e.g. COVID lockdowns, new treatment interventions and discharge from specialist services almost a year ago. Before NEON I'd taken up opportunities to participate in research. As someone who first developed anorexia in the late 1990s I'd become frustrated by the stereotypes and lack of understanding of the illness. I realise I gain meaning from participating in research as it could help others. For this reason the NEON trials were attractive to me as despite struggling to develop social skills I have a need to belong and contribute. Being interviewed as part of the research gave me a boost and even reminded me of how I once enjoyed some aspects of being a student. It was challenging to know if I was giving accurate feedback on my experience! In a way I also noticed it stirred up awkward feelings about being a person with difficulties that still dominated my identity.

Using the NEON recovery stories themselves was a welcome change to most recovery stories I'd encountered before. Things are changing in the media but my overriding experience of eating disorder recovery stories were: it was tough for me and my family, I learnt important life lessons and I'm stronger for it. In short they were glossy and the person always seemed to have not only identified but achieved a life goal (career, children, absence of illness…). I had a habit of aspiring to a generic version of these stories, rather than unpicking and respecting the personal challenges I faced. I think I felt more of a failure for this and didn't pursue what I needed.

Some stories on NEON seemed similar to this but there were many more relatable. It helped to have people you don't easily find on social media. At first I was unsure how stories that seemed so different from my own experience could help me. So many had greater adversity to cope with or conversely had strong community inclusion. At first I engaged with these as I love learning about other people. I haven't accessed NEON recently as I wasn't finding new stories (I'd accessed so many!).

Long term, hearing diverse stories across cultures, countries and lifestyles maybe helped bring a sense of self-acceptance for me. They showed it was ok to struggle and gave stories of how they got through. It also gave me a partial relief from loneliness, but less so now as I still struggle to find belonging, being out of step from my peers. I now make worry monsters for a charity and one story by a puppeteer that I found surprisingly relatable pops up in my thoughts occasionally, reminding me it's ok to take your own path.

“I realise I gain meaning from participating in research as it could help others. For this reason the NEON trials were attractive to me as despite struggling to develop social skills I have a need to belong and contribute.”

6. Power in diversity

Equality and diversity within the NEON team

> We end this report with some final thoughts about two important aspects of our own NEON story: the centrality of lived experience to the development of the study, and what we have learned about the diversity of experiences encompassed by the phrase ‘people with lived experience’.

Achieving the meaningful involvement of people with lived experience in mental health research is a crucial issue – research is the production of knowledge, and the knowledge being produced intimately affects us and the services meant for us. Meaningful involvement is also a central issue because much of the participation of members of the public in research can be regarded as being at ‘token’ level – for example, being asked to simply ‘rubber stamp’ research activities and findings that we have not been sufficiently involved in planning or executing.

As a NEON team, we hope and believe that this situation is improving, as better models of ‘co-production’ are created (where the research is designed and undertaken by researchers and people with lived experience equally), as funders increasingly see the value in genuinely co-produced approaches, and as more researchers with lived experience feel encouraged and enabled to share and discuss our own experiences of distress more freely.

However, as this happens it becomes even more important to acknowledge that not all lived experience of mental health problems is the same. Many of us – perhaps most of us – have experienced being marginalised because of our lived experience of distress. This is a social justice issue in itself. Additionally, some of us are further marginalised for other reasons – due to our race, ethnicity, sexuality, gender, age, religion or belief, economic situation or additional disability, for instance. We are likely to have experienced mental health discrimination differently, and it is therefore likely that our differing needs are at risk of being even more overlooked by researchers and services. All of this may make it even more difficult for us to tell our stories, and/or for other people to be able to hear and accept them, because they are not ‘mainstream’ experiences.

You can read more about this in NEON papers #23 and #29.

Thinking about these disadvantages collectively is often referred to as ‘intersectionality’. First coined by Professor Kimberlé Crenshaw in 1989, intersectionality is a term used to acknowledge that everyone has their own unique experience of oppression and privilege that intersect in complex ways. We must therefore consider **everything** that can marginalise people, as a more accurate lived reality. Without this, our efforts to reduce inequalities and injustice towards people living with mental distress are likely to continue maintaining the same systems of oppression and inequality.

> The more we are able to acknowledge these differences, and then work to find ways to better accommodate and accept them, the more effective our approaches to reducing mental distress will be.

Viewing narratives through an equality and diversity lens has been one of the key learning processes for the NEON team. We feel we have made gradual movements over the course of the study towards a greater understanding and awareness of our differences and similarities, recognising that power is always an aspect of that diversity. This has involved conversations that have sometimes been tough for us. But necessary, nonetheless.

Examples of how equality and diversity issues have been raised and addressed in NEON

In the words of one of the team, working on the NEON study has been like creating a ‘living equality impact assessment’. It’s been a continuous process of exploration, consideration and learning that has sought to put equality and diversity at the heart of everything we’ve done. We have moved, for example, from a focus primarily on what people have said in their stories to a greater consideration of who is telling the story, and how their whole identity is important, not just their mental health experience. We have discussed our own differences as a team, and how we can promote and better support other people from marginalised backgrounds to tell their stories.

One important factor in this work has been having leaders who recognise and support the importance of working through equality and diversity issues. Actually hearing from Mike, the study lead, that equality and diversity had made a significant impact in how he was engaging with the entire NEON process was really something.

However, sufficient time and resources need to be invested in research studies for the additional work, which is necessarily involved in ensuring that people from minoritised groups are equally included. When it came to encouraging individual donations to the NEON Collection, we realised it was important to do some additional work to try to ensure that narratives of people from different minorities were well-represented.

We identified four groups of people whose stories we wanted to make especially sure were included, as they are at particularly high risk of mental health problems: people from Black, Asian and other minoritised ethnicities, people with minoritised sexualities, people with minoritised gender identities, and people who identify as neuro-divergent. We recognised that just sending emails to groups representing these communities would not be a sufficient approach – why should people with such lived experiences trust us, an unknown research group, with their stories? Ideally, we would have undertaken more community partnership work with organisations representing marginalised groups. However, with tight project time scales, this proved harder than we had anticipated. Drawing on personal knowledge of relevant community organisations within the local area, we made approaches to a number of them.

After receiving a positive response from one and sharing details of the study, we were asked how the research team might potentially work with anyone who might be interested. This challenged us to think about the process of working with and supporting individuals to share their narratives safely and creatively in potentially vulnerable contexts, which we realised was not something we had the capacity to offer. It made us think about the implications of involvement work with vulnerable members of the public, and that it was not just a simple case of finding, asking and retrieving.

The best way we found of ensuring that narratives from minoritised perspectives were well-represented in the NEON Collection was to liaise with people with lived experience of those perspectives who had created collections within their own communities – such as the Taraki collection of narratives from Punjabi men.

Future thoughts

Based on our experiences, we recommend the following for ensuring that people with additional and intersecting experiences of discrimination are included in story-based mental health work:

- **Potential narrators may want to take some time to think through whether they want to share their stories at a particular time, with a particular audience.** Our experience has been that it doesn't necessarily get easier to do this over time. For example, it can open up an individual's 'Pandora's Box' of painful memories again. Or people's reactions might not be what we would wish them to be – for example, it can be challenging for people to accept how much racism or homophobia we can and still do experience. We have produced some guidelines for people thinking about telling their stories in mental health contexts.

  View our guidelines on sharing stories.

- **More flexible, creative ways of making and telling stories are needed.** For example, people from LGBTQ+ communities may be more likely to tell our authentic stories within the 'security' and greater familiarity of LGBTQ+ organisations and settings, rather than in mental health organisations. This could mean partnering with national organisations like Stonewall, specific local organisations, or with people who have edited collections for specific groups.

- **As researchers working with stories from minoritised groups, we need to look for the diversity within different minoritised communities as well.** This is where intersectionality provides not just a useful analytical tool, but a responsibility to keep investigating diversity and encouraging new voices to come forward.
- **The use of carefully-constructed equality monitoring will help to ensure that we build on what we have started**, as well as encouraging others to shape the scene through an equality and diversity lens as we have tried to do.
- **More diverse representation in lived experience groups and in Patient and Public Involvement** is likely to encourage more and more people to feel confident enough to tell their own unique stories.

NEON experiences:
Donna Franklin (LEAP member)

> Joining the NEON study as a member of the LEAP has been an important and motivating forward step that has supported my mental health recovery.

Having nearly qualified as a clinical psychologist, my experience of clinical training was one of triggered anxiety, as race-based traumatic stress was activated by an incident of racialised othering at the start of the training process, which continued throughout. As a Black woman, visible and seeking to succeed, mine was not training but an experience of navigating white supremacy and its fragility.

With no previous mental health difficulties, the drastic and acute loss of my emotional equilibrium through heightened levels of fear, and the development of generalised anxiety disorder becoming chronic traumatic stress (the result of having to function within an isolating environment of whiteness and its unspoken status quo norms) was emotionally draining and illness-inducing. Experiencing ongoing exposure to and episodes of white fragility, as the white racial stress of intolerance showed throughout the training process, my experience unfolded as one of racial injustice in the making. With my presence as a Black woman, a visible marker of racial difference, there was little opportunity to talk, acknowledge difference or to find commonalities.

“Creating a sense of joint ownership through collaborative power-balanced equity, the NEON study has produced meaningful and worthy outcomes.”

Though recognised, the levels of stress were insufficiently addressed to enable a commensurate level of care needed to ensure a safe and functioning experience with meaningful dialogue regarding my ongoing experience of events. Seeking to maintain a normal functioning within an environment where my presence as a Person of Colour aroused for others stress-inducing defensive moves, a background of racialised disadvantage set within a context of whiteness and its supremacy was my landscape.

Within the NEON study, through the creation of trusting relationships and rebuilding of confidence (the steps needed to revisit the painful experience of race-based trauma), I have, through my re-engagement with the academic space as part of the NEON LEAP, experienced meaningful involvement and co-production. Creating a sense of joint ownership through collaborative power-balanced equity, the NEON study has produced meaningful and worthy outcomes. Reaching a place of confidence to be able to share my long-buried story of racism on an international conference stage, I have told and rewritten an epistemic injustice, so encouraging a renewed strengthening of my racialised identity as a post-traumatic growth from the distressing experience of institutional racism.

7. Study publications

Academic journal publication

The following documents have been published by the NEON study in academic journals. All academic journal publications are freely available to the public. We have included the URL for the version of the publication that can be freely accessed.

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