



**“Not the story you want, I’m sure”: Mental health recovery  
and the narratives of people from marginalised  
communities**

**Joy Llewellyn-Beardsley**

**School of Health Sciences, University of Nottingham**

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## Abstract

**Background:** The dominant narrative in mental health policy and practice has shifted in the 21<sup>st</sup> century from one of chronic ill health or incurability to an orientation towards recovery. A recovery-based approach is now the most frequently used in services in the Global North, and its relevance has also been explored in Global South settings. Despite the ubiquity of the recovery approach, people experiencing poverty, homelessness, intersecting oppressions (based for example on race, ethnicity, gender, sexuality or ability), and other forms of social marginalisation remain under-represented within recovery-oriented research. More inclusive research has been called for to ensure that knowledge of recovery processes is not based solely on the experiences of the relatively well-resourced.

Personal narratives of recovery from mental distress have played a central role in the establishment of the recovery approach within mental health policy and practice. Originating in survivor/service-user movements, the use of ‘recovery narratives’ has now become widespread for diverse purposes, including staff training to improve service delivery and increase empathy, public health campaigns to challenge stigma, online interventions to increase access to self-care resources, and as a distinctive feature of peer support. Research suggests that recovery-focused narratives can have benefits and also risks for narrators and recipients. At the same time, the elicitation of such narratives by healthcare researchers, educators and practitioners has been problematised by survivor-researchers and other critical theorists, as a co-option of lived experience for neoliberal purposes.

Following a systematic review of empirical research studies undertaken on characteristics of recovery narratives (presented in [Chapter 4](#)), a need for empirical research on the narratives of people from socially marginalised groups was identified. What kinds of stories might we/they be telling, and what are their experiences of telling their stories? What do their experiences tell us about the use of stories within a recovery approach?

**Aim:** Drawing on a body of critical scholarship, my aim is to conduct an empirical inquiry into (i) characteristics of recovery stories told by people from socially

marginalised groups, and (ii) their experiences of telling their stories in formal and everyday settings.

**Method:** I undertook a critical narrative inquiry based on the stories of 77 people from marginalised groups, collected in the context of a wider study. This comprised narratives from people with lived experience of mental distress who additionally met one or more of the following criteria: (i) had experiences of psychosis; (ii) were from Black, Asian and other minoritised ethnic communities; (iii) are under-served by services (operationalised as lesbian, gay, bi, trans, queer + communities (LGBTQ+) or people identified as having multiple and complex needs); or (iv) had peer support roles. Two-part interviews were conducted (18 conducted by me). Part A consisted of an open-ended question designed to elicit a narrative, and part B was a semi-structured interview inviting participants to reflect on their experiences of telling their recovery stories in different contexts. Following Riessman's analytical approach, I undertook three forms of analysis: a structural narrative analysis of Part A across the dataset (informed by a preliminary conceptual framework developed in [Chapter 4](#)); a thematic analysis of Part B where participants additionally reflected on telling their stories; and an in-depth performative narrative analysis of two accounts (parts A and B) from people with multiple and complex needs.

**Findings:** In a structural analysis of Part A, the recovery narratives told by people from marginalised groups were found to be diverse and multidimensional. Most (97%) could be characterised by the nine dimensions described in the preliminary conceptual framework (Genre; Positioning; Emotional Tone; Relationship with Recovery; Trajectory; Turning Points; Narrative Sequence; Protagonists; and Use of Metaphors). Each dimension of the framework contained a number of different types. These were expanded as a result of the structural analysis to contain more types: for example, a 'cyclical' type of trajectory was added), and a more comprehensive typology of recovery narratives was produced. Two narratives were found to be 'outliers', in that their structure, form and content could not adequately be described by the majority of existing dimensions and types. These served as exemplars of the framework's limitations.

In a thematic analysis of Part B, my overarching finding was that power differentials between narrators and recipients could be seen as the key factor affecting participants' experiences of telling their recovery stories in formal and everyday settings. Four themes describing the possibilities and problems raised by telling their stories were identified: (i) 'Challenging the status quo'; (ii) 'Risky consequences'; (iii) 'Producing acceptable stories' and (iv) 'Untellable stories'.

In a performative analysis of two narratives of people with multiple and complex needs (Parts A and B), I found two contrasting ways of responding to the invitation to tell a recovery story: a 'narrative of personal lack' and a 'narrative of resistance'. I demonstrate how the genre of 'recovery narrative', with its focus on transformation at the level of personal identity, may function to occlude social and structural causes of distress, and reinforce ideas of personal responsibility for ongoing distress in the face of unchanging living conditions.

**Conclusion:** The recovery narratives of people from socially marginalised groups are diverse and multidimensional. Told in some contexts, they may hold power to challenge the status quo. However, telling stories of lived experience and recovery is risky, and there may be pressure on narrators to produce 'acceptable' stories, or to omit or de-emphasise experiences which challenge dominant cultural narratives. A recovery-based approach to the use of lived experience narratives in research and practice may be contributing towards an over-emphasis on individualist approaches to the reduction of distress. This over-emphasis can be seen to reflect what has been identified as a global trend towards the 'instrumental' use of personal narratives for utilitarian purposes based on market values. Attention to power differentials and structural as well as agentic factors is vital to ensure that the use of narratives in research and practice does not contribute towards a decontextualised, reductionist form of recovery which pays insufficient attention to the economic, institutional and political injustices that people experiencing mental distress may systematically endure. A sensitive and socially just use of lived experience narratives will remain alert to a variety of power dimensions present within the contexts in which they are shared and heard.

## **Dedication**

To the 77 participants who trusted us with their stories. I have spent over five years with them and could spend five years more. I was regularly moved to inspiration, tears and rage while reading them. I hope that what follows does justice to the many experiences of injustice, resistance and resilience I found within them. Thank you.

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And in memory of my Dad, John William Beardsley, who didn’t get to see me wear my floppy hat.

## Thesis-related outputs, activities and awards

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**Based on Chapter 7:** Llewellyn-Beardsley J, Rennick-Egglestone S, Bradstreet S, Davidson L, Franklin D, Hui A, McGranahan R, Morgan K, Pollock K, Ramsay A, Smith R, Thornicroft G, Slade M. (2019). 'Not the story you want'? Assessing the fit of a conceptual framework characterising mental health recovery narratives. *Social Psychiatry and Psychiatric Epidemiology*, 55, 295-308

**Based on Chapter 8:** Llewellyn-Beardsley J, Rennick-Egglestone S, Pollock K, Ali Y, Watson E, Franklin D, Yeo C, Ng F, McGranahan R, Slade M, Edgley A (2022) 'Maybe I shouldn't talk': The role of power in the telling of mental health recovery stories, *Qualitative Health Research*, 32 (12):1828-1832. doi: 10.1177/10497323221118239

### Articles under review

**Based on Chapter 9:** Llewellyn-Beardsley J, Rennick-Egglestone S, Callard, F, Pollock K, Slade M, Edgley A. (2023) 'Nothing's changed, baby': mental health recovery and the narratives of people with multiple and complex needs. *Social Science and Medicine – Mental Health, under review*

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- 2020            Institute of Mental Health, University of Nottingham Publication Award: 'Best publication co-authored with a person with lived experience of mental distress or a current or former user of mental health services' for Llewellyn-Beardsley J et al (2020) *Not the story you want? Assessing the fit of a conceptual framework characterising mental health recovery narratives*, *Social Psychiatry and Psychiatric Epidemiology*, 55, 295-308.
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## **Recovery**

*noun*

1. a return to a normal state of health, mind, or strength.
2. the action or process of regaining possession or control of something stolen or lost.

“I think recovery stories are not gonna be like a little supplementary thing that helps mental health improve. I think they are gonna be the reason mental health basically re-shapes itself from the ground up. In the fact that the longer time goes on, fewer and fewer people who work in mental health will be in that weird situation of not having had a mental health episode of their own”

- (Participant A22)



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## Chapter 1: Introduction

*“Stories ... carry in their DNA a blueprint for survival” (Yorke, 2013: 203)*

A fascination with stories, and their power to effect individual and social change, runs through my multi-disciplinary, multi-professional life like a golden thread. It can be seen in my obsessive reading habit as a child and from my choice of English literature as the subject of my first degree. But it is also there in my practice as a community and youth worker – where I used stories as powerful tools of validation with LGBTQ+ young people and others – and in my later choice to undertake an MA in sociological research methods, where I found a natural home in narrative approaches. This fascination with stories grew stronger when I found myself, after years in the helping professions, burned out and having my own ‘lived experience’ of extreme distress. It was then I turned back to stories with fervour – not to fiction this time, but to memoir and personal accounts; not seeking to escape, but to survive.

‘Locating myself’ as a researcher (Riessman, 1993) is an important feature of narrative inquiry, my chosen methodology for this thesis. Narrative theorists Jean Clandinin and Michael Connelly observe that ‘narrative inquiry characteristically begins with the researcher’s autobiographically-oriented narrative associated with the *research puzzle*’ (Clandinin & Connelly, 2000: 41, their italics). This is intended to provide transparency about the researcher’s role in what is termed the co-construction of narratives between speakers (participants) and hearers (researchers and subsequent audiences) (Squire, 2013). With this researcher reflexivity as a central tenet of narrative inquiry, and having asked other people to share their stories of distress and recovery, it seems only appropriate to begin with something about my own positioning here.

### 1.1 Locating myself

What drew me to researching narratives of mental health recovery? My relationship with stories and wellbeing is both simple and complex. Simple, because at all the crisis points of my life, it is a shift in my story of myself, made possible by accessing the stories of ‘others like me’, that has enabled me to move forward. More complex, because stories have also been told *about* me and my ‘kind’ which are damaging, derogatory and threatening. And because, despite what I have needed to believe at times, sometimes

stories have made things worse, or have not been enough. Two examples from my own experience might illustrate this complexity.

The first is from the late 1980s. I grew up Roman Catholic in a working-class community in the East Midlands. I knew from around the age of seven that I was gay, although the only words I had for this were the ones that had been shouted at me in the primary school playground – ‘lesbo’ – and the ones I had heard on the telly – ‘poofter’, ‘queer’, ‘like *that*’. So I also knew that the fact that I *was* gay should be a secret, and a shameful one, to be kept to myself. I read vociferously, but no gay or lesbian characters appeared in any of the novels I had access to. But one day aged around 15 I went to Ilkeston’s Carnegie Library on the marketplace in the centre of town, to do some revision. It was a much grander building than the small porta-cabin library closer to home that I usually went to, with many more shelves full of books. On one of them I found a particular book whose title I have forgotten. I have tried and failed to find it since, but it was a book of young people’s experiences of coming out as gay, lesbian and bisexual (there was even less general awareness of trans issues then, let alone more nuanced expressions of gender and sexuality). Page after page of stories of *people like me* poured out in front of me as I stood there in front of the shelf, not able to move. There were no names, not even any locations, just a male or a female symbol at the start of each new account. But there was story after story of people – *real* people! My age! In this country! – who not only felt like me, but were proud of it, too. Proud, despite the difficulties they described with family and friends. They liked who they were! They *liked* that part of themselves!

I couldn’t risk borrowing the book from the library. I couldn’t risk anyone finding it. But in a pre-internet world, just knowing that this book existed, that these young people existed, was gold dust. I have since learned that there was a gay youth group in Ilkeston in the 80s, thanks to the radical county council of the time – but the chances of me finding out about it, in a Catholic family, going to a Catholic school, with the rampant homophobia of the 1980s raging around our small market town, were practically zero. I was in my early thirties before I came out to my family. But that book was like a secret talisman. I knew that other people like me existed, and what was more, that they were happy.

The second example is from 2016 when I was 44, the year before I began this PhD. I had always been considered by those around me a ‘high achiever’, apparently destined for

success in whatever I did. But the periods of depression I had experienced since childhood had got more and more severe, as I burned out of several jobs in the voluntary sector in quick succession. After being a youth worker in several fields – from the Catholic church to substance misuse and sexual health services – I had found my calling (I thought) as the founding director of a charity which ran Sheffield’s LGBTQ+ youth group among other projects. Over five years I had transformed the charity from a grant-making trust, funding small short-term projects with staff on zero-hours contracts and young people not knowing month to month if there would still be a group for them, to a flourishing organisation running long-term services which have now become well-established in the city. But it took a lot out of me. It was the aftermath of the financial crisis of 2008, and we were losing funding streams weekly, it seemed. I eventually burned out of the role, and then other subsequent management roles – and lost any sense of myself as a competent adult, never mind a high-achiever. My despair increased and, as ever, I turned to stories for answers, particularly memoirs about depression. One such memoir I came across was Sally Brampton’s *Shoot the Damn Dog* (Brampton, 2009). I loved it. Not only was it moving and helpful, but also, and vitally for me at the time, it described a woman who was highly successful in her career as a journalist, novelist and professor. She came across on the page as vibrant, passionate, good at things, in love with life AND someone who had experienced a ‘headlong dive into deep depression’. Not a sad loser who had failed at life, or any of the other unhelpful stereotypes I had about myself and other people experiencing mental distress – but someone with friends, children, a nice home, and an incredible way with words. And she had survived her depression. How did she do it? I was desperate to know.

I found the book so helpful that after I’d finished it that I googled Sally Brampton and clicked on the first result. It was a story in *The Guardian*. I started reading but then realised in shock that it was her obituary (Markwell, 2016). Sally Brampton had died, three months before. Not only this, she had killed herself, walking into the sea near her home in St Leonard’s-On-Sea. Wrapped in my own depression as I was, my strongest response to this news was not sadness for her and her family but a sense of being cheated. Her stories and strategies hadn’t worked! Whatever Sally had written about in her memoir could be of no use to me now. None of her experiences had helped her in

the end to move on permanently from despair, it turned out, and I feared that I wouldn't be able to, either. I tipped for a while into even deeper bleakness.

But then with time I did get better. Having experienced periods of serious depression from my early childhood to my early forties, I am entering into my fifties having not experienced that horrifying level of despair for over six years.

So what, as I learned a narrative researcher might ask, was the turning point for me? There were many. But the culmination of many turns towards a kinder way of being with myself was reading book called 'The Compassionate Mind' (Gilbert, 2013). I subsequently went on my first Buddhist retreat, and quite suddenly found I could rewrite a core story I had told myself about my adult life. For three weeks after I attended the retreat, I walked around the Peak District in a haze of delight, thinking that my whole life and all the choices I had made up to that point now made sense to me. As I wrote in my journal at the time: *"I can feel my life integrating"*. What had been a story of failure to live up to my early promise as a so-called 'high achiever' could now be re-written as a search for meaning. As a young person, my early distress had been eased by going to a Catholic youth retreat centre, where the abuse I experienced at school was transformed into friendliness and kindness and the beginning of a lifelong interest in personal growth. I lived and worked in community there as a young adult for a year, and it was one of the most meaningful and rewarding times of my life. Later, it was very healthy for me to leave the Church behind as I became more and more aware of my sexuality, my feminism and the incongruence (for me) between these things and the teachings of the Church. I had a good 15 years of angry and enjoyable atheism. But I missed the deep sense of community I'd had whilst living at the retreat centre, and the sense of a deeper purpose my belief had given me. That had gone, seemingly forever, as I sought meaning in work and status, and found again and again that this wasn't enough.

For me, with this history, discovering Buddhism and finding a flourishing Buddhist centre in Sheffield was a dream come true. Could it really be possible to have a spiritual community, and to practice with others who had the same values as me, but without what I thought of (like a true daughter of the Buddha) as 'all that supernatural shite'? Amazing! But the really crucial change for me was how this changed the way I could tell the story of my life. I had chosen to work part-time for years, ostensibly to write a novel

in my spare time, which I hadn't been able to do. Three unfinished manuscripts lay in a box in my attic, adding to my sense of failure in my career. I often berated myself for having chosen to work part-time, earn a lot less, and STILL have no novels to 'show for it'. So, as I wrote in my journal a year after my first Buddhist retreat:

*coming back to [a spiritual perspective on life] meant that all the choices I have made, many of which I've questioned, hugely regretted and been quite bitter about, actually make sense. [...] Since experiencing the richness of vocation that living in community as a part of the Briars team gave me, I've wanted space in my life to explore meaning, be creative, not just get caught up in the rat race, get back to that place of living out [of] that kind of depth. [By committing myself to Buddhism] I was honouring the part of me that knew, very young, that money and status were not going to leave me feeling fulfilled.*

Being able to re-write my life in terms of a search for meaning instead of a series of failures brought me an enormous sense of release, freedom and integrity. And it was soon after becoming a Buddhist that the job of researcher for the Narrative Experiences Online (NEON) study came up, the study which enabled me to work on this thesis. I couldn't believe my luck. Here was a job which combined my professional experience of working in mental health and my academic experience not only of research methods but of literature too – AND for which 'having lived experience' was not something to hide but an essential requirement! I came into the NEON study full of the possibilities and power of storytelling for wellbeing, and full of gratitude that I had found work that might be able to offer those opportunities to others.

And although I would quickly discover the factors that gave me my *research puzzle* (Clandinin & Connelly, 2000), namely, that recovery stories could also be a source of pain, and of entrenchment in the status quo, I have not lost my belief in the power of individual stories to give us hope and to help us re-narrate our own lives. It feels important to make clear that what I seek to critique here is not individual narrators themselves, or the validity of their stories, but of the potentially normative use of such stories within mental health research, services and training. As I was writing my systematic review of characteristics of recovery narratives in 2018 (Llewellyn-Beardsley et al., 2019), a colleague put me in touch with a friend of hers, Angela Woods,

who with Akiko Hart and Helen Spandler was writing a critique of recovery narratives as a genre at the same time. We exchanged emails and enthusiasm for our work, and their subsequent paper (Woods et al., 2019) was crucial for me in maintaining a critical eye as I continued my investigation. I want to echo what they say, when they highlight that:

*the Recovery Narrative is emotionally charged: indeed, that is its power and its purpose. It emerges from a place of intense suffering, and it requires emotional labour to produce and perform. It is also tied into individuals' lives, their hopes and their pain, and is enveloped in discourses around empowerment. Our aim is not to invalidate, silence or call into question individuals' accounts of their passage through extreme distress. Nor is this about holding the Recovery Narrative up to particular standards—whether aesthetic, academic, clinical or political. We believe that it is possible to critique the Recovery Narrative as a genre without resorting to personal critiques of individual meaning-making. Moreover, we argue that it is precisely the framing of Recovery Narrative as a genre which allows us to recognise some aspects of the labour of that meaning-making, to see and to challenge dominant forms of self-presentation within mainstream mental health and many survivor contexts (Woods et al., 2019).*

I hope that what I offer here is a contribution to a plurality of experiences of recovery, and of resisting 'recovery', within narrative research on mental health. Continued alerts to the 'dangers of a single story' (Adichie, 2009) are, I believe, crucial in ensuring that people may continue to find stories which mirror and validate their own experiences, and help them to envision different futures for themselves – as happened for me, a long time ago, in a smalltown library not so far away.

## **1.2 Organisational context for writing this thesis**

My work on this thesis was conducted while I was employed as a research assistant on the Narrative Experiences Online (NEON) study, funded by the National Institute of Health and Care Research (NIHR) Programme Grants for Applied Research programme (*Personal experience as a recovery resource in psychosis: Narrative Experiences Online (NEON) Programme, RP-PG-0615-20016*). In this section I delineate the boundaries between my work for the NEON study and for this thesis.



The NEON study was undertaken by members of the Recovery Research Team in the School of Health Sciences at the University of Nottingham from 2017-2023. The NEON team consisted of the Chief Investigator, Mike Slade, a Programme Co-ordinator and Senior Research Fellow, Stefan Rennick-Egglestone, a team of research assistants, a statistician and an administrative team. I was line managed by Stefan and he is also one of the supervisors of this thesis.

The NEON study aimed to investigate whether having access to recorded recovery narratives could improve health-related quality of life for people affected by mental health problems. Central to the study was the development of a web-based intervention, based on a collection of recorded recovery narratives. The scientific framework for the study was the 2015 Medical Research Council (MRC) Framework for Developing and Evaluating Complex Interventions (Craig et al., 2006). The study comprised three stages: (i) theory development on the characteristics and impact of recovery narratives; (ii) intervention development studies which integrated knowledge produced by the theory studies; and (iii) three randomised controlled trials to evaluate the intervention (Slade et al., 2021). The first two empirical studies for my thesis took place in the context of the theory development stage of NEON. My systematic review and narrative synthesis of findings (presented in [Chapter 4](#)) resulted in a conceptual framework describing characteristics of mental health recovery narratives. My structural analysis of 77 narrative interviews with people from marginalised groups (presented in [Chapter 7](#)) validated and extended the framework. Both of these studies were used as foundational knowledge in developing the NEON intervention. My third and fourth studies (thematic and performative analyses of the 77 interviews, presented in [Chapter 8](#) and [Chapter 9](#)) were undertaken independently from the NEON study while I continued to be employed on NEON as a research assistant: that is, they were unplanned (not included in the study proposal) and not related to the work of developing the intervention or trials. I planned these two analyses as an intrinsic part of this thesis, including defining the aims, objectives and methods for them, and I carried out all the analysis work. Further information about the work I undertook for this thesis and the work I was simultaneously undertaking for the NEON study is presented in [Figure 1](#):

Figure 1: Timeline of my work for the NEON study & this thesis

NEON stage (timeline)	My work for the NEON study at this time	My thesis work at this time
<b>(i) Theory studies</b> <i>(2017-2019)</i>	Systematic review and conceptual framework of characteristics of recovery narratives	Chapter 4: Systematic review and narrative synthesis
	Interviewing 18 of 77 participants from under-researched groups	
	Validation and refinement of the conceptual framework using 77 interviews	Chapter 7: Structural analysis
	Co-work on development of conceptual frameworks for impact and curation of recovery narratives	
<b>(ii) Intervention development studies</b> <i>(2018 - 2020)</i>	Building the NEON Collection of recovery narratives	
	Development of an inventory to characterise recovery narratives (INCRESE)	
	Training and support of NEON Collection coders	
	NEON Intervention development work	
<b>(iii) Three RCTs evaluating the intervention</b> <i>(2020 - 2023)</i>	Recruitment of trial participants	Chapter 8: Thematic analysis
	Engagement of trial participants	Chapter 9: Performative analysis
	Process evaluation interviews and analysis	Chapters 1,2,3,5 and 10.

This method of completing a PhD is an established, though less usual method – see, for example, Le Boutillier (2017) – and the context has, of course, affected the ways I thought about and conducted my research. For me, it has provided both benefits and drawbacks.

To represent these, I offer below two versions of this section, which outlines how I differentiate my own research from that of the larger study. The first version was written at what I think of as the halfway point of my doctoral study, when the foundational research for the NEON trials had been completed and my first two papers published (Llewellyn-Beardsley (2019, 2020). It is written in the third person (‘the candidate ...’) and represents my early approach of framing my research within the ‘developing theory’ stage of the MRC’s Framework for Developing and Evaluating Complex Interventions (Craig et al., 2006). It describes using systematic methodologies (systematic reviews) and language (‘validation’ of frameworks) drawn from a post-positivist research paradigm, wherein knowledge in the form of an authoritative truth is derived from empirical evidence (Gordon, 2016). This approach is appropriate for an ontological stance of realism, but this was not my chosen research orientation, and as my analysis continued, I becoming increasingly uncomfortable with that research paradigm for this topic (recovery) with this population (people from marginalised groups).

The second version of this section was written after almost a year of space, thought, and a certain distance from my organizational context – granted unexpectedly by a global pandemic. It represents the moment when I dropped the ‘we’ and took up the ‘I’ when talking about my work; when I stopped talking about myself in the third person and re-inserted myself back into my own research. The practical ways in which my research is differentiated from that of the larger study are outlined in version one. These are important to distinguish, but I believe version two, outlining a more philosophical and critical separation from the NEON study, is what has more meaningfully enabled the work presented within this thesis to be truly my own.

### **1.2.1 Version one**

“All research conducted as part of the PhD has been undertaken solely or led by the candidate as follows:

**Systematic review and narrative synthesis (Chapter 4):** the candidate conducted a systematic review and narrative synthesis of mental health recovery narratives characteristics. With the support of additional analysts, she led on developing a conceptual framework of recovery narratives characteristics, and was lead author of the subsequent paper (Llewellyn-Beardsley et al., 2019).

**Validation of the conceptual framework (Chapter 7):** the candidate undertook a conceptual framework validation study as part of a wider NEON interview study. She designed the validation method and part A of the topic guide, and designed part B with another analyst. She led the recruitment of participants from two NHS Trust sites, two voluntary sector sites, and from staff and student networks within the University of Nottingham, through communication with and providing support to local gatekeepers. She recruited and conducted interviews with 18 of 77 participants, listening again to audio recordings to improve accuracy of transcripts. She led on creating a structural narrative approach to data analysis, providing training and support for additional analysts and conducting sole analysis of 20 of the 77 transcripts. With support from the additional analysts, she led on development of the recovery narratives typology. She was lead author of the subsequent paper (Llewellyn-Beardsley et al., 2020).

Studies Three ([Chapter 8](#)) and Four ([Chapter 9](#)) were undertaken solely by the candidate, independent of the NEON study”.

### **1.2.2 Version two**

All of the above can be said to be an accurate representation of the work I conducted, but it is not the whole story. The organisational context of the NEON study was beneficial for me in many ways – first and foremost, I received a salary, not a student stipend, which allowed me to live for five years without financial worries. Second, it provided me with the structure of an initial programme to follow, the leadership and experience of senior academics and managers, and the companionship and support of a team of other researchers. These factors, I believe, protected me from much of the stress and anxiety faced by many doctoral students (see, for example, Levecque et al. (2017), Schmidt & Hansson (2018)). This was crucial for my own wellbeing, and I am grateful to the whole team for the support and opportunities for learning they provided me with.

However, a challenge I faced was finding the time and mental space to develop my own thinking, outside of the pressures of the 'day job' of producing papers and the theoretical and practical requirements of creating an intervention and setting up clinical trials. It was easier too, in an inter-disciplinary team that did not necessarily share the same philosophical orientations to research, to dismiss any misgivings of my own about what seemed to me to be unspoken assumptions, and to 'just get on with it,' i.e. the practicalities of data collection, without first discussing the overall research paradigm of the inquiry. I subsequently learned that this is a step which can often be missed out in health science research. In their handbook of theory and methods for applied health research, Catherine Walshe and Sarah Brearley (2020: 1) attribute this to the "practical, solution-finding, how-do-I-do-this? human tendency" of many health researchers, which can lead us to want to focus only on the technical methods of undertaking research. It is not surprising that, given the particular organisational structures, financial pressures and practical demands made on staff within both universities and the NHS, attention to the philosophical assumptions underlying research is often not prioritised. And yet, the risk of this inattention is that the research produced under these conditions continues to perpetuate the status quo. As Walshe and Brearley (2020) go on to stress, our philosophies, whether spoken or not, shape the whole of the process, including our relationship to our participants, and thus the kinds of knowledge we produce.

In my third year of employment, however, I was unexpectedly granted some headspace. An unlooked-for benefit for me of the COVID-19 pandemic was the reclaiming of three hours a day from the commute from Sheffield to Nottingham, which provided me with more time and energy for reflection. I was also physically distanced from the rest of the team, which gave me the mental space to hear my own thoughts about the work we were undertaking – thoughts that I had found difficult to give space and credence to alongside the immediacies and demands of being a member of a 'high-performing mental health research group' (Slade, 2021).

At the same time, the Black Lives Matter (BLM) movement was growing in prominence, in response to the grievous continuing violence against Black people both in the USA and here in the UK. Through reading Black authors (Akala, 2018, Eddo-Lodge, 2018, Hirsch, 2018, Saad, 2020) and examining my own white privilege and conditioning in the summer of 2020 I was reunited with some of the critical theory that had formed my

academic training prior to the PhD; from the feminist theory of bell hooks (1987) and Audre Lorde (2018) of my literature degree, to the critical pedagogy of Paulo Freire in my youth work training (Freire, 1970/2017), and the decolonising methodologies of my sociological research training (Smith, 2021). Unexpectedly (though in hindsight, unsurprisingly) through engaging with personal anti-racist work, I was confronted anew with my own state of queer 'otherness'; and reminded of how historically and geographically contingent my current sense of security within my own identity is. For example, when I was born, 'homosexuality' was still listed as a mental disorder in the DSM-II, and was not declassified as such by the World Health Organisation until 1990, when I was 18. The deepest relationships I sought were described in government legislation as 'pretend' and silenced as unspeakable during my Roman Catholic teens in the 1980s. Throughout my twenties and into my thirties I was not legally allowed to form an official partnership within any of my relationships. When I first started working with LGBTQ+ young people in 2003, Section 28 of the Local Government Act 1988, which banned local authorities and schools from 'promoting homosexuality', was still in place, and school receptionists were telling me that they 'didn't have any of those [LGBTQ+ students] here' so they wouldn't be needing our services. I was 42 before I was 'given' the option to marry my life partner. And I am lucky, compared with my queer ancestors, that these rights were fought for and achieved by activists in time for me to enjoy and benefit from them. And, of course, these rights depend on me being 'lucky' enough to have been born in the UK, and not, for example, Russia – and these rights could quite easily be taken away again, as they have been, for example, in parts of the United States.

So my whole life has been framed by state systems which have variously attempted to story and define my embodied self. This reminder of my constructed 'otherness', while exploring my own involvement in the othering of Black and Brown people, returned me full-square to my research training as a sociologist and my engagement with ontological and epistemological questions – and thus to a renewed sense of wanting to 'trouble' the way I was constructing my findings. When you have been a person who has been defined by the state you live in as shameful, disordered, illegal – and then 'permitted' – within the space of your own lifetime, it is perhaps easier to see such systems and the categories that emerge from them as constructs; to question them, and ask further questions about how they may shape and author people's lives – in short, to want to

take a critical approach to one's research, where issues of power are central. Here, there is no separation between theory and practice, between how knowledge is constructed and what that construction can do to your body, your mind – your world. Philosophical constructions of knowledge become the central issue.

That critical voice was there for me to some extent from the beginning; as demonstrated for example in the discussion section of my systematic review ([Chapter 4](#)), and the 'outlier' narratives presented in my structural analysis ([Chapter 7](#)). But the physical and mental space granted, by accident, from my organizational context enabled my own disquiet to come to the foreground about ways of analysing data in what I saw as the realist context of NEON, rather than a context which states that, for research with structurally disadvantaged communities, politics matter *a priori*. This move can be represented by a shift away from thinking of *stories as things*, whose characteristics are seen as there to be discovered and mirrored accurately within measures, which could in turn be validated, refined and then used to rate or code stories; to thinking of *stories as processes*, not separable from the contexts and conversations within which they are constructed; contexts which, for those who are structurally disadvantaged, will be imbued with asymmetrical power relationships.

This shift resulted in a move away from thinking of my research in terms of the MRC framework. The framework is based in an evidence-based medicine paradigm (Sackett, 1997), which posits that healthcare-related decisions should be made on the basis of the best evidence. This approach stems from a (post-)positivist ontology which does not problematise the concept of 'evidence' (Feinstein & Horwitz, 1997) or what the 'best' might mean in different contexts (Booth et al., 2019)<sup>1</sup>. Instead I adopted the more critical theory-informed approaches of [Chapter 8](#) and [Chapter 9](#). To me, this had enabled a more symbolic and meaningful separation of my own work and thinking from the philosophical underpinnings of my immediate organizational context.

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<sup>1</sup> Although I note that the new MRC framework updates the guidance and takes a more pluralistic approach to intervention design, encouraging researchers to conduct research with "an appropriate choice of methods, rather than provid[ing] detailed guidance on the use of specific methods" (Skivington et al 2021)

### 1.3 Structure of the thesis

The thesis is in ten chapters, broken down as follows:

**Chapter 1: Introduction** locates my positioning as a narrative researcher in terms of (i) the personal experiences of mental distress and the power of stories that led me to undertake the thesis, and (ii) the organisational context in which it was produced.

**Chapter 2: Recovery - background and context** traces three distinct discourses of recovery, and explores the benefits of the recovery model to mental health practice, and the problems it raises.

**Chapter 3: Narratives in mental health – background & context** sets out key definitions, traces the evolution of the recovery narrative as a phenomenon of interest within mental health research and practice, and explores current uses of recovery narratives by mental health services, including benefits, risks and critiques of such use, which led to the formulation of my systematic review aims and research questions.

**Chapter 4: Systematic review** addresses gaps in the recovery literature by reviewing research on the characteristics of stories which can be described as ‘recovery narratives’, and synthesises findings into a preliminary conceptual framework.

**Chapter 5: Methodology** locates this enquiry in the ontological and epistemic tradition of narrative inquiry, detailing my methodological considerations and outlining the aims and objectives of my research.

**Chapter 6: Methods** describes my selection of procedures through which a narrative inquiry methodology was translated into research action, and the ethical considerations stemming from this.

**Chapter 7: ‘Not the story you want’** presents a structural narrative analysis of narrative interview data. It explores the kinds of recovery stories people from marginalised groups are telling, and presents outlier narratives which delineate the limits of the framework.

**Chapter 8: ‘Maybe I’d better not talk’** presents a reflexive thematic analysis of the data, which moves away from the construction of a conceptual framework for recovery



narratives and asks what it is like for people from marginalised groups to tell their stories in formal and everyday settings.

**Chapter 9: ‘Nothing’s changed, baby’** presents a performative analysis of two case study narratives of people with multiple and complex needs; a deep dive into how immediate and socio-cultural contexts frame what is possible to be told in particular settings and an exploration of the epistemological and ethical issues stemming from this.

**Chapter 10: Discussion and conclusion** considers the three findings chapters overall, and situates their overall significance within a global context of a ‘storytelling boom’ across multiple spheres of life. The implications of the study for narrative-based research and practice are considered, and concluding thoughts are offered.

## **1.4 A note on terminology**

### **1.4.1 ‘Mental health’ terminology**

My own experiences of mental distress outlined in this chapter inform my approach to ‘mental illness’, not as a disorder but as an appropriate response to experiences of trauma and social injustice. As Patricia Deegan, psychologist and service user, wrote in 1988, I see mental distress as “rage turned inward”, which can lead to “being truly disabled, not by a disease or injury, but by despair” (Deegan, 1988: 3). This orientation is further explored in [Chapter 2](#) and [Chapter 3](#). Therefore in this thesis I refer to ‘distress’ or ‘mental distress’ throughout, instead of ‘mental health problems’, ‘mental illness’ or similar, except where citing or writing in the context of other paradigms.

### **1.4.2 ‘Lived experience researcher’ terminology**

Although I do have lived experience of distress, I do not identify as a survivor or service-user researcher, as I was not deemed ill enough to meet secondary mental health services criteria on the one occasion I was referred to them, and so do not have experiences of services. Sadly I now see that as fortunate; as was being able to access a Gestalt therapist privately for ten years because she believed in the ‘People’s Republic of South Yorkshire’ and charged me half price, or nothing at all when times were particularly hard. However, it is epistemologically key for me that research on distress should be led by people with lived experience, and this is something I foregrounded

with participants and in my analytical approach. I therefore describe myself here as a 'lived experience' researcher or an 'insider' researcher, whilst coming from an intersectionality-informed position which recognises that 'we' are not a homogenous group and that I have had the privilege of, for example, not having been treated against my will, and having much less exposure to medicalised interpretations of my experience being imposed on me.

## **Chapter 2: Mental health recovery: background and context**

In the last twenty years there has been a proliferation of research about the concept of 'mental health recovery'. The personal narratives of people with lived experience of mental distress have been central to this research. [Chapter 2](#) and [Chapter 3](#) present some background on differing conceptualisations of mental health recovery and of narratives, to provide some context for my research questions.

In this chapter I outline some definitions of recovery. I describe the origins of a recovery orientation within the consumer/survivor/service user movement from the 1970s onwards, and the subsequent adoption of the recovery approach within mental health care in the UK and other Global North countries in the early 2000s. I explore the potential usefulness of the concept, some critiques of it, and what might have gone missing in its translation from an emancipatory movement to a policy orientation.

### **2.1 'Recovery' in mental health: one word, many meanings**

The dominant narrative in mental health policy and practice has shifted in the twenty-first century from one of chronic ill health or incurability to a 'recovery' orientation (World Health Organization, 2021). A recovery-based approach is now the most common approach in mental health policy and practice within Global North countries (Barlott et al., 2020), and has also been explored for its relevance to Global South settings (Gamieldien et al., 2021). However, despite its ubiquity, recovery is a contested concept within mental health for a number of reasons, and there is little consensus among researchers or practitioners on what recovery means (Dell et al., 2021, McCabe et al., 2018, Davidson & Roe, 2007).

This conceptual confusion can be attributed to the differing social, political and health contexts within which the concept of recovery from mental distress has been used. These contexts change the meanings of recovery, and reflect wider ideological debates about the nature of mental health (Nettleton, 2020, Harper & Speed, 2012). They have been summarised in various ways.

For example, in a handbook introducing the concept of recovery to practitioners, clinical psychologist Mike Slade (2009) identifies two meanings: *clinical recovery*, in the sense of a cure from all symptoms of mental illness, and *personal recovery*, which refers to:

*a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skill, and/or roles. It is a way of living a satisfying, hopeful and contributing life even within the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness (Anthony, 1993:527).*

Both definitions thus place notions of mental distress in the context of illness.

In contrast, another clinical psychologist, David Pilgrim (2009), distinguishes three distinct recovery discourses: (i) *recovery from illness*, based on a bio-medical model of treatment wherein patients are seen as recovering from biologically-determined illness, thus aligning with Slade's concept of *clinical recovery*; (ii) *recovery from impairment*, wherein support and skills training enables patients to stay out of hospital and maximises their ability to integrate socially – thus aligning with Slade's *personal recovery*; and (iii) *recovery from invalidation*, wherein recovery is based on a more explicit social model. Here, recovery has an emancipatory imperative and an emphasis, not on patient deficits and professional expertise, but on 'experts by experience' – namely, people with lived experience of what can be termed mental *distress*, in contrast to illness. Individuals are seen as recovering from the distress caused by social exclusion (due to factors such as poverty or homelessness); stigma and discrimination (based for example on race, ethnicity, gender, sexuality or ability); trauma; and/or from the damage caused by coercive mental health services.

As will perhaps be clear from my own experiences outlined in [Chapter 1](#), this third discourse is the understanding of recovery that best describes my own current position on these debates. Since an understanding of these discourses and their differences is central to the debate on the role of 'recovery narratives' by and for people experiencing distress, I explore them here in some depth.

## **2.2 Clinical recovery ('recovery from illness')**

Studies and treatment of mental distress may always have contained ideas of recovery from illness, in its dictionary definition as a return to a normal state of health, mind or strength. In outlining the roots of the recovery movement in psychiatry, Larry Davidson and colleagues (2011) outline some of its antecedents. First, the era of 'moral treatment', a roughly 100 year period between 1790-1890 during which families who

had the financial means could send family members to asylums or ‘retreats’, where benevolent staff would restore them to a “state of mental health, maturity and satisfactory functioning” (Davidson et al., 2011: 9). Second, the exploration of the inner lives of patients which some psychoanalytically-oriented practitioners used in the contexts of long-term hospitalization. These approaches, Davidson and colleagues claim, emphasised positive and respectful treatment of people, but took place in the context of institutions, wherein people experiencing mental distress were separated from the wider community. Following the era of institutionalisation, antecedents of recovery could also be seen in the origin in the mid-1970s of the community support movement, with its innovations in terms of assertive community treatment, self-help and peer support.

These perceptions of recovery have in common a basis in clinical models of ‘mental illness’, the dominant explanatory framework used within psychiatry and thus – since psychiatry has historically been the profession exercising the most power within services (Crowe, 2022) – within mental health services as a whole (Slade, 2009). Clinical models use the language of illness or disorder, and focus on assessment of an individual and the application of ‘evidence-based’ treatments. Slade outlines three clinical models: biomedical, biopsychosocial and cognitive. The biomedical model assumes there is an underlying biological cause of distress (a disease) and that removal of the disease will ensure a return to health. Biopsychosocial models also include interpersonal, contextual and societal factors for distress, wherein an ‘internal vulnerability’ interacts with adverse environment to produce mental illness. Cognitive models add the insight that ‘cognitions (beliefs) matter’. They emphasise interpretation as a mediator of experience; that the way we see the world will affect the types of experiences we have. Thus individual beliefs, rather than a disease, may be central to experiences of distress. Despite this focus on individual meaning, Slade notes that the cognitive model is still dependent on traditional assumptions: its focus is still psychopathology, or deviance, abnormality and maladaptation, which resides inside a person, and is seen as differing in kind, not degree, from ‘normal’ problems of human distress.

In theory, clinical conceptions of recovery did at least challenge previous dominant biomedical models of chronic, incurable illness. In practice, many service users found that practitioners’ expectations of them remained generally low, involving simply

“learning to adjust and cope” with what was still seen as a largely “incurable malady” (Deegan, 1988: 2). Even in 2009, in a book explicitly addressed to practitioners, it was necessary for Slade to underline that this ‘therapeutic pessimism’ flew in the face of evidence of positive outcomes, and could destroy hope and meaning for individuals in distress. He concluded, therefore, that clinical recovery models were incompatible with the new personal recovery approach (Slade, 2009).

### **2.3 Recovery as emancipatory movement (‘recovery from invalidation’)**

The term ‘recovery’ was thus given new meaning within mental health services in the early 2000s, as explored in the next section. This new meaning was influenced by the emphasis on the possibility of recovery within a civil rights movement from the 1970s onwards (Davidson et al., 2011). The mid-twentieth century saw the growth of many social justice movements among people experiencing oppression, including people from Black, Asian, indigenous and other minoritised ethnic communities, the women’s movement, gay liberation and disability activism. Alongside these came psychiatric survivor and user-led movements, in response to widespread harms and human rights abuses occurring within services (Chamberlin, 1978, Deegan, 1988, Davidson et al., 2011). Together with the anti-psychiatry movement (Laing, 2010, Szasz, 1960) and academic scholars (Foucault, 1961/2009, Goffman, 1961/2022), some users of services became more and more critical of the hegemonic concepts underpinning clinical models of distress as illness (Crossley, 1999, Crossley, 2006, Rogers & Pilgrim, 1991).

The personal stories of people experiencing mental distress played a central role in this movement (Costa et al., 2012, Voronka & Grant, 2021). Storytelling is inextricably linked with social justice movements, with its ability to construct agency and envision new futures, shape individual and collective identities, and access the emotional and moral resources that motivate action (Ganz, 2001, Davis, 2012). As Priscilla Ridgway (2001) puts it, stories of individuals’ lives can contradict and serve to overturn ‘master narratives’ – the socially constructed stereotypical accounts that serve to stigmatise and marginalise groups of people within the social world (Saleebey, 1994). When the previously disqualified voices of people whom the dominant social group has marginalised are honoured, submerged issues of justice, power and abuse of privilege commonly come forth (Foucault, 1980; Hartman, 1994; Holbrook, 1995; White &

Epston, 1990). A revision of discourse may then occur that serves to empower the oppressed group (Ridgway, 2001).

The sharing of individual stories was central to survivor/user-led movements in providing a collective weight and power to people's individual experiences of abuses within mental health services (Morrison, 2013), and to their refutation of bleak professional prognoses for their lives (Deegan, 1988). For activists and survivor-researchers, key motivations for foregrounding the recovery aspects of their stories included offering hope to other people facing difficulties, critiquing narrow understandings of rehabilitation and myths of 'incurability', creating counter-narratives of resistance to dominant biomedical narratives, and organising for systemic change (Costa et al., 2012, Jacobson, 2001, Ridgway, 2001, Beresford, 2019, Deegan, 1996, Sapouna, 2021, Fisher & Lees, 2016).

As survivor-researcher Mary O'Hagan attests, she:

*read and listened to hundreds of people's stories of their experiences of receiving mental health services in many parts of the world. These stories came through conversations, my research, published memoirs and 'mad movement' literature. Their experiences of harm were almost ubiquitous: they talked of institutionalization, forced treatment, pessimistic prognoses, cruelty or social stigma that diminished their personhood (O'Hagan, 2016: 10).*

When heard collectively, such stories, and the experiential knowledge contained within them, enabled survivors and users to build solidarity and inspire hope in the face of widespread stigma, discrimination and denial of rights (Rhodes & De Jager, 2014). Collective sharing of stories in activist, peer support and user groups was instrumental in the establishment of Mad Studies and survivor research to gain greater authority for experiential knowledge and challenge existing professional knowledge about services and treatments (Faulkner, 2017). In these contexts, individual stories foregrounded self-defined recovery as counter-narratives to professional narratives of chronic illness and incurability. They emphasised empowerment and self-determination, as well as resistance to abuses (Kirkpatrick & Byrne, 2009).

These abuses are not simply historical. In 2019, a paper in *World Psychiatry*, co-authored by Danius Pūras, the United Nations Special Rapporteur on the Right to

Physical and Mental Health, highlighted that coercion in psychiatry and broader mental health services was on the rise worldwide (Pūras & Gooding, 2019). In an earlier Human Rights Council report Pūras commended “movements led by users and former users of mental health services and organizations of persons with disabilities” for highlighting the “failures of traditional mental health services to meet their needs and secure their rights” (Pūras, 2019: 4). He observed that these movements have “challenged the drivers of human rights violations, developed alternative treatments *and re-crafted a new narrative for mental health*” (Pūras, 2019:4, my italics).

## **2.4 Personal recovery (‘recovery from impairment’)**

In the translation of recovery from a social justice movement to a set of organising principles for services, attempts were made to provide clear definitions which differentiated recovery orientations from previous approaches to the treatment of mental distress. Slade (2009) based what he framed as ‘personal recovery’ on the most widely-cited definition by William Anthony, as we have seen. Based on this definition, Slade described four ‘recovery tasks’ for an individual experiencing distress: (i) developing a positive identity; (ii) developing a personally satisfying explanatory framework for what professionals might term their ‘mental illness’; (iii) self-management; and (iv) developing valued social roles. Julie Repper and Rachel Perkins (2009) outlined nine principles of recovery for services, presented in Figure 1:



Figure 2: Nine principles of recovery (Repper & Perkins 2009)

**Nine principles of recovery (Repper & Perkins 2009):**

Recovery is about people's whole lives, not just their symptoms · Recovery is not a professional intervention like medication or therapy · Recovery is not the same as cure · Recovery is about growth · Recovery does not refer to an end product or a result: it is a continuing journey · Recovery can and does occur without professional intervention · A recovery vision is not limited to a particular theory about the nature and causes of mental health problems · Recovery is about people taking back control over their life · Recovery is not a linear process · Recovery is possible for everyone · Carers, relatives, and friends also face the challenge of recovery · Everyone's recovery journey is different and deeply personal · Recovery is not specific to mental health problems; it is a common human condition.

Models were developed to further aid the operationalisation of personal recovery within services; for example the CHIME model, describing five dimensions of personal recovery: Connectedness, Hope, Identity, Meaning and Empowerment (Leamy et al., 2011). Standardised measures have been developed (Barbic et al., 2015, Dickens et al., 2019, Konkoly Thege et al., 2017) and guidelines for recovery-oriented service provision have been produced (Sowers, 2005, Shepherd et al., 2010).

A 2020 narrative literature review identifies eight main evidence-based personal recovery-oriented practices within services: peer support work; advance treatment directives, specifying preferred future treatment in case of crisis; 'Refocus' training on recovery principles for staff; strengths model-based case management; the individual placement and support (IPS) model of supported employment; recovery colleges; supported housing; and mental health triologue community forums (Martinelli & Ruggeri, 2020).

## **2.5 What is useful about the personal recovery model?**

The literature shows that personal recovery-oriented practices can be advantageous for service users, mental health practitioners and others. For example a five-year Canadian qualitative study of 90 stakeholders, including service users, service providers, family members, managers and others produced the Impacts of Recovery Innovations (IMRI) framework outlining 18 impacts of implementing recovery innovations (Piat et al.,

2022). Most impacts were positive, for example experiencing personal growth (both service users and staff), new opportunities for building and strengthening relationships, and new ways of operating and doing business for services. Some negative impacts were also reported, described in section 2.6 below.

In a narrative review Martinelli & Ruggeri (2020) describe five main advantages of a recovery-oriented approach: improved self-management and autonomy; reduction of health costs; greater value being placed on service-users' own expertise; greater emphasis on the personal priorities of the service user; and providing a means of empowering service users and reasserting their rights and citizenship, with the potential of greater social inclusion and a role for clinicians in helping to promote this.

## **2.6 What is problematic about the personal recovery model?**

There have been difficulties in implementing the personal recovery approach within services. Confusion has arisen and limitations have been identified (Davidson et al., 2021). A systematic review found several challenges to implementation of the approach, including compatibility issues between traditional organisational culture and recovery-oriented innovations; ongoing cultures of stigma within and outside of mental health organisations; poor learning climates due to distrust and fear based on past negative experiences; lack of leadership and staff buy-in; staff turnover; lack of resources to support personal goals; information gaps about new roles and procedures; and interpersonal relationships (Piat et al., 2021). Negative impacts of implementation reported in the IMRI framework discussed above included staff resistance to change, and increased interpersonal conflict, which the study reports was “usually as a result of norms or power relations being questioned in the recovery-transformation process” (Piat et al., 2022: 9).

Relatedly, the personal recovery approach as it has become mainstreamed within services (hereafter referred to as the ‘recovery model’) has been critiqued as problematic by researchers from a number of disciplines, including Mad studies, survivor and lived experience research (Beresford, 2019, Rose, 2014), clinical psychologists (Harper & Speed, 2012), sociologists (Rogers & Pilgrim, 2021, Nettleton, 2020), health scientists (Morrow & Malcoe, 2017), social workers (Brown, 2021) and health humanities scholars (Woods et al., 2019). They assert that the emancipatory

language of recovery has been appropriated and repackaged within neoliberal policy discourses, which grew in influence in the UK from the late 1990s (Edgley et al., 2012) and have flourished along with austerity measures under successive governments (Mattheys, 2015).

Neoliberalism is a political philosophy and set of practices of late capitalism which is based on the logic of a free-market economy and reflects a small-government approach in the context of welfare. Its effects can be seen in labour market restructuring, privatization and reduction of the social welfare state and its responsibilities (Brown, 2021). Within this context, the individual rather than the state is *responsibilised* for social risks including illness, disability, unemployment and poverty, with a focus on individual ability to self-manage and ultimately to be responsible for their own recovery (Brown, 2021, Morrow & Weisser, 2012). Such discourses reframe radical ideas within market terms of consumerism and individual responsibility, while at the same time justifying the shrinking of the welfare state (Sapouna, 2021).

Hence the recovery model can be described as a convenient ‘neoliberal smokescreen’ (Morrow, 2013), with a stress on personal responsibility for wellbeing at the expense of consideration of the community, social and structural factors which contribute towards both mental distress and recovery (Nettleton, 2020). Critical approaches to the recovery model claim that this over-emphasis on individual agency overshadows the material realities of people’s lives, leading to the promotion of a form of ‘recovery without context’ (Topor et al., 2021). Thus it is claimed that, while discourses of *recovery from illness* and *recovery from impairment* have been absorbed by contemporary health policies and services, the critical discourse of *recovery from invalidation* has not (Nettleton, 2020).

Demonstrating this shift in meaning from emancipatory to market-based contexts, psychologist David Harper and medical sociologist Ewen Speed conducted an analysis of UK mental health policy documentation (Harper & Speed, 2012). They found that the recovery model within policy could be characterised by three discursive, interlinking and problematic strands:

### **2.6.1 Individualisation**

First, recovery is portrayed as a highly individualised approach, which makes emotional distress an explicit problem of individual identity rather than, for example, an effect of trauma or structural inequalities. Harper and Speed point out that Anthony's canonical definition (1993) requires a person accepting that they have an illness, thus endorsing the clinical model and placing the onus on the individual, who must change their attitudes, values, feelings, goals, skills and roles in order to effect change within their own life. They critique Slade's four 'recovery tasks' (2009), described in section 2.4, as inviting people to take personal responsibility for their own wellbeing, and shifting responsibility for the social risk factors of mental distress entirely to the person. Thus, "rather than effecting social change, the marginalised other is required to change their personal outlook" (Harper & Speed, 2012:12).

### **2.6.2 The persistence of a deficit model**

Second, there is an implicit, and paradoxical, continuing reliance on ideas of deficit within the recovery model. Although the focus within policy documents was on supporting the individual experiencing distress to 'develop strengths', this implies that people experiencing distress do not already have them; that they must be personally 'impaired' in some way. Thus mental distress remains associated with personal 'lack' which needs to be 'fixed'. Harper and Speed note that this approach does not therefore offer alternative ways of understanding the nature of emotional distress; it simply reframes existing understandings of mental 'illness', a word which, they observe, remains present in Anthony's definition. As such, the recovery model reifies difference and sustains the subordinated status of mental health service users.

### **2.6.3 The de-emphasis of collective approaches**

Third, structural causes and collective responses to distress are de-emphasised within policy. Social determinants of mental distress are well-established, and include poverty, unstable housing, long-term unemployment, social exclusion and isolation, and forms of stigma and discrimination based on health status, gender, race and ethnicity, sexual orientation, ability, religious and cultural orientation (Davidson et al., 2021, Compton & Shim, 2015). Harper and Speed find that inequality and social issues are not ignored entirely within policy, but are either (i) referenced in a way that restricts the meaning of

'social' to the interpersonal realm (for example, support from friends, family and colleagues); (ii) restricted to the level of personal identity (for example, references to people having 'a sense of empowerment' rather than a calling for actual redistribution of power or resources); or (iii) acknowledged, but the task is still described as being for the individual to reframe the effects of social inequality in terms of their "individualised, responsabilised self" (Harper & Speed, 2012:8).

Thus, the contexts of distress are obscured, and with them the fact that there are material conditions which facilitate the ability to overcome adversity (White, 2001). What is missing is acknowledgement that the extent to which people can make changes in their lives will depend on their access to power and resources – including educational, physical, social and political resources (Smail, 1990).

Harper and Speed stress that their intention is not to dismiss the personal elements of recovery, but rather to rebalance awareness of personal with political needs among practitioners and service users, so that the personal and the political complement each other. They consider it vital that conceptualisations of individual experience can be tied back to collective and structural experiences of distress, inequality and injustice.

## **2.7 Is the recovery model recoverable? Broadening the concept**

Given these criticisms, Harper and Speed conclude by asking if the recovery model is 'recoverable' from this co-option by neoliberal policy agendas, or whether it is inherently limited. This question is still being asked ten years on. For example, a critical scoping review (Karadzhov, 2021b) illuminates the continuing "scarcity of empirical research and the paucity of sociologically-informed theorisation regarding how recovery is shaped by the socio-structural conditions of living". The review concludes that a "profound limitation" of the recovery model is that it "has remained under-researched, under-problematized and under-theorized, especially in the context of homelessness and other forms of socio-structural disadvantage" (Karadzhov, 2021b: 1).

Some studies have considered ways in which the recovery model might be broadened to include more socio-structural perspectives.

### **2.7.1 Mutual recovery**

The concept of 'mutual recovery' has been suggested, for example – representing a shift away from professional-dominated, one-sided forms of help (Spandler et al., 2007, Crawford et al., 2013). These arts-based approaches diminish the role of expert and are led instead by creative arts practitioners. Thus they directly address an original concern of early recovery pioneers; namely, the artificial boundaries which can exist between practitioners (the helpers) and those experiencing distress (those needing help at that point in time). Instead it recognises the universality of experiences of distress, and the capacity of both practitioner and person-currently-in-distress to recover. Mutual recovery is thus described as a relational concept which offers new opportunities to build egalitarian, appreciative and connected communities of mutual hope, compassion and solidarity. It has been used as the theoretical basis of many arts-based approaches including digital storytelling (De Vecchi et al., 2017) music-making (Ascenso et al., 2018), singing (Perkins et al., 2018) and art (Fenner et al., 2022). However, to date this form of recovery retains an individualist approach, restricting its social focus to the level of interpersonal relationships.

### **2.7.2 Relational recovery**

In a review of research that viewed recovery as an inherently social process, Rhys Price-Robertson and colleagues (2017) suggest 'relational recovery' to address critiques of the individualistic nature of the recovery model. This form of recovery is based on the idea of humanity's fundamental interdependence; that people's lives and experiences cannot be separated from the social contexts in which they are embedded. They note that although the recovery model recognises relationships or connectedness as a component of the recovery process, an overemphasis on the 'inner', subjective experiences of people with lived experience largely obscures interpersonal contexts of recovery. They argue that interpersonal relationships can more accurately be seen as suffusing all aspects of recovery, including experiences such as hope, identity and empowerment, and note that:

*recovery frameworks such as CHIME fail to rigorously account for the complex ways in which experiences like hope are actually developed and sustained in the daily lives of people with a lived experience; lives that are never hermetically*

*sealed from the 'outer' contexts of which they are a part (Price-Robertson et al., 2017:112).*

They suggest a way forward for mental health systems through developing approaches that acknowledge the irreducibly relational nature of recovery. However, again, the focus remains on the interpersonal rather than the structural.

### **2.7.3 Social and structural recovery**

Alain Topor and colleagues (2011) go beyond the relational in a review of research which emphasises the social aspects of recovery. They describe 'social recovery' as involving the contributions of others such as supportive relationships and responsive services, but also add 'structural recovery', which recognises the importance of the social environment and society to the process of individual recovery, such as access to adequate material conditions.

Consideration of the social conditions of recovery beyond the realm of relationships is also promisingly included in a proposed framework for recovery generated from a systematic review of 25 systematic reviews and qualitative meta-syntheses (Dell et al., 2021). The authors found that personal transformation was contingent on four factors, and name 'social and environmental conditions which support access to basic resources and safety' as the first factor. However, the framework remains firmly entrenched in the language of individual-level deficit, wherein the overarching definition of recovery is the transformation from "a negative identity state marked by despair, brokenness, and helplessness to a positive state of psychological well-being" (Dell et al., 2021: 238). Any 'enlightenment' (another of the four factors on which recovery is seen to be contingent) achieved by the individual is restricted to "acceptance of the illness as *a part of oneself*, and insight into how to promote wellbeing" (Dell et al., 2021: 238, my italics).

In contrast, Harper and Speed (2012), in common with Topor and colleagues (2011), suggest a return to focusing on *causes* of harm and subsequent distress, emphasising structural facilitators of recovery such as stable income, good housing, employment and the prevention of abuses and harms, as much as ameliorative measures. In his critical conceptual review of personal recovery and socio-structural disadvantage, health scientist Dimitar Karadzhov (2021b) highlights the continued lack of detailed critical

considerations of how multiple forms of oppression and marginalisation can intersect to influence the experience of recovery. Psychiatrists Erika Carr and Allison Ponce (2022) argue that it is crucial that public mental health professionals consider how to leverage their privilege and position to address social justice for people with severe mental distress. They outline an integrated application of the concepts of mental health, citizenship and social justice, illustrated by two examples of leadership in public mental health settings which resulted in demonstrable micro, meso and macro-level impacts (Carr & Ponce, 2022). Health scientists Marina Morrow and Julia Weisser (2012) situate this refocusing of recovery within a social justice framework. They suggest that, in order for recovery to remain a relevant concept in transforming the mental health system, a reformulation of recovery processes which foregrounds an intersectional social justice approach is required. Critical theory-based approaches such as community psychology and liberation psychology (Montero et al., 2017), and therapeutic models based on social constructionism such as Open Dialogue (Seikkula & Olson, 2003), aim to address the issues of power often associated with mental healthcare systems, and could offer a model of such a social justice-based approach to recovery-based services.

## **2.8 Implications for thesis**

In this chapter I have traced the backgrounds of three recovery discourses, summarised as *recovery from illness*, *recovery from impairment*, and *recovery from invalidation*. I discussed issues arising in the translation of 'recovery' from civil rights contexts to healthcare policy and practice contexts. I have explored what may be useful about the recovery model within services and what may be problematic, highlighting that a lack of attention to causes of mental distress at social and structural levels is a key critique of the recovery model. Implications for the thesis include the clarification of my own position towards mental distress as fitting with a *recovery from invalidation* discourse, and the adoption of a critical paradigm for my research, in order to foreground an intersectional social justice approach to recovery narratives, as Morrow & Weisser (2012) suggest.



## **Chapter 3: Narratives in mental health: background and context**

Just as with recovery, definitions of narrative and the way stories are used in mental health can shift depending on the context. In this chapter I describe three approaches to using stories within mental health research and practice, which can be seen to align with the three recovery discourses outlined in [Chapter 2](#). I situate my work in this thesis within a narrative inquiry approach, and outline definitions of narrative in this field. I trace the evolution of the ‘recovery narrative’ as a development of a well-known area of sociological research, the illness narrative. I describe uses of recovery narratives within mental health practice, outlining their benefits, risks and some critiques of their use by survivor researchers and others. I summarise the questions raised for me by the background provided in [Chapter 2](#) and [Chapter 3](#), which led to the undertaking of a systematic review.

### **3.1 Approaches to narratives in mental health**

An interest in narratives expanded from the fields of literature and linguistics into the social sciences in the mid-twentieth century, often referred to as the ‘narrative turn’ (Riessman, 2008). This interest has led to an extraordinary and extensive narrative-based literature across many academic disciplines, including the health humanities (Crawford et al., 2005), psychology (Crossley, 2000, McAdams, 1993, Polkinghorne, 1988, Sarbin, 1986), psychotherapy (Kleinman, 1988, McLeod, 1997), sociology (Andrews et al., 2013, Frank, 1995/2013, Plummer, 2019, Riessman, 2008), nursing (Holloway & Freshwater, 2009), occupational therapy (Mattingly, 1998), sports psychology and disability (Smith & Sparkes, 2005) and clinical medicine (Charon, 2008, Greenhalgh & Calman, 2017). Within health-based research, interest in personal narratives has translated into the investigation of ‘illness narratives’ as a key source of understanding the experiences of people with chronic conditions, including cancer (Frank, 1995/2013), HIV and AIDS (Ezzy, 2000), arthritis (Swift & Dieppe, 2005), diabetes (Kumagai et al., 2009) and now long COVID (Rushforth et al., 2021). For example, medical sociologist Arthur Frank (1995/2013) distinguished three genres of illness narrative: restitution (where the narrator is restored to their former healthy status after the interruption of illness); chaos (where the illness experience is

characterised as meaningless, empty and devoid of purpose) and quest (where the narrator attains a higher purpose through their illness experience), to map the contrasting ways in which narrators interpret the biographical rupture to an expected life course that chronic illness can represent (Bury, 1982). This typology has proven highly influential in the study of illness narratives, though is not without its critics (see, for example, Gammelgaard, 2019, Woods, 2014).

A question running through the development of narrative study is: why explore narratives, and what is the purpose of examining the structure, form or influence of a story? For the sociologist Catherine Riessman, one answer is that the study of narratives can further knowledge and understanding of human actions, decisions and meaning making (Riessman, 2008). Psychiatrist and medical anthropologist Arthur Kleinman saw much illness-related storytelling as being oriented to making sense of the experience of illness by answering questions like ‘why me?’, ‘what caused it?’ and ‘what can I do to get better?’ (Kleinman, 1988). Told to an audience, he found that illness narratives may fulfil the function of recruiting empathic witnesses and inspiring morally-motivated action (Kleinman, 1988). Narrative in all forms bears a message, idea, expression or account of experience – areas which are highly pertinent to health research (Bingley, 2020).

However, the kind of knowledge produced depends on the underlying epistemological assumptions of the researchers. This can clearly be seen in the different ways in which mental health researchers and practitioners approach stories.

### **3.1.1 Narrative coherence: stories as assessment tools**

Some use the stories of participants or patients in order to assess them – for example, their states of mind and/or levels of awareness of their ‘condition’, referred to as ‘insight’. Those using this approach may equate mental distress with the breakdown of an individual’s coherent life story, whether as an inherent aspect of mental illness (Lysaker et al., 2001), or as a response to traumatising events (Crossley, 2000). For example, Paul Lysaker and colleagues (2002: 204) describe developing the Indiana Psychiatric Illness Interview to provide “a means of assessing various aspects of awareness of illness as it is embedded within a personal narrative”. Their subsequent Narrative Coherence Ratings Scale, described in the same paper, rated the coherence of

narratives, based on how understandable or acceptable those stories were seen to be to others.

This approach to stories can be seen as aligned with clinical discourse of *recovery from illness*, with the researcher or practitioner positioned as expert, and people's stories the raw material to which assessment tools can be applied. Levels of (in this case) coherence and insight within a narrative, as gauged by the practitioner, are seen to be indicative of how 'ill' a participant might be.

The coherence paradigm generally implies that (i) good and competent narratives will proceed as a linear, chronological way, from a beginning and middle to an end; and that the end will bring thematic closure; (ii) the function of narrative telling is primarily to create coherence in regard to experience, which is understood as being somewhat formless (which may be understood either as a merit or a disadvantage of narrative); (iii) persons live better and in a more ethical way if they have a coherent life-story and coherent narrative identity (Hyvärinen et al., 2010). However, the privileging of coherence has been problematised by narrative and trauma researchers (Hyvärinen, 2010, Salmon & Riessman, 2008, Vanaken et al., 2021), as has the assumed inability of people with experiences of psychosis to construct a 'coherent' narrative (Saavedra et al., 2009).

Similarly, conceptions of 'insight' have been challenged. Traditional conceptions of insight in psychiatry refer to 'the capability of psychiatric patients to recognise and accept that they are suffering from a mental illness' (Thirioux et al., 2020). Lysaker and colleagues (2002) developed an alternative, that of 'narrative insight', which views the stories of people in distress as adaptive strategies. 'Narrative insight' forms a component of new, narrative-based cognitive treatments such as Narrative Enhancement and Cognitive Therapy (Yanos et al., 2019) and Metacognitive Reflection and Insight Therapy (MERIT) (Leonhardt et al., 2018). This construct is mooted as a replacement for traditional, hierarchical constructions of insight (Bouvet et al., 2019). However, it remains a hierarchical approach based on a deficit model, being delivered by professionals and seeing those for whom the intervention is targeted as personally lacking in certain skills or abilities, capable only of possessing 'impoverished narratives' (Lysaker et al., 2003). Narrative insight is challenged by alternative concepts such as 'outsight' (Smail, 2005), which, in contrast to an individual's ability to see that they are

ill, seeks to redress a sense of wholly personal responsibility for distress and restore a greater perspective to individuals through increasing their knowledge and awareness of the social and structural causes of mental distress.

### **3.1.2 Narrative identity: stories as meaning-making and identity-constructing processes**

Another way of working with narratives has been developed within psychotherapeutic research and practice. Practitioners working within psychodynamic approaches may view people's narratives as a way of gaining access to other areas of experience, such as relationship themes or other unconscious content (McLeod, 1997). Approaches which developed from these theoretical underpinnings include Dan McAdams' work on life stories (McAdams, 1993, McAdams & Bowman, 2001, McAdams & McLean, 2013) and John McLeod's work on narrative and psychotherapy (McLeod, 1997). This approach sees narrative as fundamentally connected with the creation of a sense of personal identity. 'Narrative identity' is the internalised and evolving story of the self that a person actively constructs to make sense and meaning out of his or her life (Ricoeur, 1991, Holstein & Gubrium, 2000, McAdams, 2011, McLean et al., 2020). Stories are seen as a means of bringing order to disorder. Psychologist Jerome Bruner (1990), for example, suggested that stories are used to make sense in particular of those experiences which in some way violate our expectations of what 'should' happen. Storytelling facilitates managing 'trouble' in the world, as we seek to make sense of experiences that are new or unexpected. It is through this process of making sense of trouble that a storied self is seen to emerge (McLean, 2008). Similarly, sociologist Michael Bury conceives of chronic illness as biographical disruption, and illness narratives a means of repairing such disruption (Bury, 1982).

These approaches can be seen as aligning with the *recovery from impairment* discourse. As McAdams puts it:

*the implicit goal of many psychotherapy regimens – from narrative therapy itself (Angus & McLeod, 2004) to various forms of cognitive-behavioural therapy – is to help the client develop a better story for life, a story that promotes adaptive coping rather than feeding the beasts of depression and anxiety (McAdams et al., 2022).*

Such approaches have been criticised for invoking the telling of ‘deficit’ narratives (Gergen, 1990) and positioning the therapist as expert, a “vision of human possibility as unattainable as the heroism of cinematic mythology” (Gergen & McNamee, 1992: 171). They are primarily concerned with individual-level factors of identity transformation, wherein it is the responsibility of the individual to allay the ‘beasts’ of mental distress through adjusting their maladaptive thinking. There is not room here for contextualising information: the monsters in this story are the states of depression and anxiety themselves, not what may have caused them.

### **3.1.3 Narrative power: stories as emancipatory strategies**

In contrast, more critical and emancipatory approaches to stories have been developed in both research and practice, which can be seen to align with the *recovery from invalidation* discourse. Within research, social constructivist approaches treat stories not as “objective, spontaneous outpourings” (Kaiser et al., 2020:8), but as situated within and contingent upon their contexts (Given, 2008). Critical constructivist approaches note further that stories are constructed within a “hierarchy of credibility” (Plummer, 2019:6), wherein some ways of understanding are more available and socially sanctioned than others (Johnstone et al., 2018:6).

These more socially acceptable narratives can be referred to as the dominant meta-narratives of a particular society, or those which a critical mass of people accept as ‘common sense’ (Hagström & Gustafsson, 2019). Such meta-narratives provide an overall context within which personal narratives function; for example, the dominant biomedical narrative within the Global North, which defines distress in terms of mental dysfunction and disease, and both describes and dictates how people conceptualise their own narratives. Even those producing ‘counter-narratives’ which oppose dominant themes are constructing their stories *in relation* to the dominant account (Adame & Hornstein, 2006). Dominant narratives privilege some people’s accounts and marginalise others (Coghlan & Brydon-Miller, 2014). Therefore, it matters whose stories are legitimised and whose are not. And since “we do not tell stories about ourselves under conditions of our own choosing” (Zussman, 2000: 6), the types of narrative available in any given historical moment are crucial in terms of the choices available to the narrator (Plummer, 1994/2002).

Therapeutic interventions have been derived from these critical and emancipatory approaches, such as narrative therapy (White & Epston, 1990). Narrative therapy arose as a direct challenge to existing therapeutic practices and concepts (Smith, 2022). Notably, its founders Michael White and David Epston came from social work backgrounds, not psychiatry, psychology or counselling. Narrative therapy was one of the first clinical practices grounded in ideas of postmodernism, post-structuralism and critical theory (Freedman & Combs, 1996). It takes a collaborative approach to working with clients, in which clients are the experts on their lives. It views the stories people develop as incorporating dominant social and cultural stories of (for example) gender, ethnicity and power, as well as personal stories co-constructed in interaction with others (for example family, friends and professional supporters). As in postmodern literary criticism, narrative therapists help clients ‘deconstruct’ the storylines around which they have organised their lives, jointly assessing the plot, characters and timeline for meaning, and looking for other ‘truths’ that also exist. Arguably, this is the therapeutic approach most closely aligned to a narrative inquiry methodology.

Researchers using this emancipatory approach view stories in terms of how they may contribute to social change. Stories can encourage others to act; they may invite political mobilisation and change, as evidenced by the ways stories “invariably circulate in sites where social movements are forming” (Riessman, 2008: 8). Stories “often bring to light marginalised people’s experiences, changing our [*sic*] perceptions of them” (Chase, 2018:957). Narrative researchers also investigate “how institutions regulate storytelling practices, contributing to vulnerable people’s oppression” (Chase, 2018:957). Many narrative researchers with an interest in emancipation use Central and South American *testimonios* as a model: first-person eyewitness accounts narrated by those who lack social and political power, about repression, exploitation and marginalisation (Beverley, 2022). For example, Saskia Witteborn’s (2012) work on the *testimonios* of forced migrants found that purportedly protective spaces (for example refugee and asylum shelters; the communities in which refugees settle) are often ‘spaces of risk’, exposing them to numerous hazards. She heard *testimonios* in different contexts, including research interviews, public forums and virtual spaces, and found that forced migrants had the most control over their stories on websites they created

themselves, “without regulating intermediaries like advocacy organisations or researchers” (Witteborn, 2012: 424).

Researchers have cautioned, however, against seeing testifying practices in themselves as embodying social change, since their potential for change depends on the conditions, histories and structures that surround their production. Hence control must accompany voice (Chase, 2018).

### **3.2 Definitions of narrative**

Since ways in which narratives are defined and used depend upon the theoretical underpinnings of different approaches, Riessman (2008) notes that it is important to be clear about one’s own working definitions. As might be expected in such a wide-ranging field, definitions of narrative abound, and are disputed (Andrews et al., 2013), as is the necessity for defining narratives at all (Tamboukou, 2008).

My own definitions have been influenced by developments in the field of narrative inquiry, my chosen methodological framework. Susan Chase (2018: 946-948) outlines this expansion of definitions of narrative in her overview of theoretical advances in the field. Since questions of the legitimacy and validity of certain types of account *as* narratives are central to the use of stories in mental health research and practice, I refer to Chase’s overview here at length.

Early narrative researchers within the health and social sciences borrowed from linguistic theorists such as William Labov, and defined narrative comparatively narrowly as, for example, discourses consisting of clauses that match the temporal sequence of past events (Mishler, 1995). Labov’s work was a watershed moment in the history of narrative research in social sciences, but it implicitly conceived of stories as self-contained monologues with recurrent formal features, not influenced by the context, such as the listener/questioner (Salmon & Riessman, 2013).

In the late twentieth century narrative turn, narratives began to be defined more broadly (Clandinin, 2012). Chase notes that an orientation to time has always been included in definitions of narrative, but has shifted from a focus on the narration of *past events* to the narration of experience more generally. This allows for accounts about feelings and thoughts, and about present, future and hypothetical experiences, to be

considered as narratives. Narratives do not just relate experiences, but can make sense of them without necessarily ordering them chronologically.

The 'visual turn' challenges assumptions that narratives are primarily written or oral. Researchers of images (such as photographs and art) and physical objects (such as public memorial spaces) treat them as socially situated narrative 'texts'. This has in turn expanded to include interactive, embodied social processes (Andrews et al., 2013, Riessman, 2012), which encourage the attention of researchers to emotions, nonverbal communication and possibilities for dialogue and the building of community through narrative co-creation. For example, in her study of Black South Africans women's experiences of apartheid, Puleng Segalo (2014) encouraged women to meet together and create embroideries as a way of externalising their embodied experiences of trauma. These textile-based narratives conveyed individual and collective suffering that had previously been silenced, and, as the women met together over several months, formed the basis of a valued community space in which they could eventually speak about the difficulty, and the importance, of recounting the past (Segalo, 2014).

Narratives as embodied social processes have also been studied by Brett Sparkes and Andrew Smith (2012), in their study of men who have become disabled after spinal cord injuries. After interviewing the men, they reflected on their own engagement with interviewees, including their visceral reactions to their participants' conditions and their own fears about physical vulnerabilities. This experience highlighted for them the limits of empathy – the ability to imagine oneself in the embodied, storied world of another. Rather than a failure of narrative, acknowledging this limit is seen as key to respecting the difference of others, which can help researchers to avoid superficial or disingenuous relationships with participants.

Another expansion of the concept of narrative highlighted by Chase is the study of institutional narratives, as embedded in discourse and materials produced by different entities and organisations. These can include official speeches, reports, websites, policy documents or everyday talk in schools, workplaces, social media, courtroom and health services. Chase (2018) notes that not all of these materials are narratives, but when they express something about who 'we' are (for example as a profession, organisation or nation), what we are doing and why, the collective narratives they express can be



explored. Harper and Speed's (2012) analysis of narratives of mental health recovery embedded in UK policy documents, outlined in section 2.6, is a good example of a study of institutional narratives.

In the light of these expansions within narrative inquiry research, in this thesis I adopt Chase's working definitions, firstly of personal narrative:

*A personal narrative is a distinct form of communication. It is meaning-making through the shaping of experience; a way of understanding one's own or others' actions; of organising events, objects, feelings or thoughts in relation to each other; of connecting and seeing the consequences of actions, events, feelings, or thoughts over time (in the past, present, and/or future) (Chase, 2018: 951).*

Institutional narratives are defined as:

*Meaning making through the shaping of the institution's and/or its members' actions; [organisational] expressions of who 'we' are, what we're doing, where we've been, where we're going and why" (Chase, 2018: 952).*

### **3.2.1 How do 'stories' and 'narratives' differ?**

Frank (1995/2013) defined *stories* as what a person tells at individual (micro) level, and *narratives* as stories when considered collectively - for example within published collections or research datasets (meso level), or as cultural discourses identifiable within, for example, media, policy or legislation (macro level). Smith and Sparkes (Smith & Sparkes, 2009) use *stories* similarly, to refer to the actual tales people tell, and *narratives* when considering the dimensions and properties comprising particular stories. Plummer (2019: 4) states that "stories direct us to what is told, while narratives tell us how stories are told". I have found these distinctions to be useful as rough guides. However, so many scholars have distinguished them in so many ways - for contrasting examples, see Polkinghorne (1988) and Kim (2015) - that, following Francesca Polletta and colleagues (2011), I use the terms interchangeably in this thesis. Within my findings, when referring to narratives operating at macro level, I have used more specific terms such as dominant, master or meta-narratives.

### 3.3 Narrative research on mental health recovery

Narratives of lived experiences of recovery began to appear in the research literature from the late 1980s, including foundational work by Patricia Deegan (1988, 1996, 2002), Nora Jacobson (2001) and Priscilla Ridgway (2001). These scholars either documented their own experiences or synthesised the experiences of themselves and others.

Collectively these narratives raise a number of issues, including:

- (i) shifting descriptions of recovery processes away from using traditional and objective scientific, psychiatric and psychological language, to the use of more humanistic and subjective concepts such as hope and meaning, journeys not outcomes;
- (ii) asserting the personhood and agency of the person experiencing distress; recognising inherent strengths and the active participation and coping strategies that were necessarily involved in their own recovery. This contrasted with acceptance of a passive role and adaptation to permanent disability formerly expected by services;
- (iii) challenging the artificial boundaries between people experiencing distress and other people. This was the “simple yet profound realization that people who have been diagnosed with mental illness are human beings” (Deegan, 1996: 92); that ‘the psychiatrically disabled’ are not a distinct and separate group of people but share the same fundamental needs and aspirations as anyone else. A core feature of the narratives was addressing the “pain of being cast into the role of Other” (Ridgway, 2001: 340).
- (iv) demonstrating that recovery is embedded in social factors; that it is about being able to “live, work, and love in a community in which one makes a significant contribution” (Deegan, 1988:1) and an active reaching out to others (Jacobson, 2001).

A systematic review synthesised 36 early personal accounts of recovery and suggested that four key components emerging from the movement were: (i) finding and maintaining hope; (ii) re-establishing a positive identity; (iii) building a meaningful life and (iv) taking responsibility and control (Andresen et al., 2003). The authors’ stated

intention was to identify a definition of recovery and develop a model of recovery from, in this case, schizophrenia which was faithful to the experiences of people who have recovered. However, despite the work of Deegan, Ridgway and Jacobson being included in the synthesis, it is notable that their concerns about being 'othered' and the importance of social factors are missing from the four key components outlined by Retta Andresen and colleagues.

In the twenty years since, narrative research on mental health recovery has grown and contrasting approaches have emerged: those which use narratives as a means of accessing other information, and those investigating aspects of the narratives themselves.

Studies using narratives as a means of accessing other information take a broadly thematic approach. These studies are concerned with the *content* of participants' narratives, and what can be learned about recovery from them – see, for example, Brown (2008). The objectives here are of increasing academic and clinical understanding of the nature of recovery (Hall, 2011) and providing a source of knowledge and hope for survivors (Ridgway, 2001). A systematic review of four narrative inquiry studies identified four higher-order concepts: recovery is possible; recovery is a journey; being in control of your own recovery is crucial; and the role of community in recovery (Rhodes & De Jager, 2014). The aim of the review was to elevate the expertise of people with lived experience to stand alongside quantitative findings, seen as the kind of evidence required to influence clinical policy and practice.

A second approach to recovery narratives is broadly structural, assuming that the *way* individuals narrate their experiences, and the kinds of narratives they construct, can also offer important understanding of recovery. These studies investigate various characteristics of recovery narratives, for example types of genre and tone (Thornhill et al., 2004), trajectories (Thomas & Hall, 2008), or ways in which recovery narratives are positioned in relation to the dominant clinical narrative (Adame & Knudson, 2007).

### **3.4 Uses of recovery stories in mental health practice**

Personal stories have thus been described as a key 'recovery technology', both embodying the values associated with recovery and providing a means of realising those values (Smith-Merry et al., 2011). The development and sharing of recovery

narratives has become a central practice within recovery-oriented healthcare. Among the audiences for recovery narratives are practitioners and policymakers, students in training to become practitioners, and other people with lived experience. People have developed and shared their own stories, for example through 'writing for recovery' groups (Taylor et al., 2014) and the widely-offered storytelling courses offered at UK Recovery Colleges (for example, [slamrecoverycollege.co.uk/telling-your-story.html](http://slamrecoverycollege.co.uk/telling-your-story.html)). The reciprocal sharing of recovery stories is also a distinctive feature of peer support (Moran et al., 2012, Truong et al., 2019). Online narrative-based interventions have been developed to increase access to self-care resources (Slade et al., 2021, Williams et al., 2018). Recovery narratives have been used in staff training to improve service delivery and increase empathy (Salter & Newkirk, 2019). They have also formed the basis of public health campaigns and 'living library' initiatives to challenge stigma (González-Sanguino et al., 2019, Kwan, 2020).

There are undoubted benefits of these narrative-based interventions, both for people with lived experience, carers and professionals. For example, participants in a Telling My Story course at a recovery college run by an NHS trust in the East of England reported that telling their own stories was a cathartic experience which enabled the externalising of difficult internal experiences, making them more manageable to process. Sharing was facilitated by a sense of safety which came from knowing that others would understand and empathise, having had similar experiences. Expressing previously hidden parts of themselves led to a sense of liberation; while hearing others' stories provided personal inspiration (Nurser et al., 2018).

Writing for Recovery was a user-led project by and for people with lived experience and carers, which ran at the University of Brighton, UK as part of a wider narrative inquiry (Grant et al., 2012a, Grant et al., 2012b). It took an emancipatory approach to recovery, formulating it in terms of transcendence of the "social invalidation, discrimination and abusive effects of institutional psychiatry" (Taylor et al., 2014: 1). The project aimed to "facilitate the development of individual and group re-storying recovery identities, removed from perceived or actual institutional mental health expectations" (Taylor et al., 2014: 1), and resulted in publication of an anthology of participants' work. The reported benefits included new friendships, the re-storying of more positive identities in a safe space, development of community resilience by working through experiences

of social injustice, anger, fear and betrayal, and growth in self- and social confidence, which was supported by testimony from participants' significant others (Taylor et al., 2014). The emphasis on *sharing* stories marks this way of using stories as distinct from the forming of stories in therapeutic interventions such as narrative therapy (White & Epston, 1990, White, 2007) which typically happen at private level (Nurser et al., 2018).

In addition to the mutual sharing of experiences through courses, studies have reported benefits to people with lived experience from accessing recovery narratives through videos, which were found to authenticate difficult personal experiences (Williams et al., 2018) and through reading eating disorder memoirs, where participants found they mitigated social isolation (Shaw & Homewood, 2015).

A systematic review identified five types of impact of recovery narratives for people accessing them: connectedness; understanding of recovery; reduction in stigma; validation of personal experience; and a range of emotional and behavioural responses (Rennick-Egglestone et al., 2019a). A change model was developed which identified seven helpful outcomes of accessing recovery narratives: connectedness to others experiencing similar things; validation of own experiences; hope about what might be possible and about human nature; a sense of empowerment, appreciation of the narrator, reference shift (a fundamental change in belief or understanding about the possibility of recovery) and stigma reduction (Rennick-Egglestone et al., 2019b).

One might echo Diana Rose (2014) in asking, who could be against recovery, and its narratives? The right and ability to define one's own experiences and externalise negative dominant discourses is described by Steven Onken and colleagues (2007) as the primary mechanism in recovery. As it has been a core challenge for people with lived experience to establish our/their perspectives as legitimate within services (Slade & Sweeney, 2020), the use of recovery narratives by services could be seen as empowering; providing opportunities to (re-)claim often-denied epistemic authority (Fricker, 2007) over individual biographies, and to effect change in healthcare systems (Fisher & Lees, 2016). However, the use of recovery narratives by services is complicated by the contested understandings of recovery outlined in [Chapter 2](#) and by the historic use of people's stories to diagnose them, outlined in this chapter, section 3.1.

### 3.5 Critiques of recovery narratives

The elicitation of recovery-focused narratives by healthcare researchers, educators and practitioners has been problematised by a growing number of Mad studies scholars, survivor-researchers and other critical theorists sensitised by them (Costa et al., 2012, Church, 2013, Fisher & Lees, 2016, Russo, 2016, Voronka, 2019, O'Donnell et al., 2019, Woods et al., 2019, Sapouna, 2021, Voronka & Grant, 2021, de Bie, 2022, LeBlanc-Omstead & Kinsella, 2022). Many researchers who critique the genre stress that it is important to make the distinction that they are not focusing on or criticising individual accounts of mental distress or the desire to share one's story. As Woods and colleagues (2019: 224) state, "we do not call for a more critical engagement with Recovery Narrative ignorant of what is at stake personally, ethically and politically". Rather, the focus is on the recovery narrative as an overarching category or type; on how it is mobilised, and with what effects, within research and practice.

The thrust of objections can be seen in the titles of a number of papers by activists and educators. In a paper described as formative by subsequent researchers of the subject, "Recovering our stories: a small act of resistance" Lucy Costa and colleagues (2012) describe a community event they organised to disrupt the "appropriation and over-reliance on" the lived experience personal story and the use and abuse of stories as "sought-after commodities" (2012: 85); and to "alert the community to the dangers of storytelling" (2012: 91). The event was aimed equally at activists, service providers, people already critical of sharing their stories, and people who might be invited to share their story. A primary aim was to equip those potentially being cajoled into sharing their stories with tools to enable questioning of and resistance to the practice. They "elucidate how our stories are increasingly being used to harness support, funding or press coverage for the systems that we recognise as being part of the problem" (2012: 98). In "Storytelling beyond the psychiatric gaze: resisting resilience and recovery narratives" Jijian Voronka (2019) explores the politics of recovery narratives in practice, using her own storytelling activities as a case study to unsettle the frequent representation of storytelling as benign. She offers an account of how her own public storytelling came to hold multiple meanings as it was processed by different audiences and as it landed materially in different places. In "Service-user narratives in social work education; Co-production or co-option?" Lydia Sapouna (2021) critically reflects on her

own use of recovery narratives as an Irish social work educator and researcher. She is grounded in critical pedagogy practices (Freire, 1970/2017) but recognises the challenges presented when training students expected to practice within dominant biomedical systems.

The concerns raised by these and other researchers can be summarised as follows:

### **3.5.1 The commodification of recovery narratives by research and services**

One, that narratives with a focus on the possibility of recovery, which were central to the history of organising resistance and change in mental health systems, have now become a sought-after commodity by organisations, who may use them to harness support and funding for their own services. As Costa and colleagues (2012) highlight, in this context recovery stories may function to gain support from authorities such as politicians and funding bodies, to cast the organisation in a favourable light, build the 'brand' of a service or research team and raise funds during times of economic constraint.

In a study exploring the views of 18 peer workers with lived experience of mental distress and homelessness, Jijian Voronka and Jill Grant (2021) found that peers described telling their stories in situations which severely limited both what they could say and how it could be heard. This prevented them from challenging the systems they were employed within but, more than that, for some peers this constituted a material extraction of their resources. As one participant put it, storytelling is not just powerful, it is economically valuable in a neoliberal context. She spoke of researchers "jumping into" mental health as a currently lucrative field, and gave the example of a narrative anthropologist 'taking' peer stories, then turning them into data which then advances their career. Thus, "my story helps you advance" (Voronka & Grant, 2021:8).

### **3.5.2 Compliance with, not transformation of services**

Two, that this co-option of recovery narratives sustains a harmful system and encourages compliance with, not transformation of, mental health services (Voronka, 2019, Sapouna, 2021). This can be seen in Voronka and Grant's (2021) findings from peer workers in Canada, above. Another stark example is given in a multiple-case study investigating elicitation of recovery narratives in global mental health contexts (Kaiser et al., 2020). One ethnographic study described an inpatient clinical service in Indian-

controlled Kashmir run by the police (Varma, 2016). Patients approaching their discharge date were required to recount an 'acceptable' recovery narrative, demonstrating their improvement as a result of their inpatient treatment as a prerequisite to discharge. The resulting recovery narratives were found to have a highly formulaic quality, with the expressions of gratitude and obeisance to the police for 'curing' them which were particularly important ways of evaluating a patient's sincerity and wellbeing, i.e. their fitness to be discharged. Furthermore, the study authors note, the relationship between patients and doctors, and the modes of dependence generated by the recovery narrative, mirrored relations of dependency between (occupied) Kashmiris and the (occupying) Indian state more broadly. By publicly articulating their gratitude for Indian state care, patients unintentionally helped shore up the state's counter-insurgency imperatives. Thus exploring the context in which recovery narratives are shared reveals how clinical relations and treatment outcomes can have social and political impacts.

### **3.5.3 The privileging of certain types of account**

Three, that certain types of account tend to be privileged in these contexts, such as balanced, 'safe' stories that do not discomfit or challenge mental health professionals and researchers (Sapouna, 2021, O'Donnell et al., 2019). For example, Sapouna (2021) describes how current use of narratives in professional training may privilege certain types of knowledge through narratives that are considered 'inspirational' or 'insightful,' at the expense of other expressions of distress. She reflects on her own experience of choosing narratives for inclusion in a social work education curriculum:

*Do I only include articulate narrators in education? What about people who struggle to share their stories? What about the incoherent and overwhelming stories? What about people who refuse to share their stories, don't they have a story to share? What about those who identify as 'unrecovered' and in need of long-term support? Do we privilege certain types of narrative-generated knowledge over others? Being involved in critical education does not render my teaching immune from such acts of privileging. As said earlier, I have privileged well-articulated stories of trauma and distress and critiques of medicalization. Recognizing this inadvertent act of privileging I create opportunities to regularly discuss these matters with students, particularly after listening to moving, well-*



*articulated testimonies of trauma and psychosis. Not all people have words for their experiences, not all stories make sense neatly. We therefore need to create spaces to listen [to], validate and explore diverse forms of expression, including narratives that are chaotic, incoherent, angry in a way that is not easily justified (for example because of trauma) (Sapouna, 2021).*

Thus, mental health professionals selecting narratives for use act as ‘gatekeepers’ for the kinds of knowledge available to people training as professionals, as well as to people using services.

Guidance on producing recovery stories (SAMHSA, 2018, Network) and the aforementioned ‘Telling Your Story’ courses in Recovery colleges function in the same way. Angela Woods and colleagues (2019) analyse such guidance and find within them a strong moral imperative to provide insight and inspiration for others, for example in the US Substance Abuse and Mental Health Services Administration (SAMHSA) guide to digital storytelling:

*Why should you share your story? Because:*

- *it helps to reduce negative attitudes and stereotypes*
- *It may encourage others to seek help, and*
- *It can be a healing and empowering experience for you, too (SAMHSA, 2018).*

While potentially helpful for individuals, the similarities found in guidance and course structures may collectively contribute to a “narrowing of narrative horizons” (Fisher & Lees, 2016: 602) wherein conventional clinical narratives are simply replaced with new “dominant recovery narratives”, as an investigation of narrative-based interventions at UK Recovery Colleges has highlighted (Nurser et al., 2018:26). Nurser and colleagues found that positive reframing was somewhat imposed by the course structure. Thus such courses and guidance may be seen to act as ‘gatekeepers’ for the kinds of knowledge available – and not available – to other people experiencing distress, shaping what it may be possible to imagine. These forms of ‘Recovery Narrative’, dependent upon “tight adherence to generic conventions” for their efficacy (Woods et al, 2019:

206) may put pressure on narrators to conform to particular types of narrative, depending on their context (De Wolfe & The Borderline Academic, 2019).

Furthermore, as Sapouna (2021) describes, those whose experiences do not fit with the templates found in such courses and guidance may be “needlessly and wrongly distress[ed]” (Woods, 2011:77). Another case included in Kaiser and colleagues’ (2020) study described an Australian non-profit which trained people with lived experience to share their stories with the public. Narrators were instructed to avoid ‘risky’ subjects like self-harm and suicide, follow a structure of beginning, middle and positive ending, and speak positively about mental health services to encourage others to seek help. After the training, some participants were invited to become speakers but many were not. The selection process was not explained, leaving the experience unresolved for participants whose stories were not deemed appropriate to share. The resulting stories that were shared fitted a narrow template of being ‘risk-free’ and reflecting well on mental health services, arguably reinstating professional power and a central role for services at the expense of validating other experiences of recovery (Fisher & Lees, 2016).

#### **3.5.4 Reinforcement of personal responsibility for recovery at the expense of consideration of social and structural factors**

Four, that such narratives, or how they are heard in the current political climate, can reinforce an emphasis on individual-level recovery factors such as personal resilience at the expense of acknowledging structural factors, such as access to good housing (Voronka, 2019, Harper & Speed, 2012). Woods and colleagues (2019) point out that, as a key ‘technology of recovery’ (Smith-Merry et al., 2011) the recovery narrative focuses attention on individuals’ ‘recovery journeys’ rather than the “social, political, cultural and economic context in which people become mentally distressed and recover” (Morrow & Weisser, 2012:325). Costa and colleagues note that, in their own experiences of witnessing storytelling within social service agencies: “issues of systemic poverty and discrimination, an appalling lack of choice in services, and mistreatment are conveniently left out of the story” (Costa et al., 2012:89). Voronka (2019) gives the example of foregrounding her experiences of homelessness and inadequate services as a young woman, contrasting her experience with that of her brother, who subsequently took his own life while in transitional housing. She was routinely congratulated on her

‘strength’ and ‘resilience’ by the mental health professionals in the audience. She writes: “however hard I try to frame my political narrative as something other than a personal family tragedy of weakness, poverty, and mental illness, meta-narratives of heroic overcoming through resilience and recovery strategies prevail. The conditions under which I am heard outweigh and overwhelm me” (2019: 24).

Nor are stories recognised as recovery narratives in other contexts exempt from this tendency towards individualization. While mental health services, charities and campaigns in a neoliberal context may promote narratives of returns to productivity via treatment and medication, survivor and activist movements may promote narratives of rejecting medication and finding the tools to cope with trauma without drugs and/or through spiritual renewal (De Wolfe & The Borderline Academic, 2019).

### **3.6 Implications for thesis: are ‘recovery narratives’ recoverable?**

Chapter 2 and Chapter 3 map the background from which my systematic review and subsequent research questions emerged. My own positioning felt contradictory. I had come into the NEON study highly positive about the power of storytelling to effect individual and social change, based on my own experiences of re-narrating my own story and my work within LGBTQ+ communities, outlined in Chapter 1. I wanted others to have access to stories that might help them feel less alone and less self-blaming for their distress. Above all, I wanted people to access stories that would give them hope that there was a way out of their distress. The NEON aim of designing an online intervention where people could access ‘recovery narratives’ seemed ideal for this and, initially, straightforward.

And yet I could not ignore that some of the very people whose stories had been used as the basis for the recovery model were now critiquing the use of recovery narratives in practice and in research. Questions arose for me. Could the recovery narrative genre be recoverable from this kind of co-option? What exactly was meant by a ‘recovery narrative?’ What kinds of stories were being badged with this or similar labels? An important first step seemed to be to explore how recovery narratives had been characterised in the research literature to date.

## **Chapter 4: Systematic review: Characteristics of recovery narratives and preliminary conceptual framework**

### **4.1 Introduction**

In this chapter I outline the procedures undertaken to carry out a systematic review of the characterisation of recovery narratives in empirical studies. I describe my findings in the form of a preliminary conceptual framework, and discuss their relevance to the wider literature.

I chose to undertake a systematic review from the many forms of review available (Grant & Booth, 2009), as I initially framed my research in terms of the 'development' phase of the MRC framework for developing complex interventions (Craig et al., 2006). Methodologically speaking, systematic reviews were specifically recommended within this earlier version of the framework, based in an evidence-based medicine (EBM) paradigm (Sackett, 1997).

A more appropriate choice for a narrative inquiry methodology may have been a narrative literature review. Often discussing theory and context, narrative literature reviews can be useful for describing the historical and social relevance of a topic, which can serve to provoke thought and controversy regarding theory and clinical practices (Green et al., 2006). [Chapter 2](#) and [Chapter 3](#), although not literature reviews, are intended to provide some of this context. However, undertaking a broad-ranging systematic review, using a search strategy across a wide range of academic disciplines, did ensure an overview of the multiple characteristics of recovery narratives which had, to date, been identified by researchers from many different perspectives, while serving to highlight some gaps.

The review question was 'how have mental health recovery narratives been characterised in academic literature?' The aims were (i) to review published documents presenting typologies or characteristics of mental health recovery narratives and (ii) to use a modified narrative synthesis to develop a conceptual framework for the characterisation of mental health recovery narratives. The resulting paper was published in March 2019 and is available at [doi.org/10.1371/journal.pone.0214678](https://doi.org/10.1371/journal.pone.0214678).

## 4.2 Method

I carried out a systematic review of the research and grey literature following PRISMA guidance (Moher et al., 2009). Studies which met my inclusion criteria and were published in academic journals were assessed for methodological quality. I undertook a three-stage narrative synthesis of findings using a modified version of Popay and colleagues' (2006) guidance, to produce a preliminary conceptual framework of characteristics of recovery narratives. The systematic review protocol was registered with PROSPERO in March 2018 and is available from [doi.org/10.1371/journal.pone.0214678.s001](https://doi.org/10.1371/journal.pone.0214678.s001).

### 4.2.1 Eligibility criteria

The review was of empirical studies investigating characteristics of mental health recovery narratives. I created a provisional definition of mental health recovery narratives, drawing on two studies identified in a scoping search (Hall, 2011, Thornhill et al., 2004), as 'first-person lived experience accounts of recovery from mental health problems, which refer to events or actions over a period of time, and which include elements of both adversity/struggle and of self-defined strengths/successes/survival'.

Inclusion criteria were:

- Presents or substantially advances an original framework of characteristics of mental health recovery narratives (including recovery from trauma and from childhood maltreatment)
- Based on empirical data.

Exclusion criteria were:

- Presents themes arising from narrative data without discussion of the characteristics of narratives themselves
- Not primarily or partially about mental health, for example recovery from chronic pain, physical illness or drug/alcohol addiction
- Based on third-person accounts, for example stories told by family, friends, carers, professionals

- Full text not available in English.

#### **4.2.2 Search strategy**

I undertook a scoping search and found 12 publications. These informed a preliminary definition of mental health recovery narratives and my search strategy. They also confirmed that no systematic review had been carried out in this area and that undertaking one was feasible (i.e. such studies existed). I then selected six search strategies to identify relevant publications through (i) electronic databases; (ii) hand-searching of journal tables of contents; (iii) grey literature searches; (iv) web-based searches; (v) expert consultation and (vi) citation tracking.

I developed and piloted the electronic database search strategy in consultation with two research librarians with expertise in systematic reviews. Databases were selected by: conducting preliminary searches to gauge the relevance of results and the degree of overlap with other databases; including those indexing the journals of key publications found in the scoping search; and by expert consultation. Due to the cross-disciplinary nature of narrative research, databases from health sciences, social sciences, computer science and the arts and humanities were searched.

I searched fourteen bibliographic databases from inception to 27<sup>th</sup> July 2018: Applied and Complementary Medicine Database (AMED); Applied Social Science Index and Abstracts (ASSIA); Association for Computing Machinery Digital Library (ACM); Cumulative Index of Nursing and Applied Health Literature (CINAHL); EMBASE; JSTOR; Linguistics and Language Behavior Abstracts (LLBA); Modern Languages Association International Bibliography (MLA) and Published International Literature on Traumatic Stress (PILOTS) Database; MEDLINE; PsycINFO; Scopus; Arts and Humanities Citation Index and Social Science Citation Index.

I trialled a combination of subject heading and keyword searches to ensure sufficient specificity was maintained while maximising sensitivity of the search. MEDLINE was selected as the pilot database, as one of two databases which abstract the largest number of healthcare journals globally (Popay et al., 2006). The MEDLINE search strategy is presented in [Appendix 1](#). Keyword and subject heading searches were subsequently tailored to each database.

Tables of contents of five journals were hand-searched from 1<sup>st</sup> January 2000 - 27<sup>th</sup> July 2018: BMJ Medical Humanities; International Journal of Narrative Therapy and Community Work; Journal of Medical Humanities; Anthropology and Medicine; Qualitative Health Research.

I selected journals through expert consultation and by including those featuring two or more included papers from the original electronic data search. The start date was selected as the year before two prominent early papers on recovery narratives identified in the scoping search were published (Jacobson, 2001, Ridgway, 2001).

I conducted grey literature searches using Ethos, BASE and OpenGrey. I also undertook conference searches using programmes available online from two recovery-oriented conferences: Refocus on Recovery ([www.researchintorecovery.com/RoR-conference-archive](http://www.researchintorecovery.com/RoR-conference-archive)) and ENMESH ([www.enmesh.eu/Enmesh\\_Conferences.html](http://www.enmesh.eu/Enmesh_Conferences.html)).

I conducted web-based searches using Google Scholar, ResearchGate and Academia.edu, and by searching the recovery-oriented websites Scottish Recovery Network (<https://www.scottishrecovery.net>) and Boston University Repository of Recovery Resources (<https://cpr.bu.edu/resources/recovery-repository>). Due to the large number of results found on Google Scholar (n= >644,000) only the first ten pages of results were searched.

I consulted a panel of 12 experts with expertise in mental health, design research, qualitative and narrative research for additional studies which might meet the inclusion criteria.

I conducted backward citation tracking by hand-searching the reference lists of all included papers. Forward citation tracking of papers citing included studies was conducted using Scopus and Google Scholar.

#### **4.2.3 Screening and eligibility assessment**

I uploaded papers identified by the search to Endnote, and removed duplicates. I screened titles for relevance against the inclusion criteria, with a randomly-selected sample of 10% double-screened for inclusion by a second researcher to establish a pre-defined adequate concordance of 90% or above.

I subsequently screened all potentially relevant abstracts. A sample of 20% of these abstracts was double-screened for inclusion by a second researcher. I obtained the full

text for potentially relevant papers and screened them for eligibility, with reasons for those excluded at full text retrieval stage documented in a PRISMA flow diagram (Figure 2, below).

#### **4.2.4 Data extraction and quality assessment**

I designed a data abstraction table, available at [10.1371/journal.pone.0214678.s002](https://doi.org/10.1371/journal.pone.0214678.s002). The data extracted comprised: title, authorship list; publication source (e.g. academic journal; doctoral thesis); location of research team; location of participants; academic discipline of lead author; methods of data collection used; analytical approach; source of narratives (already published or researcher-generated); format of original narrative; level of narrator involvement in analysis; number of stories; demographic information about participants; mental health condition; how narratives were collectively named (e.g. narratives of healing, stories of recovery); how narratives were defined; the narrative characteristics discussed; types identified; and definitions of types.

There is little consensus regarding the most appropriate way of evaluating evidence from qualitative research within systematic reviews (Butler et al., 2016). However, in accordance with recommendations for qualitative approaches to systematic reviews (Petticrew et al., 2013) I included a structured critical appraisal stage. My aim for the appraisal was not to exclude papers based on quality, but to inform a subgroup analysis of those assessed as of moderate or high quality, to investigate any potential differences in findings or emphasis. I assessed all studies published in academic journals for quality with another researcher. Qualitative studies were assessed using the Critical Appraisal Skills Programme qualitative checklist (CASP 2017), using thresholds modified from Butler and colleagues (Butler et al., 2016). I used the Mixed Methods Appraisal Tool (Pluye et al., 2011) to assess mixed methods studies. Other forms of publication (doctoral theses, government reports and books or book chapters) were excluded from the quality assessment.

#### **4.2.5 Data analysis**

I used a three-stage narrative synthesis approach to analysis, modified from guidance for the conduct of narrative syntheses within systematic reviews (Popay et al., 2006). The principles I followed in the development of the synthesis were:



- (i) to preserve study authors' terminology in naming dimensions and types of narrative as much as possible, while maintaining clarity and avoiding potentially non-inclusive language. Authors' original terms are preserved in the tables presenting sources of information for the synthesis (Tables 2-10)
- (ii) to avoid over-combining, so as not to risk collapsing discrete concepts which might remain useful separately.

I developed a preliminary synthesis of studies using qualitative or mixed methods. Data were tabulated and analysed thematically to identify potential conceptual overlaps and/or similarities of language used to describe differing phenomena. The resulting dimensions fitted a framework commonly used in narrative and literary theory which considers narratives at three levels of form, structure and content (see, for example, Bal (2009)). These levels were adopted as superordinate categories.

Quantitative data, such as length of narratives or linguistic categories within narratives, did not form part of the narrative synthesis and are presented in summary form in Appendix 2.

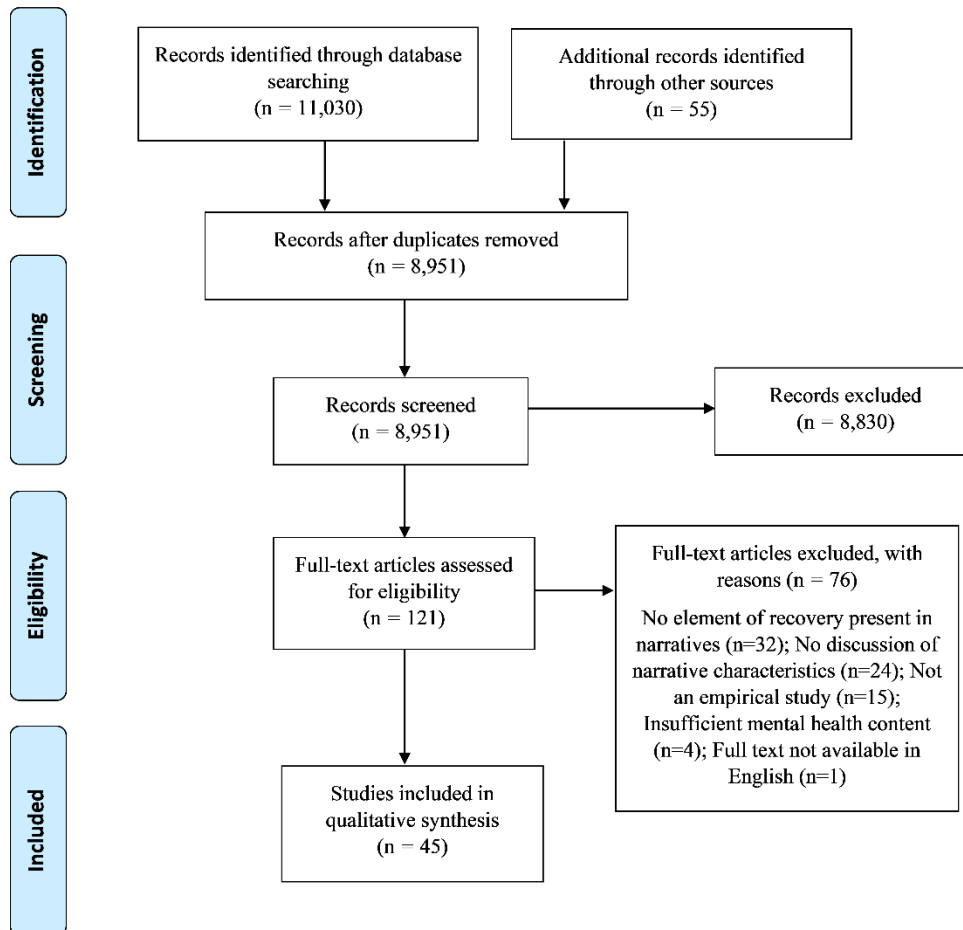
I examined relationships within and across studies, and identified subgroups of interest. Publications within these subgroups were thematically analysed separately. Potential themes were compared with the preliminary synthesis in order to identify areas of differing emphases and to assess robustness.

I assessed the robustness of the preliminary synthesis using the following methods: subgroup analysis of studies rated as moderate and high quality; subgroup analysis of studies where narrator(s) were involved in the analysis process (ranging from respondent validation or 'member checking' to co-authorship of the study); consultation with the NEON study Lived Experience Advisory Panel (LEAP), including people who have published their own mental health recovery stories; consultation with an academic panel; and ongoing discussion and critical reflection by the research team. I modified the synthesis in response to findings; for example the academic panel consultation strengthened the internal coherence of the synthesis, and the LEAP consultation resulted in clearer language being used in the presentation of the synthesis and the definitions of dimensions and types.

## 4.3 Findings

Forty-five publications were included in the review. Characteristics of included publications are available from [doi.org/10.1371/journal.pone.0214678.s002](https://doi.org/10.1371/journal.pone.0214678.s002) and a PRISMA flow diagram of the process is presented as Figure 3 below:

Figure 3: PRISMA flow diagram depicting the process of identifying relevant papers for the systematic review



### 4.3.1 Included publications

The 45 publications comprise qualitative (n=41) and mixed methods studies (n=4). Studies were conducted by research teams based in 11 countries: the UK (n=16), the USA (n=16), New Zealand (n=3), Australia (n=2), Canada (n=2), one each from Chile, Germany, Greece and Israel, and two from multinational teams (Australia/Netherlands/India/USA and Australia, New Zealand and the UK). Publication was between 1997 and 2018. Fifteen of the 45 were published between 2006 and 2008.

Thirty-one publications explicitly use the term 'recovery narrative' or close variants to describe their source data. Variants include 'stories of healing', 'redemption narratives'

and 'narrative re-storying'. This group includes a paper which contains, to my current knowledge, the earliest naming of 'recovery narratives' as a phenomenon distinct from 'illness narratives' within the research literature (Garrett, 1997). Fourteen publications do not use 'recovery' or similar terminology to describe their source narratives; however, it was clear from either the methodology or results sections that elements of strengths, successes or survival were present within the narratives. Five of these 14 papers describe source data neutrally (for example personal narratives, life history narratives, user narratives or biographical narratives); three name them as narratives both of illness/trauma and recovery; three are named by the central activity under investigation (sport, football and activism narratives) and three name them solely as illness narratives or close variants ('emotional distress' narratives and 'anorexic experience' narratives).

#### **4.3.2 Quality assessment scores**

I assessed the 29 studies published in academic journals for quality. Of the 25 qualitative studies, two (8%) were evaluated as high-quality, 10 (40%) as moderate-quality and 13 (52%) as low-quality. Of the four mixed-methods studies, two (50%) were evaluated as high quality, one (25%) as moderate and one (25%) as low quality. Sixteen studies were excluded from quality assessment, comprising doctoral theses (n=11), reports (n=3) and books or book chapters (n=2).

#### **4.3.3 Participants**

The 45 included publications analysed 629 first-person lived experience accounts. Narrators' gender was 59% (n=370) female, 34% (n=215) male and 7% (n=44) not stated. Ages ranged from 8 to 79 years old, with 43 (96%) of publications only including adult (18 years or older) narrators. 40% of narrators were identified as white and 17% as from Black, Asian or minority ethnicities, while the ethnic identity of 43% of narrators could not be identified, as 26 publications (58%) did not provide breakdowns of ethnicity. Narrators had experience of conditions or circumstances from across the spectrum of mental ill health. Those named (either by the research team or self-identified by narrators) were: anorexia, anxiety, bipolar disorder, borderline personality disorder, bulimia, childhood maltreatment, co-existing mental health and substance use issues, depression, dissociative identity disorder, eating disorders, mania,

manic depression, nervous breakdown, personality disorders, psychosis, PTSD, schizophrenia, social anxiety, survival of sexual abuse and voice-hearing.

#### **4.3.4 Narrative synthesis: nine dimensions of recovery narratives**

I derived nine dimensions from thematic analysis of included publications, with each dimension containing a number of types. Types are not presented as discrete; some included authors state that more than one may be present within a narrative. The final synthesis is presented as Table 1:

Table 1: Preliminary conceptual framework: characteristics of mental health recovery narratives

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

## Superordinate category: Narrative form

I identified four dimensions related to narrative form: Genre, Positioning, Tone and Relationship with Recovery. The central question common to all four dimensions is 'what kind of story is this?'

### 4.3.4.1 Dimension 1: Genre

Twelve publications identified different genres of mental health recovery narrative, also using the following synonyms for genre: narrative type, form, plot and theme. I synthesised four types from 20 genres, using terms adapted from a study by Hermione Thornhill and colleagues (2004). These are shown in Table 2:

Table 2: 'Genre' types synthesised from included publications (n=12)

REFERENCE:	GENRE TYPES:			
	Escape	Endurance	Endeavour	Enlightenment
Anderson (2010)	Escape	-	Endurance/ acceptance	Exploration/ discovery
Bluffield (2006)	Survival	Salvage	-	Growth
de Jager et al. (2016)	-	Turning away/ protective hibernation	-	Turning towards/ empowerment
Garrett (1997)	-	-	-	Spiritual quest
Manley (2015)	-	-	-	Quest
McCarthy (2014)	-	-	-	-
Phare (2003)	-	-	-	-
Moulding (2016)	-	-	-	Humanistic quest
O'Brien (2014)	-	-	Normalising	Conversion/ growth
Sullivan et al. (2017)	-	Recovery in the midst of chaos	Recovery as restitution	Recovery as quest
Thomas & Hall (2008)	-	-	-	Redemption
Thornhill et al. (2004)	Escape	Endurance	-	Enlightenment

All 12 publications sought to identify genres in order to examine the constructions of meaning by narrators. Nine publications (75%) cited Frank's (1995/2013) genres of restitution, chaos and quest illness narratives, discussed in [Chapter 3](#), as either

influential in identifying further recovery narrative types, or as directly applicable to their own research data.

The 'Escape' type comprises narratives of escape from and resistance to abuse, threat, stigma and persecution. Images of entrapment and/or of a fight for survival may be used (Thornhill et al., 2004). Escape can be from oppressive beliefs, systems, services or treatments. It may also refer to the narrator's escape from a negative internalised identity, as a result of maltreatment or stigma (Bluffield, 2006).

The 'Endurance' type comprises narratives of loss, trauma, difficult circumstances and/or seemingly insurmountable odds. They may employ images of weathering storms or battening down the hatches to conserve energy (de Jager et al., 2016). They may contain haunting or chaotic elements, or describe being in the midst of traumatic events (O'Brien, 2014). Success may be expressed in terms of having survived, or kept going – the narrator's priority may be salvaging, over restoring or transforming, themselves (Bluffield, 2006).

The 'Endeavour' type comprises narratives incorporating positive aspects, coping strategies and/or plans, and an acceptance of difficulties as an ongoing factor of recovery. Narrators may feel they are active agents of change (Anderson, 2010), or they may focus on doing things or keeping busy (O'Brien, 2014). Their priority may be managing or restoring order, rather than transforming themselves (Sullivan et al., 2017).

The 'Enlightenment' type comprises narratives of transformation. The narrator views the experience of illness/trauma ultimately as positive, as new perspectives have been gained from it. They may describe recovery as a journey of exploration or discovery (Anderson, 2010), leading to empowerment and/or self-actualisation (de Jager et al., 2016). The narratives may contain aspects of redemption (Thomas & Hall, 2008); of having been saved by something greater than themselves, either by spiritual (Garrett, 1997) or humanistic (Moulding, 2016) means.

#### **4.3.4.2 Dimension 2: Positioning in relation to clinical model**

Eleven publications identified ways mental health recovery narratives can be positioned in relation to mental healthcare systems. The following synonyms for positioning were also used: major theme/plot, typologies of narratives genre, and narrative types. Unlike

those in Genre, these publications specifically foreground social and political considerations of the mental health system in their identification of narrative types. The ‘mental health system’ is defined for the purposes of this thesis as being the dominant clinical mental health provision of the country involved. I synthesised three types from 13 positions, using terms I identified. These are shown in Table 3:

Table 3: ‘Positioning’ types synthesised from included publications (n=11)

REFERENCE:	POSITIONING TYPES:		
	Recovery within the system	Recovery despite the system	Recovery outside of the system
Adame (2006) Adame & Knudson (2007) Adame & Knudson (2008) McCarthy (2014)	Traditional narratives	Counter-narratives	Alternative or “good-life” narratives
Adame & Hornstein (2006)	Psychiatric empowerment narratives	Psychiatric oppression narratives	Healing narratives
Brawn et al. (2015)	-	-	Adventure stories
Buhagiar (2013)	-	-	Narratives of activism
Carless & Douglas (2008)	-	-	Action/achievement /relationship narratives
Carless (2008)	Restitution narratives	Counter-narratives	-
Grant et al. (2015)	-	Transgressive/resistance narratives	-
Matusek & Knudson (2009)	-	Divergent stories	-

‘Recovery within the system’ comprises narratives incorporating positive experiences of clinical mental health services. Diagnosis may be experienced as empowering, and treatment, services and/or relationships with practitioners as enabling, positive or a salvation.

‘Recovery despite the system’ comprises narratives of protest, in opposition to the clinical model of mental illness and/or mental health services and systems. These



narratives may incorporate experiences of maltreatment by mental health services. They may seek to recover the narrator’s own voice, sense of agency and purpose (Adame & Knudson, 2007), and may also seek to raise social awareness and challenge psychiatric authority (Adame & Hornstein, 2006).

‘Recovery outside of the system’ comprises narratives in which clinical mental health services do not feature, or feature only minimally. These narratives may not engage with psychiatric definitions or psychological concepts of personal growth; presenting experiences of living a “good life” beyond a focus on individual factors (Adame & Knudson, 2008). They may incorporate social, political, spiritual, and economic factors, often with a focus on specific areas, such as activism (Buhagiar, 2013), adventure (Brawn et al., 2015) or relationships (Carless & Douglas, 2008). They may contain elements of having a greater purpose – “helping others in the same boat” – and/or a changed understanding of what is most important in life (Adame & Hornstein, 2006).

#### 4.3.4.3 Dimension 3: Emotional Tone

Three publications identified different emotional tones present within mental health recovery narratives, with one using the term “self-positions” instead of tone (Grinter, 2012). I synthesised six types from 22 tones, using terms I identified. These are shown in Table 4:

Table 4: ‘Emotional Tone’ types synthesised from included publications (n=3)

REFERENCE:	EMOTIONAL TONE TYPES:					
	Critical	Disenfranchised	Reflective	Buoyant	Shaken	Tragic
<b>Grinter (2012)</b>	Defiant	Subordinate	Reflective-conciliatory	-	-	-
<b>Manley (2015)</b>	Challenging, critical, sarcastic, argumentative	Passive, anxious	Grateful	Confident, hopeful	-	Tragic
<b>Thornhill et al. (2004)</b>	Angry, protesting, educating	Resigned, disenfranchised, monotone	Educating, thoughtful	-	Disbelieving, shocked	-

#### 4.3.4.4 Dimension 4: Relationship with Recovery

Nine publications identified different ways of relating to the concept of recovery within mental health recovery narratives. The following synonyms were also used: recovery talk, narrative positions or types, framings of recovery, narrative motifs, core narratives and narrative genres. I synthesised four types from the 15 presented, using terms adapted from Heather Barnett and Hilary Lapsley's typology (2006). These are shown in Table 5:

Table 5: 'Relationship with Recovery' types synthesised from included publications (n=9)

REFERENCE:	RELATIONSHIP WITH RECOVERY TYPES:			
	Recovered	Living well	Making progress	Surviving day to day
<b>Barnett &amp; Lapsley (2006)</b>	-	Living well	Moving forward	Surviving day to day
<b>Beiza et al. (2015)</b>	-	Healing	Incipient healing	-
<b>Cohen (2008)</b>	Well	-	-	Getting by
<b>Eli (2016)</b>	Resolute narratives	Reconciliation narratives	-	-
<b>Hall (2011)</b>	-	Struggling successfully	-	Struggling daily
<b>LaMarre (2014)</b>	-	Ongoing recovery	-	-
<b>Ridgway (2001)</b>	-	Ongoing journey	-	-
<b>Shohet (2018) Shohet (2007)</b>	Full recovery	-	-	Struggling recovery

The 'Recovered' type comprises narratives presenting recovery as an outcome which has been achieved. Narrators see the illness or distress as being in the past. There may be a clear split between past and present selves (Shohet, 2018).

The 'Living well' type comprises narratives presenting recovery as a process within which the narrator is well-established. Narrators are living well in the presence or absence of mental illness or distress (Barnett & Lapsley, 2006) and see any continuing difficulties as things which they can overcome (Beiza et al., 2015).

The 'Making progress' type comprises narratives presenting recovery as a process in which they are seeing some progress. Narrators present confidence in their ability to

cope despite feeling relatively close to the disruptions of mental distress or trauma (Barnett & Lapsley, 2006).

The 'Surviving day to day' type comprises narratives presenting recovery as a journey on which the narrator is tentatively engaging. The narrator may be in a new, difficult or dangerous situation (Hall, 2011) where it may be difficult to realise their hopes but they still express their experiences in a recovery context (Cohen, 2008).

### **Superordinate category: Narrative structure**

I identified three dimensions related to narrative structure: Narrative Trajectory, Turning Points and Narrative Sequence. The central question common to all three is 'what shape does this story take?'

#### **4.3.4.5 Dimension 5: Trajectory**

Seven publications identified different trajectories present within mental health recovery narratives, also using the following descriptions: types of emotional distress, narrative shapes, plots and structures. These may describe the shape of whole narratives or of sequences within narratives. I synthesised four types from the 14 presented, shown in Table 6:

Table 6: 'Narrative Trajectory' types synthesised from included publications (n=7)

REFERENCE:	TRAJECTORY TYPES:			
	Upward spiral	Up and down	Horizontal	Interrupted
<b>Adame &amp; Hornstein (2006)</b>	<b>Revelation/ purposeful suffering</b>	-	<b>Continuity</b>	<b>Traumatic interruption</b>
<b>Anderson &amp; Hiersteiner (2007)</b>	<b>Spiralling towards health</b>	<b>Progressive and regressive courses of action</b>	-	-
<b>Brown &amp; Kandirikirira (2007)</b>	-	<b>Progression with downs as well as ups</b>	-	-
<b>Howard (2006)</b>	<b>Expecting</b>	-	<b>Accepting</b>	-
<b>Phare (2003)</b>	<b>Quest/progressive narratives</b>	-	<b>Restitution /stability narratives</b>	-
<b>Thomas &amp; Hall (2008)</b>	<b>Steady upward progression</b>	<b>Roller-coaster</b>	<b>Struggling/ stagnating</b>	-
<b>Vander Kooij (2009)</b>	-	<b>Journey which may move towards health or towards illness</b>	-	-

The 'Upward spiral' type comprises narratives describing a journey with an overall ascending progression toward recovery. They may be described as narratives of revelation or purposeful suffering (Adame & Hornstein, 2006), or evolution from darkness to light towards a better future (Anderson & Hiersteiner, 2007), or of overall improvement. Setbacks might occur, but they are defined as solvable problems (Thomas & Hall, 2008).

The 'Up and down' type comprises narratives describing a non-linear journey which challenges the progressive trajectory of spiralling ever forward towards health (Anderson & Hiersteiner, 2007). They contain continuing upturns towards health/wellbeing and downturns towards illness/struggle, which may be experienced as dramatic, "roller-coaster" narratives (Thomas & Hall, 2008) or narratives with "downs as well as ups" (Brown & Kandirikirira, 2007).

The 'Horizontal' type comprises narratives without significant upturns or downturns. The narrator may feel that they are stagnating (Thomas & Hall, 2008), or taking one day at a time (Phare, 2003).

The 'Interrupted' type comprises narratives describing a journey interrupted by an unexpected crisis or difficulty, after which the narrator's life has returned to its prior state (Adame & Hornstein, 2006).

#### 4.3.4.6 Dimension 6: Turning Points

Eleven publications identified turning points as being a characteristic of mental health recovery narratives, but defined 'turning points' in three different ways. I synthesised three types, shown in Table 7:

Table 7: 'Turning Point' types synthesised from included publications (n=11)

REFERENCE:	TURNING POINT TYPES:		
	Re-storying	Change for better	Change for better or worse
<b>Anderson &amp; Hiersteiner (2007)</b>	Narrators resist dominant narrative and take ownership of own stories	-	-
<b>Banyard &amp; Williams (2007)</b>	-	Large shifts/changes leading to improvement	-
<b>Beiza et al. (2015)</b>	-	-	Critical life events, positive/negative, leading to changes in lifespan.
<b>Bluffield (2006)</b>	-	-	Significant transitions or disruptions to a trajectory or turns in narrative accounts
<b>(Brown &amp; Kandirikirira, 2007)</b>	-	Point at which the opportunity to begin a recovery journey can present itself	-
<b>Hall (2011)</b>	-	-	A point in the narrative trajectory, after

			which immediately subsequent events may be negative or positive
<b>Harvey (2000)</b>	Points which open possibilities to re-story experiences/ arrive at new understandings	-	-
<b>Lapsley et al. (2002)</b>	-	Dramatic moments (leading to positive change)	-
<b>Moulding (2016)</b>	-	The point of realising others couldn't help, or the catalyst for [positive] change	-
<b>O'Brien (2014)</b>	Transition points from dominant/stigmatising narrative to personal/ positive stories	-	-
<b>Thomas &amp; Hall (2008)</b>	-	-	Points in the narrative followed by "redemption sequences" or "contamination sequences"

The 'Re-storying' type comprises narratives where turning points are considered as moments in which a narrator gains a new understanding of their experiences (Harvey, 2000). It may be the point at which a narrator resists being defined by a dominant discourse and takes over authorship of their own story (Anderson & Hiersteiner, 2007), or the transition point from a stigmatising narrative to a positive one (O'Brien, 2014).

The 'Change for the better' type comprises narratives wherein turning points are considered as moments of transition, followed by sequences leading to improvement (Banyard & Williams, 2007) or positive change (Lapsley et al., 2002). They may be positive events, such as a moment of self-acceptance or intervention from others (Brown & Kandirikirira, 2007), or difficult moments which prove to be catalysts for positive change, such as realising others couldn't help them (Moulding, 2016).

The 'Change for the better or worse' type comprises narratives within which turning points are considered as critical life events (Beiza et al., 2015) or significant transitions or disruptions in the narrative (Bluffield, 2006), followed by "redemption" or "contamination" sequences (Thomas & Hall, 2008) where events may be negative or positive (Hall, 2011).

#### **4.3.4.7 Dimension 7: Narrative sequence**

Eight publications identified different sequences within mental health recovery narratives, also using the following terms: stages, narrative shape, typologies and structure. I synthesised eight types from 37 sequences, shown in Table 8:

Table 8: 'Narrative Sequence' types synthesised from included publications (n=8)

REFERENCES:	NARRATIVE SEQUENCE TYPES:								
	Life before distress/trauma	Problems begin	Problems worsen	Impact of distress/trauma	Glimpses of recovery	Turning point	Roads to recovery	Life afterwards	
<b>Barnett &amp; Lapsley (2006)</b>	Life before the mental health crisis	Going downhill and seeking help	The mental health crisis	-	-	Contact with mental health services	Recovery	Reflections	
<b>Brawn et al. (2015)</b>	Sporting histories	Problem stories	-	-	-	Getting involved in sport	Personal benefits, community and connection	Staying involved	
<b>Brown &amp; Kandirikirira (2007)</b>	Life before illness	-	Life during illness	-	Glimpses of recovery	Critical incident leading to change in perception/realisation recovery is possible	Recovery	Hope for a better future	
<b>Garrett (1997)</b>	-	Non-recovery	-	-	-	-	Recovering period	Recovered with ongoing transformation	
<b>Grant et al. (2015)</b>	-	Narrative disruption				Narrative repair		Narrative re-storying	-
<b>Lapsley et al. (2002)</b>	Origins	Onset	Experience of mental illness	Consequences of illness	Glimpses of recovery	Turning point	The road to recovery	Life afterwards	



<b>Nurser et al. (2018)</b>	-	-	-	-	-	Expression of (potentially) previously hidden suffering	Logical organising of experience allowing for new perspective	Inclusion of hopeful and/or triumphant elements in order to inspire others
<b>Stott &amp; Priest (2018)</b>	-	Traumatic past	-	-	-	An episode of change	Ongoing recovery phase	-

## Superordinate category: Narrative content

I identified two dimensions related to narrative content: Protagonists and Use of Metaphor. The central question common to them both is ‘what resources have been deployed in the telling of this story?’

### 4.3.4.8 Dimension 8: Protagonists/antagonists

Four publications identified different protagonists and antagonists within mental health recovery narratives, also using the following synonyms: narrators, biographical types, archetypal protagonists, major players and heroes/supporting cast. I synthesised three types from the 15 presented, shown in Table 9:

Table 9: ‘Protagonist/Antagonist’ types synthesised from included publications (n=4)

REFERENCE:	PROTAGONIST/ANTAGONIST TYPES:		
	Personal level	Socio-cultural level	Systemic level
<b>Anderson (2010)</b>	The strong conqueror The scarred survivor The enlightened explorer	-	-
<b>Elran-Barak (2012)</b>	The self/narrator The bulimia/illness		The environment/outer worlds
<b>Georgaca &amp; Zissi (2017)</b>	Users/consumer Survivors	-	-
<b>Phare (2003)</b>	The hero The illness Medication	Mental health workers/agencies Family Friends	Wider community

‘Personal factors’ are the micro-level or inter/intra-personal factors within a mental health recovery narrative. Most commonly the narrator him or herself, who may be characterised (Anderson, 2010) or positioned (Georgaca & Zissi, 2017) in various ways, these may also be helping or hindering persons or factors such as medication, form of treatment or mental health professional (Phare, 2003). The illness or traumatic situation itself may function as an intra-personal protagonist in terms of being a driving force within the narrative (Elran-Barak, 2012).

‘Socio-cultural factors’ are the meso-level factors within a recovery narrative, including family and friendship dynamics, groups or local organisations, mental health staff and

services. These may be “supporters or villains”, exerting positive or negative effects on the narrative (Phare, 2003).

‘Systemic factors’ are macro-level factors within a recovery narrative, named in included publications as the wider community (Phare, 2003) and the environment or outer worlds (Elran-Barak, 2012), but also potentially including legal, healthcare, policy, political and international factors, which affect the narrative either positively or negatively.

#### 4.3.4.9 Dimension 9: Use of Metaphor

Three publications focused on the use of metaphor within mental health recovery narrative. I synthesised two types from the six presented. These are shown in Table 10:

*Table 10: ‘Metaphor’ types synthesised from included publications (n=3)*

REFERENCE:	METAPHOR TYPES:	
	Distress metaphors	Recovery metaphors
Cohen (2008)	Ill metaphors	Healthy metaphors
Stott & Priest (2018)	Illness metaphors	Recovery metaphors
Thompson (2003)	Distress metaphors	Recovery metaphors

‘Distress metaphors’ may depict a deep descent of the self, a “spiralling out of control” (Cohen, 2008). They may convey a sense of disconnection and alienation, or of chaos, lack of control, loneliness or suffering (Elran-Barak, 2012). They may be focused on past or current distress or an imagined future return to the experience of distress (Thompson, 2003).

‘Recovery metaphors’ may depict health as the main road to which one must return (Cohen, 2008). They may convey a sense of connection, bonding and integration, a regaining of control of life, partnership with others, or victory in the fight against illness (Elran-Barak, 2012). They may be focused on past, present or hoped-for future experiences of recovery (Thompson, 2003).

#### 4.3.5 Subgroup analyses

I undertook four subgroup analyses of papers published in academic journals: those assessed as moderate and high-quality; with narrator involvement at analytical level; focusing on psychosis; and focusing on trauma.

In the analysis of moderate and high-quality papers (n=15, 52%) I found that the following items from the conceptual framework were not present: two dimensions (Protagonists and Use of Metaphor); one type of Genre ('Endeavour'); two types of Emotional Tone ('Buoyant' and 'Tragic'), and one type within Relationship with Recovery ('Recovered'). Within the Narrative Sequence dimension three types were found ('Experience of mental distress/trauma', 'Turning point' and 'Experience of recovery').

My analysis of papers with narrator involvement at analysis stage (n=11, 24%) found that eight of the nine dimensions and all corresponding types were present. The Emotional Tone dimension and its types were not found in these papers. Within the Narrative Sequence dimension I found eight more detailed types: 'Life before distress/trauma'; 'Problems begin'; 'Problems worsen'; 'Impact of distress/trauma'; 'Glimpses of recovery'; 'Turning point'; 'Roads to recovery'; and 'Life afterwards'.

My analysis of papers focusing exclusively on narratives of psychosis (n=12) found no significant differences of emphases when compared with papers focusing on other diagnoses or experiences.

All papers focusing on trauma (n=6) focused on dimensions relating to the superordinate category of narrative structure, namely Trajectory, Turning Points and Narrative Sequence. All six discussed Turning Points. One also included discussion of Genre (Thornhill et al., 2004).

#### **4.4 Discussion**

My systematic review identifies the existence of a sizeable body of qualitative and mixed-methods literature describing multidimensional ways in which mental health recovery narratives have been characterised. Forty-five publications were identified by the review search. The literature was multidisciplinary and published in a wide range of journals, spanning 21 years of research. The 45 papers represent analysis of 629 first-person lived experience accounts of mental distress and recovery, from narrators representing many demographics. A key contribution of this review is to collate these disparate narratives.

The narrative synthesis then moves beyond this work by providing what is arguably a more comprehensive framework for characterising narratives than any single study can

offer. Through my synthesis I found that mental health recovery narratives can be characterised under at least three superordinate categories: narrative form, structure and content, and at least nine dimensions: Genre, Positioning, Emotional Tone, Relationship with Recovery, Trajectory, Turning Points, Narrative Sequence, Protagonists and Use of Metaphor, each with numerous types. The review and subsequent conceptual framework thus speak to the following issues raised in [Chapter 2](#) and [Chapter 3](#):

#### **4.4.1 Characteristics of recovery narratives are presented as highly diverse, with fluid meaning-making processes**

A key finding of this review is that none of the included publications claim a 'right way' to characterise mental health recovery narratives or to narrate recovery. Recovery narratives in the published literature reflect distinctly varied ways in which people both recover and narrate their recovery from mental distress and/or trauma. Care is taken by authors of some included publications to stipulate that narrators speak from a wide range of circumstances, and that no type of recovery narrative should be pathologised or, by implication, valorised, in relation to others (de Jager et al., 2016). Participants in the included studies do not present single or static types of narratives. As with 'small stories' or exchanges in everyday life (Bamberg & Georgakopoulou, 2008), narrators of recovery stories work with interpretive repertoires (Toth, 2014) which can be revised (Ibarra & Barbulescu, 2010), allowing narrators to manage their positions to suit different purposes, audiences and contexts. Narratives may change over time, as for example in Howard's (2006) study of exiting recovery identities.

#### **4.4.2 Structural issues are characterised, but individual factors are emphasised**

Four included papers of the 45 characterised narratives by types of protagonist/antagonist, or helping and hindering persons and factors. These were described chiefly at the level of individual agency (the 'strong conqueror'; the 'self' versus the 'illness'; 'survivors' and 'medication'). Just one paper (Phare, 2003) characterised protagonists/antagonists at socio-cultural level (mental health workers, family and friends), and only two characterise what could be described as systemic-level factors: 'community' (Phare, 2003) and 'the environment/outer worlds' (Elran-Barak, 2012). This can be seen to support critiques that research focuses mainly on individual-level factors in mental health recovery, and concerns raised by Fisher and

Lees (2016), among others, that the multiple processes of recovery should not be reduced or erased by emphasis within narratives of individual progress towards economic independence. There was also little discussion within analysis of how multiple forms of structural oppression can intersect and be mutually reinforcing or produce different outcomes for members of marginalised communities. Implications for future research include taking a narrative approach more informed by intersectionality theory (Crenshaw, 2017), as recent narrative analyses within systematic reviews have chosen to do (Ross et al., 2018).

#### **4.4.3 Recovery narratives incorporate social, political and human rights factors**

Conversely, recovery narratives have been characterised by genre, as have illness narratives, and add a new type, first identified by Thornhill and colleagues (2004): narratives of “Escape”. The presence of these narratives, characterised by escape from services or from treatments experienced as damaging, highlights the political factors involved in mental health recovery. They support human rights-based approaches to mental health recovery (Grover, 2010), and approaches which de-emphasise individual recovery factors in favour of the role of transformation of systems and services (Forrest, 2014).

Recovery narratives have additionally been characterised by consideration of narrative positioning in relation to a clinical model of mental health. Positioning relates to the “social and emotional stances that individuals take vis á vis real or imagined others” (Thorne & McLean, 2003: 171). The ‘Recovery despite the system’ and ‘recovery outside of the system’ types of narrative foreground the importance of inter-personal and social factors within recovery, such as positive relationships and participation in sports or arts activities.

#### **4.4.4 Recovery happens both outside of and within mental health services**

Frank’s (1995/2013) ‘restitution’ type of illness narrative foregrounds the dominant clinical model of illness. Similarly, the review includes papers identifying narratives of ‘recovery within the system’, wherein narrators have experienced treatment, medication and/or relationships with mental health staff as positive factors in their recovery. Papers also identify narratives which challenge the clinical model, providing evidence and mirroring other research that recovery can and does happen without the

intervention of services (see, for example, Slade & Longden, 2015). Narratives of 'Recovery despite the system' emerged from survivor/ service user movements, and directly oppose dominant clinical discourses. Narratives of 'Recovery outside of the system' disengage altogether from services and treatment.

Narratives opposing or outside of the mental health system have played a crucial role in survivor/service user activism as we have seen. Given this, there is a risk that, in survivor-led contexts, narratives endorsing mental health treatments or services may be dismissed in their turn as conforming to the dominant clinical model, rather than expressing authentic experience – the narrator perhaps performing the role of the 'good patient'. The potential for narrative conformity within particular contexts has been researched, including Frank's exploration of Alcoholics Anonymous groups (Frank, 2010b). It has been commented on by those critiquing uses of recovery narratives in services, who nonetheless note that survivor and activist movements have their own dominant narratives, such as those of rejecting medication or of spiritual experiences, which may also function to suppress other kinds of experience (De Wolfe & The Borderline Academic, 2019). Dismissing any particular type of narrative risks creating new "dominant recovery narratives" (Nurser et al., 2018: 26) in their turn, in what Plummer (2020 p.64) refers to as a "continuing paradox of othering", and dismissing the equally valid experiences of those for whom interaction with the mental health system has been positive – although it is also important not to lose sight of the fact that the health service and mental health systems wield much more systemic power to define experiences than survivor and service-user groups.

#### **4.4.5 Recovery narratives challenge the centrality of coherence**

Frank (1995/2013) defines his chaos narratives as lacking narrative order, with a central plot that life can never get better. This type can be seen to mirror the 'stories as assessment' approach to narrative research discussed in section 3.1, which finds the narratives of people experiencing particular forms of distress, for example psychosis, as inherently lacking insight or coherence. The review challenges this finding in several ways.

First, the review includes narratives (synthesised as 'Endurance' narratives) which present recovery as being possible in the midst of considerable chaos – see for example Sullivan et al. (2017). Chaotic narratives may still be recovery narratives.

Second, subgroup analysis of studies focusing on narratives of psychosis found no difference in characteristics or emphasis when compared with narratives of other forms of mental distress. It is noteworthy that people experiencing psychosis narrate recovery with the same characteristic features and multi-dimensional meanings as other narratives. This finding challenges the stereotype of people experiencing psychosis as being incompetent or incapable of insight into their experiences.

Additionally, as discussed in section 3.1, the implication that coherence is a prerequisite of meaningful narrative is in itself problematic. Although Frank asserts a moral and clinical imperative to honour chaotic tellings, he still describes chaos as “the pit of narrative wreckage” (Frank, 1995/2013:110). Theorists have been criticised for imposing requirements of coherence on narrative (Baldwin, 2005), and the pre-occupation with linearity is contested by health humanities and other critical scholars (Saavedra et al., 2009). The review supports this criticism. Such requirements of narrative were abandoned by literary theorists, writers and poets in favour of modernist and postmodernist approaches over one hundred years ago. Instead of being anti-narrative, the ‘Endurance’ type redefines recovery narratives to include those with elements of “fragmentation, amorphousness, entropy, chaos, silence, senselessness” (Stone, 2004: 18). This supports the inclusion of narrators who do not story their recoveries as linear, and/or those whose experiences are not easily expressed within the limits of language.

#### **4.4.6 Recovery narratives challenge the concept of linearity**

A core domain of the recovery model is non-linearity (Leamy et al., 2011). This is reflected in the Trajectory dimension of the synthesis, primarily by the ‘Up and down’ type which incorporates examples such as “lengthy, progressive and regressive” narratives, “roller-coaster” narratives, or “progression with downs as well as ups”. Anderson and Hiersteiner (2007) provide an account in their study of recovery from childhood sexual abuse of being explicitly challenged by their participants on their assumption of inviolate progress within a narrative storyline. Even the ‘Upward spiral’ trajectory type reflects this, qualified as being “steady” upward progress with recognition of setbacks (Anderson & Hiersteiner, 2007).

In contrast, the Narrative Sequence dimension comprises what are presented as surprisingly linear progressions through eight sequences, from experiences of



distress/trauma through a turning point to recovery. Following DiClemente and Prochaska's lead with their transtheoretical model of change (1998), it would be possible to adapt presentation of this theme to represent a more non-linear or spiralling progression, with narrators returning to earlier sequences or cycling through them. This adaptation is further validated by the 'Change for the better or worse' type of Turning Point, which does not assume straightforward progression, and links recovery narratives with research on lives in transition such as the "contamination" and "redemption" sequences of McAdams and Bowman (2001). Implications for research include investigating whether a non-linear or spiral model is a better fit for some narrators' experiences of recovery.

## **4.5 Narratives and narrators currently missing from the literature**

An important contribution of the review and narrative synthesis was to highlight the kinds of recovery narratives, narrators or other factors missing from research on recovery narrative characteristics to date, and some significant gaps were noted.

### **4.5.1 Group or collective narratives**

All included studies except one focused on the narratives of individuals. The exception was Kim Anderson and Catherine Hiersteiner's study (Anderson & Hiersteiner, 2007) which used group interviews to construct a group narrative of recovery/survival of childhood sexual abuse. Research could be undertaken on characteristics of collective narratives, which may more accurately represent the significance of socio-economic and systemic factors in mental distress highlighted within survivor activism, Mad Studies (O'Hagan, 2016), and survivor-informed psychological frameworks (Johnstone et al., 2018).

### **4.5.2 Non-text based narratives**

All narratives in their original formats were either written or spoken, and none were generated or accessed by researchers online. Two publications complemented their collection of written/spoken narratives by additionally undertaking art and music-based interventions (O'Brien, 2014, Vander Kooij, 2009). Work has been undertaken to capture non-text based recovery narratives via other media, for example using visual methods such as Photovoice (Barry et al., 2021), and these may have different characteristics. Recovery narratives shared in online contexts are also likely to have

different characteristics. Online stories have been described as ‘shared stories’, characterised by narration shared between multiple tellers; intertextual references which connect shared texts; distributed linearity whereby narrative content is produced and reproduced across multiple units, such as a post and its successive comments; and an assumption of commonly-held beliefs (Page, 2018). Research implications include exploring characteristics of narratives in these formats for similarities and differences.

#### **4.5.3 Narratives of people from Black, Asian or other minoritised ethnicities**

The included studies came from a small range of mainly white-majority countries. Only 17% of participants could be identified as being from Black, Asian and minoritised ethnicities. The recovery approach has been criticised for being based on mono-cultural assumptions, predominantly from the Global North (Price-Robertson et al., 2017), so broader concepts, including more collectivist and interdependent approaches to recovery, need to be incorporated (Tse & Ng, 2014).

#### **4.5.4 Narratives of children and young people**

Most narrators were adults. Two studies included the narratives of children (Alisic et al., 2016) and young people (Beiza et al., 2015), so further research would be needed to explore whether recovery narratives of children and young people had different characteristics.

#### **4.5.5 Narratives of people who do not use mental health services**

Most included studies used convenience samples of participants who were currently using or had previously used mental health services, hence narratives of recovery from those who have not used services are under-represented in existing research.

#### **4.5.6 Narratives of people experiencing economic or educational social exclusion**

Some of the included studies used purposive sampling of recovery narratives described by researchers as ‘exemplary’ (Thornhill et al., 2004) or ‘seminal’ accounts (Ridgway, 2001) that were “exceptional in their richness, coherence and completeness” (Matusek & Knudson, 2009: 699). These foregrounded narrators who possess “the transcultural, intellectual, cultural and symbolic capital to tell their tales with considerable authority” (Grant et al., 2015: 281). Notably, they commonly relate ‘enlightenment’ narratives. This may have been an important choice in the beginning of survivor activism, in terms of

mobilising survivor self-determination (Grant et al., 2015) and challenging dominant discourses. However, it may have led to an under-representation of narratives from those experiencing recovery without access to similar socio-economic, cultural or environmental resources. The resources and social capital available (or not) to a narrator influence the kinds of narratives they may be able to relate. De Jager and colleagues (2016), in their study of narratives of hearing voices, note for example that narrators of their 'empowerment' narratives were all members of Hearing Voices Network groups and also had access to supportive professionals, whereas narrators of 'protective hibernation' narratives did not have access to such resources. Implications for research include a focus on the recovery narratives of those who have not had access to such economic, educational and other resources or support, which may extend the preliminary framework.

#### **4.6 Strengths and limits of the review**

The comprehensive search strategy is one strength of this review, reflecting multidisciplinary interest in narrative approaches. Another is the consideration given to 'participant involvement at analytical level' within the included studies. A subgroup analysis was carried out on studies which incorporated participant validation or co-production at analytical level. This emphasis could be seen as being in line with the principles of agency and 'giving' voice to people from marginalised groups, which are claimed as central to both recovery and narrative research paradigms (Spector-Mersel & Knaifel, 2018). It is noted that just 24% (n=11) of included studies involved participants at analytical level. Further research on recovery narratives could ensure greater co-production of findings at this level, although some established methods of achieving this within qualitative research, such as the principle of 'respondent/participant validation' or 'member checking', is contentious (Motulsky, 2021).

The review is limited by its search for publications available in English only. This led to included publications which in the main reflect criticism that recovery-related research is monocultural (Slade et al., 2014). It is likely to have resulted in a framework which does not reflect the range of ways in which mental distress and recovery are characterised worldwide, as similar work has found (Haroz et al., 2017). Further research could be conducted on characteristics of recovery narratives in other

languages, in order to include broader understandings of cross-cultural or global mental health narratives.

A second limitation is that the involvement of an external Lived Experience Advisory Panel was at a consultative level. The emergence of models of collaborative data analysis (Jennings et al., 2018) can support potentially more meaningful involvement of external panels of people with lived experience as co-analysts than took place in my review.

## **4.7 Summary**

This review extends the literature on mental health recovery narratives, by synthesising ways in which they have been characterised to produce a preliminary conceptual framework. The framework extends previous characterising work such as that of Frank (1995/2013), and adds weight to the calls of survivor-researchers and others to ensure that a diverse range of experiences are represented as ‘recovery narratives’ in public health campaigns, professional training and practice.

Correspondingly, the preliminary conceptual framework is not presented as a definitive or exhaustive list of types; but as a network or ‘plane’ of linked concepts that together provide a comprehensive understanding of a phenomenon (Jabareen, 2009: 51).

Following the example of Smith and Sparkes (2009), my aim in creating a conceptual framework was not to suggest what a recovery narrative *is*, but what its possibilities are – what a recovery narrative *can be*. Narrators express their recovery through many types and shapes of story, drawing on a variety of resources to do so. The diversity of characteristics found in this review echoes Jacobson’s 2001 hope, recalled by Spector-Mersel and Knaifel (2018: 5), that recovery narratives when presented in all their variety may “teach us to respect pluralism and difference, cautioning us from offering the one and only path towards a ‘proper’ recovery”.

## **4.8 Implications for thesis**

The gaps in the recovery narrative literature highlighted by this review led to the formulation of my aims and objectives and informed my methodological approach (for example, paying attention to issues of intersectionality), as outlined next in Chapter 5.

## **Chapter 5: Methodology**

### **5.1 Introduction**

In this thesis, narrative is both the subject under investigation (the phenomenon) and the method of investigation (Clandinin & Connelly, 2000). In [Chapter 2](#) and [Chapter 3](#) I explored some of the background and context giving rise to the phenomenon of the ‘recovery narrative’ genre. [Chapter 4](#) explores in more depth how this phenomenon had been characterised in the research literature. In this chapter I turn to narrative as *method* of investigating the research questions which arose from my systematic review.

I begin by stating my aims and objectives, and discussing why paying attention to choice of research paradigm is crucial in health research. I describe a number of narrative approaches to research and some critiques of them, before identifying narrative inquiry as my chosen methodological approach and discussing its suitability for my research questions. I then explore types of narrative interviewing and three forms of narrative analysis (structural, thematic and performative/ dialogical), outlining my rationale for using them. I conclude with a consideration of quality within narrative inquiry research.

### **5.2 Aims & objectives**

#### **5.2.1 Aim**

To conduct an narrative inquiry into the possibilities and problems afforded by the ‘recovery narrative’ as a distinct genre within mental health research and practice.

#### **5.2.2 Objectives**

(i) To explore characteristics of recovery narratives told by people from marginalised groups;

(ii) To explore experiences of telling recovery stories in formal and everyday settings, from the point of view of people from marginalised groups.

## 5.3 Philosophical underpinnings

### 5.3.1 Choosing a research paradigm

All research is guided by a set of beliefs about the world and how it should be understood and studied (Denzin & Lincoln, 2018). This set of beliefs can be referred to as the overarching research paradigm (Kuhn, 1962), formed of four interconnected elements of inquiry: (i) our understandings of the nature of reality (*ontology*) and (ii) how we build knowledge of that reality (*epistemology*), which together inform (iii) the justification (*methodology*) for (iv) chosen ways (*methods*) of gathering and analysing information about the world (Tracy, 2013, Denzin & Lincoln, 2018).

Key paradigms within which research takes place have been outlined in different ways (see, for example, Bryman (2016), Denzin & Lincoln (2018)). Sarah Tracey groups them into four central paradigms: the (post)-positivist; interpretive (sometimes referred to as constructivist); critical; and postmodern or post-structural. Their differing assumptions are outlined in Table 11:

Table 11: Assumptions of Four Primary Paradigmatic Approaches (Tracey, 2013)

	<b>(Post-)Positivist</b>	<b>Interpretive</b>	<b>Critical</b>	<b>Postmodern/Poststructural</b>
<b>Ontology (nature of reality)</b>	Single, true, apprehensible	Socially constructed	Constructed through power relations and shaped over history	Multiple, fragmented, layered, fluid & multi-faceted
<b>Epistemology (nature of knowledge)</b>	Discovered: a priori, true, objective	Produced; dependent and value-laden; subjective, co-created	Mediated, hidden, distorted and produced through power relations	Relative, sceptical, 'truth' is a myth; knowledge is as much fantasy as it is reality
<b>Goal of research</b>	To measure, predict, control; to be formally generalizable, reliable and a mirroring representation	To understand why and how; to be useful and interesting; to provide opportunities for participant voice	To ask 'what should be?' to improve and transform; to disrupt power relations	To highlight chaos, show multiple points of view, and examine absence and the relativism of meaning
<b>A good researcher ...</b>	Expertly uses research and measurement devices; brackets out background and biases so they do not taint research findings	Is a self-reflexive research instrument, aware of biases and subjectivities; background is imperative for understanding the research	Considers social class and powerful structures such as 'isms' (sexism, homophobia, racism, ageism); asks how the scene is affected by, and constructs, power relations	Acknowledges the crisis of representation, writes stories that open up multiple themes, examines the re-appropriation and layering of reality
<b>Method (strategies for gathering, collecting and analysing data)</b>	Viewed as value-free; multiple methods (often quantitative and experimental) triangulated to ensure accuracy and validity	A value choice with ethical and political ramifications; multiple methods show the contexts' layered and partial nature; hermeneutical; seeks <i>verstehen</i> [understanding]	Qualitative methods often coupled with historical considerations of power and class	Qualitative methods often coupled with considerations of various and overlapping mediated representations of the scene
<b>Focus</b>	Building knowledge through analysis of objective behaviour (behaviour that can be measured, counted or coded)	'Making sense' of scene from the participants' point of view – examining not only behaviours but intentions and emotions	Pointing out domination; aiming towards emancipation and transformation	Highlighting absence, pastiche, hyper-reality, simulacra and rhizomatic [multiple, interconnected, self-replicating] meaning

Making informed decisions about which research paradigm best suits our area of inquiry is a vital step in producing robust and coherent research, since the theoretical assumptions of the researcher frame the questions we decide to ask, how to go about answering them, and by what criteria our findings are evaluated (Green & Thorogood, 2018). Crucially, our philosophical assumptions also have vital consequences for the *shaping* of our data and thus the knowledge we produce. This can be seen in the different ways of using lived experience narratives in mental health research outlined in section 3.1. Research from a positivist/post-positivist perspective will be concerned with directly observable and (to varying extents) measurable phenomena, such as symptoms and their reduction. It can therefore be seen as aligning with a *clinical recovery* perspective. For researchers aligned with a *personal recovery* perspective, the focus is on how people interpret and give meaning to their own experiences (Anthony, 1993). Therefore an interpretivist approach might be more appropriate. And for research from a *recovery as emancipatory movement* perspective, which views what is happening for people experiencing mental distress as both rooted in and a response to questions of unequal distribution of power, a critical approach is necessary. Critical approaches to recovery are often also informed by postmodern and post-structuralist ideas – see, for example, Hardin (2003), Weaver (2021).

### **5.3.2 Critical qualitative health research**

Kay Aranda (2020) outlines three key reasons why critical approaches to qualitative research are particularly pertinent to health research at present. First, qualitative ways of researching have a vital contribution to make to questions of experience, challenging whose knowledge matters. The rise of service user involvement, for example, attempts to alter the balance of power over what constitutes knowledge and experience (Beresford, 2013), challenging dominant paradigms of research previously driven by the interests and concerns of professionals. Second, there is recognition that healthcare practitioners' encounters with individuals, families and communities are founded on generating life histories and ongoing narratives through assessments, planning and other healthcare interactions. Aranda sees the rise of narrative-based research in health and social care as a result of this recognition. She points to the capacity of narrative and participatory research practices to give voice to those excluded, made invisible or 'othered' in health and care systems, such as children, young people, people living with



mental health or learning disabilities, autism or dementia. Third, many issues practitioners want to research arise out of their sense of something being missing, absent or problematic in people's experiences of services or care. This can drive demand for critical reflexive understandings of the self and others, and for consideration of wider socio-political perspectives on healthcare contexts.

These reasons encapsulate my desire to select not just a qualitative framework within which to explore my research questions, but one which centres critical, reflexive perspectives. Undertaking research based in a critical paradigm enables an opening up of phenomena, such as the nature of recovery or the genre of recovery narratives, in order to question the taken for granted, and reveal hidden assumptions within such concepts. A critical approach also enables exploration of the operation of normative discourses at work in everyday interactions, practice and relationships (Aranda, 2020). These principles address my twin aims of exploring the kinds of recovery stories that people from marginalised communities are telling, and their experiences of telling them in everyday and more formal contexts. I "stand firmly behind the belief that critical qualitative inquiry inspired by the sociological imagination can make the world a better place" (Denzin & Lincoln, 2018: 14).

## **5.4 Narrative methodologies**

### **5.4.1 Narrative approaches in qualitative health research**

A narrative-based methodology seemed the obvious choice within which to carry out my research, given that narratives and experiences of storytelling are the phenomena under question. A narrative ontology conceives of social reality as primarily storied, implying a unique relationship between story and life (Frank, 1995/2013, Barthes & Duisit, 1975). A narrative epistemology maintains that we seek to understand the world and our place within it through subjective and culturally-rooted processes of meaning-making, or 'narrative knowing' (Bruner, 1987, Bruner, 2003, Polkinghorne, 1988). It will be clear from the 'locating myself' section of [Chapter 1](#) that I have found a storied view of the world to be a useful one, though not without its problems.

However, narrative-based research is a highly diverse field and there is no single methodology associated with it (Riessman, 2008). In her outline of the development of narrative inquiry, Clandinin (2006) describes the differing epistemological stances of

researchers using narrative approaches. These stem from the antecedents of contemporary narrative research being located in two different traditions, both in opposition to (post-)positivism. First, humanist approaches within western psychology, with their focus on individual case studies, biographies and life histories, as seen in the interpretivist work, for example, of Dan McAdams (McAdams, 1993, McAdams, 2011, McAdams et al., 2022) and Arthur Frank (2010b, 1995/2013). Second, structuralist, poststructuralist, postmodern, psychoanalytic and deconstructionist approaches to narrative in the humanities (Squire et al., 2013). These have translated into the more critical work of, for example, sociologist Kenneth Plummer (1994/2002, 2019).

The importance of providing a rationale for one's choice of narrative methodology is therefore stressed by many narrative researchers (Bingley, 2020, Clandinin, 2006, Riessman, 2013). It is particularly important within my research area, given the role that narrative approaches have played in recovery-based research to date. Narrative inquiry has been identified as being a 'sister' paradigm of personal recovery, sharing ten distinct emphases: a concern with meaning, identity, change and development, agency, holism, culture, uniqueness, context, language and giving voice (Spector-Mersel & Knaifel, 2018). The concept of developing a voice and reclaiming ownership of one's experience has often been described as central to the personal recovery approach (Anthony, 1993, Coleman, 1999, Ridgway, 2001). We have seen in [Chapter 2](#) that recovery narratives originated as a reclaiming of agency within survivor and user-led movements, functioning as counter-narratives to mainstream clinical narratives. However, as outlined in [Chapter 3](#), the increased use of recovery narratives within services has called into question their emancipatory function (Fisher & Lees, 2016). Narrative research which remains at the level of individual identity transformation may run the risk of replicating the risk of commodification described in section 3.5. This may be particularly inappropriate for the stories of people from marginalised communities. A narrative methodology which is situated within a critical research paradigm was therefore a crucial framework within which to answer my questions.

#### **5.4.2 Critiques of narrative approaches**

Before outlining my own choice of narrative methodology, however, it is important to acknowledge some critiques of narrative approaches to research.

Chase (2018) notes that two problems have been identified. First, that the term 'narrative' can be used indiscriminately, describing many forms of data – accounts, objects, performances - without describing *how* they are narratives. Thus, the concept becomes meaningless (Riessman, 2013). Second, without a sense of the concept's boundaries, non-narrative ways of communicating and meaning-making can be marginalised in our understanding of social life. The idea that humans are an innately narrative or storytelling species is challenged by some (Strawson, 2004, Woods, 2011). What Frank refers to as 'narrative exceptionalism', or the belief that narrative is distinctive among human capacities and distinctively necessary for human flourishing (Frank, 2010a), has been called 'narrative essentialism' by critics (Atkinson, 2010).

It is clearly not the case that humans bring meaning to their lives *only* through storytelling. Chase concludes that "narrative researchers need to keep in mind that individuals, groups and institutions use both narrative and non-narrative modes of communicating and meaning-making" (Chase, 2018: 962).

Another critique of narrative approaches is that they can lead to a view that stories are only and always beneficial. This may stop us seeing how they can also cause harm (Woods 2011). Frank for example acknowledges that his earlier work was not attentive enough to the dangers of stories, or what they can do *to/with* people, as well as for them (Frank, 2010a).

Bingley (2020) identifies another issue, related more to debates about quality in qualitative research: what is meant by truth and validity in narrative-based research? She alludes to the considerable philosophical and sociological literature debating this aspect of narrative research (see, for example, Polkinghorne (1988), (2007)). Debate hinges on the extent to which personal narrative is regarded as factually correct or can ever be so without an objective record (a more positivist perspective), or instead is seen as a subjective reflection on, and/or interpretation of, experience (a more constructivist perspective). She cites Todorov's assertion that this tension demonstrates the 'inferiority complex' between the natural and social sciences, which can lead to social scientists taking up positivist positions more appropriate to the natural sciences in relation to their research focus, forgetting that "their 'object' is precisely not an object but another subject" (Todorov, 1984: 19).

Bingley notes however that these debates belie a misunderstanding of the nature of story. Narrative theorists such as Ricoeur (1991) posit that narratives may hold and convey a perceived, experiential truth within them, influenced and shaped by events, purpose and interpretation. Riessman (1993: 64) argues that “a personal narrative is not meant to be read as an exact record of what happened, nor it is a mirror of the world ‘out there’”. She concludes that this is the case precisely because “narratives are always located in discourses (for example scientific, feminist and therapeutic)”. This includes, of course, the narrative of the research analyst, whether their philosophical orientations are made explicit or not. It is this foregrounding of the wider discourses within which individual narratives are constructed, and the ‘hierarchies of credibility’ (Plummer, 2019) within which they operate, which distinguishes critical narrative methodologies from others.

## **5.5 Narrative Inquiry**

### **5.5.1 Principles of Narrative Inquiry**

Narrative inquiry has become a field of its own, with a distinctive nature and significance (Kim, 2015). It emerged from the work of scholars including Bruner (1990), Clandinin (2012) and Riessman (1993, 2008b), and is based on social constructivist assumptions about storying lives, relationships and experiences (Hickson, 2016). It positions human experiences as inherently narrative (its *ontological* position): experience unfolds in time, embedded in the larger narrative of an individual’s life, which in turn is situated and understood within larger cultural, social, and institutional narratives (its *epistemological* position) (Clandinin & Caine, 2008). The focus is “not only on a valorising of individuals’ experience but also an exploration of the social, cultural and institutional narratives within which individuals’ experiences [are] constituted, shaped, expressed and enacted” (Clandinin & Rosiek, 2012): 43. This form of narrative inquiry is a way of understanding individuals’ experiences which pays attention to three particular elements within that experience: time, context and the relational engagement between researcher and research participants (Clandinin & Caine, 2008). Attending to these elements of meaning-making creates a ‘methodological three-dimensional space’ that allows for inquiry into both researchers’ and participants’ storied life experiences (Clandinin & Caine, 2008). In essence, then, narrative inquiry

involves the reconstruction of a person's experience in relationship both to the other and to a social milieu (Clandinin & Connelly, 2000).

In their work mapping the methodology, Pinnegar and Daynes (2012) suggest that how fully a researcher embraces narrative inquiry can be indicated by how far they turn in their thinking and action across what they refer to as four 'turns towards narrative'. These are: (i) a change in the relationship of the researcher to the researched, away from a position of objectivity defined from positivist, realist perspectives towards one of interpretation and understanding; (ii) a move from the use of numbers and related quantitative concepts such as 'reliability' and 'validity' of findings towards ways of evaluating the quality of a piece of research which better suit narrative data; (iii) a change from a focus on the general and universal to the local and specific; and (iv) a turn from one way of knowing the world to an understanding that there are multiple ways of knowing and understanding human experiences. Pinnegar and Daynes use the word 'turn' strategically, to emphasise the movement from one way of thinking to another.

### **5.5.2 Being a 'critical narrativist'**

In the four turns described above, what I find useful is the mirroring of my own movement throughout the process of this thesis towards becoming what Helen Hickson (2016) has termed a 'critical narrativist'. Questions of the relationship between researcher and researched and the acceptance of alternative epistemologies in particular are rooted in issues of power. In Hickson's approach, researchers aim to explore the ways in which participant narratives are informed by power, oppression, and discrimination. I could see the role of power playing out, whether acknowledged or not, in the various recovery discourses and ways of using narratives in mental health research reviewed in [Chapter 2](#) and [Chapter 3](#). I have framed my research as a narrative inquiry throughout, but the implications of my methodology for the choices I was making sank in over time, influencing my approach to my data more deeply with each successive analysis. In this sense I believe I have *become* a narrative inquirer over the course of this study. This journey is charted in the reflexive pauses which conclude my findings chapters. It can be seen in my progression through the three forms of narrative analysis I selected for interpretation of my interview data.

## 5.6 Narrative and semi-structured interviewing

As we have seen, “methods are not simply neutral tools” (Bryman, 2016: 17). As the final part of the four interconnected elements of inquiry, I now describe my chosen methods of data collection and analysis. For my two research objectives, I required a method which would enable me to generate (i) narrative data from participants (i.e. their recovery stories), and (ii) data about their experiences of telling these stories.

Arguably, the most important methodological strategy to produce empirical narrative data has been the narrative interview (Collado & Boden-Stuart, 2022). Riessman (2008) notes that narrative interviews were classically defined by Mishler (1986) as ‘conversations during which the parties engage in ongoing negotiation of meaning’. They differ from other approaches in that the model of a ‘facilitating’ interviewer who asks questions and a vessel-like ‘respondent’ who gives answers is replaced by two active participants who jointly construct narrative and meaning (Riessman, 2008). Narrative interviews are therefore open-ended and relatively unstructured, to encourage the participant to tell stories rather than just answer questions. Stories might relate to the participants, their experiences, or events they have witnessed (Tracy, 2013). There are various types, including the oral history (Dunaway & Baum, 1996), which queries those who have witnessed past events for the purposes of (re)constructing history, and which often focus on the perspectives of individuals from marginalised groups whose voices might otherwise be lost. Life-story interviews (Atkinson, 1998, McAdams, 2008) also elicit stories but ask participants to discuss their life as a whole. Researchers who study life narratives tend to use small numbers of interviewees. Interviews may involve several meetings and last many hours. Alternatively, Corrine Squire (Squire, 2013) notes that researchers who are interested less in biography and more in the commonalities and differences across groups of individuals, tend to use larger interviewee numbers, and interviews of around 1-2 hours’ length. She calls this ‘experience-centred narrative research’ and gives the example of her own work in South Africa, where she wanted to examine how people talked about HIV in differently-resourced situations, and how gender might affect such talk. As I was interested in how people with differently intersecting experiences of marginalisation told stories of recovery, I chose this approach to meet my first objective

of exploring characteristics of recovery narratives told by people from marginalised groups.

My second objective called for exploration of participants' experiences of telling recovery stories in differently-resourced situations (for example, with their family or friends, with healthcare professionals, or while delivering a keynote speech at a conference). To fulfil this objective, a semi-structured approach to interviews seemed most appropriate, as they are of particular relevance where researchers have more narrow and specific research questions (Low, 2013). I wanted to ask about participants' immediate experience of telling their stories in the interview context, in order to explore in a collaborative way how the immediate context might have contributed to the way they had told their stories. I was also interested in whether or not they felt they changed the way they told their stories, depending on the context they were in, and whether there were ever any parts of their stories that felt untellable.

To fulfil both objectives, I therefore designed a two-part interview schedule. Part A consisted of a single, open-ended question, designed to elicit a narrative (Riessman, 2008). Part B consisted of a semi-structured topic guide which invited participants to reflect on their experience of telling their story in the interview, and on how their own storytelling might vary in different settings.

## **5.7 Three forms of narrative analysis**

Narrative analysis refers to a family of methods for interpreting texts that have in common a storied form (Riessman, 2008). It is widely recognised that the question of *how* to analyse narrative material is particularly challenging (Chase, 2018). Step-by-step accounts, found in other qualitative approaches such as grounded theory, are relatively rare (Squire et al., 2013). What all forms of narrative analysis have in common is a focus on each account in its entirety (Josselson, 2011). Brett Smith emphasises two aims of the narrative analyst: (i) to keep the story intact, and (ii) to hold the focus on *what* is told and *how* it is told (Smith, 2013). Riessman notes that this is the most fundamental distinction between narrative analysis and other forms: accounts are preserved and treated analytically as units, rather than fragmented in thematic categories as in other forms of qualitative research such as grounded theory (Riessman, 2008).

Narrative scholars have created typologies outlining forms of narrative analysis (see, for example, Bury, 2001, Cortazzi, 2001, Mishler, 1995, Phoenix et al., 2010). Riessman offers a working typology of four approaches: structural, thematic, dialogical/performative and visual, with the caveat that these are broad groupings with sometimes overlapping or blurred boundaries (Riessman, 2008: 53-182). Across all four types, Riessman stresses the major role of the interviewer in constituting the data we then analyse: through our presence, by listening and questioning in particular ways, we critically shape the stories participants choose to tell. I chose to use three of these forms of analysis (excluding the visual) within my narrative inquiry, although as documented below I made a different choice when it came to thematic analysis.

### **5.7.1 Structural narrative analysis**

Structural narrative analysis originated in sociolinguistics. It focuses on the components of a story and pays attention to *how* stories are put together to achieve a narrator's strategic aims (Riessman, 2008). The emphasis is on the different elements used to construct the narrative, which play an important role in linking events and creating meaning for audiences (Bengtsson & Andersen, 2020). The approach was developed through analysing what were considered to be prototypical stories, and coincided with cognitive research that attempted to show that the human mind processes these segments as independent units (Bamberg, 2020).

A foundational example of this is the work of Labov (1972), which separates narratives into six elements: an abstract (summary or point of the story), orientation (to time, place or situation), complicating action (the event sequence, usually with a turning point), evaluation (narrator's commentary on meaning and associated emotions), resolution (outcome of the plot) and a coda (ending and return to the present). Labov's work has since been critiqued for its limitations, including the decontextualisation of segments of narrative, which paid no attention to historical, interactional and institutional factors which may have contributed to the construction of the narrative (Riessman, 2008). This approach risks being highly selective, and may ignore contradictory narratives in the same story, or other stories from the same narrator (Bingley, 2020). Riessman notes however that Labov's work remains a touchstone of narrative analysis, with most narrative scholars citing it either to apply the method or, as in my own case, depart from it.



Structural analysis can also refer to genre, or to an overarching ‘storyline’, my chosen focus here. Attention to genres can be useful as they create ‘horizons of expectation’ for readers (Mishler, 1995). For example, a story about an experience could be told comically, or as tragedy, satire, romance or another form (Riessman, 2008). Examples of genre analysis include Plummer’s exploration of gay men’s ‘coming out’ stories over time (Plummer, 1994/2002) and, in health research, Frank’s classic work on narratives of illness (Frank, 1995/2013). Thornhill and colleagues (2004) note that the restitution type of illness narrative, where the narrator anticipates repair and a return to normal life, is most favoured in our current culture. As can be seen in the systematic review of [Chapter 4](#), Frank’s typology has been influential for scholars of recovery narratives, with many studies citing it or using it as a basis for their own analysis.

Attention to structure matters in mental health research, as with other areas, because certain forms of storytelling are privileged in powerful institutions, including healthcare systems. When speakers do not conform linguistically, they can be misunderstood or worse, defined as deficient in cognitive ability (Riessman, 2008) – as can be seen with studies assessing ‘narrative coherence’ outlined in section 3.1. And as Riessman reminds us, the narrow way that competence is defined can impede social justice. I began my inquiry with a structural analysis in order to investigate whether the types of stories told by people from marginalised communities could be characterised by the conceptual framework generated from my systematic review, or whether these participants were telling fundamentally different kinds of story. Procedures for this are outlined in [Chapter 7](#).

### **5.7.2 Thematic (narrative) analysis**

All narrative analysis is concerned with content, but in thematic analysis, it is the exclusive focus (Riessman, 2008). The over-arching question is, what is the story about? (Bengtsson & Andersen, 2020). As in other forms of thematic analysis such as grounded theory, the approach involves the identification of patterns and similarities (Bingley, 2020). Narrative approaches differ from other forms, however, in that the story is kept intact and analysed as a whole. Riessman (2008: 12) sees this as the fundamental difference between narrative thematic analysis and other forms. In category-centred methods of analysis (such as inductive thematic analysis or grounded theory), “long

accounts are distilled into coding units by taking bits and pieces – snippets of an account often edited out of context”. This may be useful for making general statements across many subjects; however for Riessman, category-centred approaches eliminate the sequential and structural features that are hallmarks of narrative, and which honour the individual agency and intention of the narrator. In narrative thematic analysis, theorising is developed from a single case, rather than from categories across a number of cases (Riessman, 2008).

For example, Williams’ (1984) work on illness narratives explored meaning-making around the genesis of arthritis, using Bury’s (1982) theory of narrative reconstruction of a disrupted life course. He undertook narrative interviews with 11 people, then developed three of them into case studies which illustrated three different ways of making sense of a diagnosis of rheumatoid arthritis: a political critique of workplace conditions; a social psychology narrative of the stress of motherhood; and a transcendence narrative rooted in religious beliefs. Here each theme is pertinent to each individual story, rather than present across all three.

It is important to note here that not all studies which involve narratives as phenomena employ narrative methods of analysis. Other studies may use narrative data, such as interviews in which participants are invited to tell a story; but analyse them to produce themes that apply across a dataset. Research on recovery narratives has largely used this method to date – for example, Ridgway’s (2001) grounded theory analysis of four women’s accounts of recovery, and Brown & Kandirikirira’s (2007) inductive thematic analysis which generated six internal (individual and self-controlled) and six external (social/environmental) themes present across the dataset of 67 accounts. These and others have produced valuable knowledge about recovery processes and preoccupations; however it would not be accurate to call them narrative analyses simply because the phenomena of interest is a narrative.

This distinction caused me some trouble when I came to a point in my analysis where I wanted to explore themes across my large dataset. Was there a place for a cross-case thematic analysis within a narrative inquiry methodology? I did not want my research to be methodologically incongruent, as can often happen with narrative-based research (see the examples given in Spector-Mersel & Knaifel (2018)). My structural analysis

(Chapter 7) had on the whole produced neat findings; that the conceptual framework developed from my systematic review was comprehensive and relevant to the stories of marginalised groups. But something was troubling me about my data. I was seeing a sense of unease in some of the interviews about the process of telling recovery stories, and I wanted to see if this was an experience that was common amongst my participants, many of whom faced multiple experiences of marginalisation. This called for analysis across the dataset.

Usefully, Riessman (2008) notes that category-centred models of research (such as thematic analysis) can be combined with close analysis of individual cases, commenting that each approach provides a different way of knowing a phenomenon, and each can lead to unique insights. Crucially, she also maintains that:

*In narrative study, however, attention shifts to the details – how and why a particular event is storied, perhaps, or what a narrator accomplishes by developing a story that way, and effects on the reader or listener. Who elicits the story, for what purpose, how does the audience affect what is told, and what cannot be spoken? In narrative study, particularities and context come to the fore* (Riessman 2008: 12-13).

As other studies have done – for example, Shukla et al. (2014) – I therefore chose to undertake a cross-case (reflexive) thematic analysis, to complement the structural analysis and a planned performative analysis. I do not contend that the form of thematic analysis I undertook was a *narrative* thematic analysis. However, by paying particular attention to the questions Riessman asks above in the development of my themes, I believe this cross-case form of analysis has earned its place within the context of an overall narrative inquiry. Procedures for this are outlined in [Chapter 8](#).

### **5.7.3 Performative narrative analysis**

If thematic and structural approaches examine *what* is told and *how*, performative (also referred to as dialogical) approaches explore *who* a narrative is directed at, and when, why and for what purposes (Riessman, 2008). Within performative analysis, the interviewer becomes an active presence in the text. Narrators are seen as co-constructing their own stories in dialogue with (i) micro-level contexts (for example

research participants managing their stories around their perceptions of the interviewer or the conventions of research interviews) and (ii) macro-level contexts, wherein the influence of a repertoire of culturally dominant narratives existing about them (and ‘people like them’) can be found in personal narratives. These dominant narratives can also be referred to as *meta-narratives*, defined here as socially-sanctioned ways of interpreting experiences that may suppress personal perceptions and dictate how to define the self (Sakalys, 2000).

More than the previous two forms then, performative analysis demands that attention be paid to the contexts in which stories are told, which provide specific opportunities and limitations for the teller (Bengtsson & Andersen, 2020). As Riessman notes: “stories don’t fall from the sky (or emerge from the innermost ‘self’); they are composed and received in contexts – interactional, historical, institutional and discursive, to name a few” (Riessman, 2008: 105). Performative approaches are informed by literary theory, including the work of Bakhtin (2010), who theorised that form and meaning emerge *between* people in social and historical particularity. He argues that narratives are polyphonic, or multi-voiced. The narrator does not have the only word; authority over meaning is dispersed and embedded, between narrator and reader/listener, and between differing voices within the same narrator. Thus the analyst can, for example, identify hidden discourses that speakers take for granted, and locate gaps in personal narratives.

After undertaking my thematic analysis, which explores participants’ accounts of telling their stories in different contexts, I wanted to take a closer look at how the research interview context itself was contributing to ways in which participants were constructing their recovery narratives. I was particularly interested in the interviews where participants appeared to be struggling to tell their stories, or expressed the concern that they were not giving me what I wanted. This analysis represents the culmination of my narrative inquiry and, I believe, was the point at which I fully embodied the four turns towards becoming a narrative inquirer outlined above. Procedures for the analysis are outlined in [Chapter 9](#).

## 5.8 Quality in narrative inquiry

The issue of quality in qualitative research is part of a much larger and contested debate about the nature of the knowledge produced by qualitative research; whether its quality can legitimately be judged according to a single set of general principles; and, if so, how (Mays & Pope, 2020). One of the difficulties in qualitative health research has been when quantitative, (post-)positivist assumptions are imported into qualitative studies (Sheard, 2022). For example, in a qualitative paradigm, based on interpretivism, the avoidance of ‘bias’ has been described as illogical, incoherent, and ultimately meaningless (Braun & Clarke, 2021).

Thus the challenge for qualitative research has been to define sets of criteria for high-quality research which remains consistent with the underpinning philosophy of the chosen paradigm.

Molly Andrews (2021) sets out a ‘non-exhaustive checklist’ for high-quality narrative research, outlined in Table 12:

*Table 12: Quality indicators in narrative research (Andrews, 2021)*

<b>Quality</b>	<b>Description</b>
<b>Truthfulness</b>	Truth claims are often difficult to make in narrative research. While there are exceptions to this, e.g. the personal accounts of public figures describing their engagement in well-documented events, generally this is not the case. Nonetheless, the pursuit of truth must be a central driver of scholarship. What is meant here is captured in Bakhtin’s description of the word truth: “truth is not born, nor is it to found, inside the head of an individual person. It is born between people, collectively searching for truth, in the process of their dialogic interaction” (Bakhtin, 2013: 10). So in this sense, truth is not necessarily verifiable or objective, though it may be one or both of these. To distinguish what is meant here from a claim which can sustain factual scrutiny, I use the term ‘truthfulness.’
<b>Trustworthiness</b>	The reader must have a sense that they are in trustworthy hands. Catherine Riessman has used the term ‘persuasiveness’ in a similar way, arguing that interpretations of data should be “plausible, reasonable, and convincing.” This is not achieved by championing uncritical certainty. Rather, “persuasiveness is strengthened when the investigator’s theoretical claims are supported with evidence from informants’ accounts, negative cases are included, and alternative interpretations considered” (Riessman, 2008: 191). This produces a “kind of objectivity suited to the narrative enterprise” (Riessman, 2015: 229).
<b>Critical reflexivity</b>	In order for a guide to be considered trustworthy, it is important to know something about who they are. While it is important not to

	<p>become overly engaged in a personal confessional, scholars should indicate the positioning of their own situated knowledge. This includes some discussion of who one is, and who one is not, in relation to the subject of the investigation. Riessman describes reflexivity as ‘a hall of mirrors’ and argues that it exposes “the inseparability of observer, observation, and interpretation” (Riessman, 2015: 221). Acknowledgment of situatedness of knowledge challenges some of the dogma of more traditional research methods such as the concepts of reliability and universalizability.</p>
<b>Scholarship and Accessibility</b>	<p>Research outputs should be both scholarly and accessible. This can be a difficult balance to strike. While it is important to demonstrate theoretical engagement, this should not be at the expense of being understandable. Part of this is a question of audience: who does one see oneself writing to? What is the purpose of the research? If, for instance, research participants are not able to understand what is being written about them, then at the very least this disjuncture needs to be acknowledged and addressed.</p>
<b>Ethical sensitivity</b>	<p>Although most scholarship proceeds only with the ethical clearance of universities, often the concerns which are identified are rather circumscribed, e.g. focusing on data storage, anonymisation, etc. Yet questions of the negotiation of power permeate all stages of the research, from research design to data gathering and analysis to publication.</p>
<b>Co-construction of meaning</b>	<p>Narrative research rests on the principle that meaning does not exist in any pure form but rather is something which is created, recreated, contested and resisted throughout the research process. Thus narrative scholars should be sensitive to the ways in which meaning is remade by the speaker, listener, transcriber, interpreter and reading audience</p>
<b>Attention to the untold</b>	<p>Narrative scholars must beware not to limit the scope of their interest to the stories which they hear. This starts with the research design: who is and is not part of the research, and what does this mean for what kind of stories are given fertile ground to emerge? Attention must also be paid during data gathering: what stories are told, and what remains unsaid? Mark Freeman (Freeman, 2004) has used the phrase “the presence of what is missing” to indicate the lacuna that might have an important though unarticulated and unspecified effect on the data which is produced. Scholarship on ‘untold stories’ needs to develop more nuanced ways to attend to this absence, while avoiding imposing unwarranted interpretation on such blank spaces.</p>
<b>Awareness of temporal fluidity</b>	<p>Narrative research is built upon shifting ground; narrative scholars must approach their work with a profound realisation that life does not stand still. Les Back has commented that ‘Making the social world hold still for its portrait can seem like gross violence, reducing its mutable flow to frozen moments preserved in the hoarfrost of realist description.’ Narrative research should confront the limitations of such ‘frozen moment’ analysis, while paying close attention to the particulars of the data gathered.</p>
<b>Multi-layered stories</b>	<p>Even the most intimate of stories bears a relationship to the external world. Narrative research should investigate the coexistence of different levels of storytelling, investigating the interconnectedness</p>

	between the micro and macro. Stories always exist in relation to other stories, which may be identified but which are often (and most powerfully) unnamed, and they are situated in particular ways vis a vis dominant, expected storylines.	I
<b>Contextualisation of the research</b>	Stories are produced in a specific context, at a particular moment in history, for an audience – some known, some unknown and/or anticipated – with some kind of purpose. Narrative scholars must consider this broader terrain in their analysis of the materials they collect.	

adopted these 10 indicators as guidelines for how to conduct and assess my research, and return to a consideration of them in my findings chapters.

## 5.9 Summary

This chapter has described my research questions and the philosophical paradigm within which I set out to investigate them. I have discussed a number of approaches to research and my rationale for selecting narrative inquiry as my methodological framework, including considerations of critiques of the approach and indicators of quality within it. I now turn to a description of how I went about translating my methodological approach into practical methods for investigating my research questions.

## **Chapter 6: Methods**

### **6.1 Introduction**

In this chapter I describe the procedures through which I translated a narrative inquiry methodology into research action. It contains information about the procedures and processes which applied to the research as a whole. Procedures for each of the three analyses are detailed separately in [Chapters 7, 8 and 9](#).

### **6.2 Study context**

Data collection for this thesis was undertaken in the context of my work as a research assistant on the Narrative Experiences Online (NEON) study, ([researchintorecovery.com/neon](http://researchintorecovery.com/neon)), funded through the Programme Grants for Applied Research scheme of the National Institute for Health and Care Research in England from 2017-2023. A detailed description of how my work for this thesis is distinct from this organizational context is provided in section 1.2. Findings using the same dataset have been published elsewhere, on post-traumatic growth (Slade et al., 2019), impacts of recovery narratives on recipients (Rennick-Egglestone et al., 2019b), institutional injustice within mental health systems (Hui et al., 2021) and experiences of people with psychosis who choose not to use services (McGranahan et al., 2021).

The two-part (narrative and semi-structured) interviews on which my findings are based were conducted by me and three other NEON study researchers between March 2018 and January 2019. All participants were given the option to donate their stories elicited during the interview to the NEON online intervention if they so wished.

### **6.3 Sampling and recruitment**

#### **6.3.1 Sampling**

As part of the NEON team I interviewed 18 of a total of 77 people with lived experience of mental distress (hereafter 'lived experience') from four marginalised groups, spanning a range of people from groups that were under-represented in my systematic review and in wider recovery-based research.

People experiencing poverty, homelessness, intersecting discriminations based for example on race, ethnicity, gender, sexuality, ability or class, and other forms of



structural inequality – all known social determinants of poor mental health (Alegría et al., 2018) – remain under-represented in research on mental health recovery (Karadzhov, 2021a, Padgett et al., 2016, Williams et al., 2015, Morrow & Malcoe, 2017). More inclusive research has been called for (Happell, 2008, Bellack, 2006), to ensure that knowledge of recovery processes is not based solely on the experiences of the relatively well-resourced.

In addition to the relationship between distress and structural inequalities, experiences of mental distress and stigmatisation often co-occur (Azhar & Gunn, 2021, Colizzi et al., 2020, Devendorf et al., 2020, Gronholm et al., 2017, Robinson et al., 2019). According to Goffman’s classic definition, having a stigmatised identity is associated with being discredited and discounted by others; a “relationship of devaluation” in which an individual “is disqualified from full social acceptance” (Goffman, 1963/2022: 9) and is faced with the challenge of finding ways to adapt to, refute or reframe this devalued identity. It therefore seems particularly likely that mental health-related narratives might be particularly “carefully constructed and contextually situated”, rather than “unconscious productions” (Jacobson, 2001: 250). Thus these accounts, and their experiences of telling their stories, are even more vital to pay attention to.

Stigmatisation intersects with other forms of discrimination related to the structural inequalities highlighted above – based, for example, on race, ethnicity or sexuality (Jackson-Best & Edwards, 2018). It can also be associated with particular diagnoses, such as psychosis, and people in particular occupations, such as peer workers.

As a NEON team we therefore used purposeful sampling with additional snowball sampling, in order to access information-rich cases likely to yield in-depth understanding (Patton, 2002) and representation from people experiencing structural inequalities and additional stigmatisation. We chose the following four groups to focus on, which are not mutually exclusive and which I refer to collectively here as ‘people from marginalised groups’:

Group A comprised people with self-identified experiences of psychosis, who are more likely to experience stigma and discrimination than those experiencing other forms of mental distress (Colizzi et al., 2020, Gronholm et al., 2017). Group B comprised people from Black, Asian and minority ethnic communities, who experience persistent

inequalities when accessing mental healthcare (Lawrence et al., 2021). Group C comprised people from groups who are currently not well-served by mental health services, which, as the lead researcher on recruitment for this group, I operationalised as lesbian, gay, bisexual, trans and queer (LGBTQ+) communities (Rees et al., 2021) and people with multiple and complex needs (co-occurring experiences of homelessness, substance misuse issues and/or contact with the criminal justice system in addition to mental distress) (Kuluski et al., 2017). Group D comprised peer support workers, trainers or researchers in employed or voluntary roles, since peer workers report marginalisation and discrimination around their role and use of their lived experience (Firmin et al., 2019, Voronka, 2016). Inclusion criteria common to participants from all groups were: people aged over 18; willing to discuss experiences; able to give informed consent; and fluent in English.

### **6.3.2 Recruitment**

Participants were recruited across England; Groups A and B primarily from London, and Groups C and D primarily from the Midlands. Group A participants (experiences of psychosis) were recruited through primary care services, online support groups, Hearing Voices networks and online advertising. Group B participants (Black, Asian and minority ethnicities) were recruited in London through community groups, a Recovery College and secondary mental health services. I led on the recruitment of group C participants (those not well-served). LGBTQ+ participants were recruited through university staff and student networks, and adverts placed online on local LGBTQ+ websites. Participants with multiple and complex needs were recruited through voluntary and community sector organisations, including a homelessness charity and a sex workers' rights and support organisation, and secondary care mental health services, including an NHS substance misuse service and a specialist mental health nurse service for homeless people. Group D participants (peers) were recruited through community groups and secondary care mental health services.

All participants were given an information sheet prior to giving their consent, describing the study in more detail (presented in [Appendix 5](#)).

## **6.4 Data collection**

### **6.4.1 Qualitative Interviews**

Each participant took part in a 40-120 minute interview conducted by NEON researchers either in health service, university or community venues, according to their preference. The interview comprised two parts. In part A we asked an open-ended question designed to elicit a narrative (Riessman, 2008), with minimal or no interruption from the researcher in order to facilitate fluent story-telling (Spector-Mersel & Knaifel, 2018). The participant was asked to share their mental ill health and recovery experiences as a story over time, with a beginning, middle, current situation and future thoughts, a framing which was adapted from McAdams' Life Story Interview (McAdams, 1993). We also stressed that there was no right or wrong way for participants to tell their stories. In part B a semi-structured topic guide invited participants to reflect on how they had found telling their story in the interview; how their own storytelling might vary in different settings; and how other people's recovery stories had impacted them (findings from this last question are reported elsewhere (Rennick-Egglestone et al., 2019b)). The full topic guide is presented in [Appendix 3](#). Participants received £20 cash or vouchers post-interview as an honorarium. Interviews were recorded, transcribed and anonymised. Field notes were written immediately post-interview, including reflexive thoughts on the role of the interviewer within the narrative process. The field notes template is presented in [Appendix 4](#).

## **6.5 Data analysis**

I undertook three forms of analysis, and the distinct procedures for these are outlined in [Chapter 7](#) (structural analysis); [Chapter 8](#) (reflexive thematic analysis) and [Chapter 9](#) (performative analysis).

## **6.6 Ethical considerations**

Ethical sensitivity is one of the indicators of high-quality narrative research noted by Andrews (Andrews, 2021). As she points out, this extends to more than a consideration of issues such as informed consent and data storage, important though these are. For narrative inquiry, questions of the negotiation of power are ethical questions which permeate all stages of the research (Andrews, 2021).

### **6.6.1 Overall ethical approach**

One of the ways in which I addressed potential researcher/participant power imbalances was through undertaking 'insider research' as someone with lived experience myself, and through foregrounding this fact with participants.

It was important to me to convey to participants in a sensitive and appropriate manner that the research was being undertaken, not 'on' people with experiences of distress, but by and for people with experiences of distress. This addresses issues of power at epistemological level, contributing in a small way to redressing epistemic injustice, whereby a person is wronged in his or her capacity as a knower (Fricker, 2007), and which is routinely endured by those with lived experience – although I note what Diana Rose refers to as the long tradition in critical theory of critique of 'experience' as a foundational category (Rose, 2017). As Rose notes, any concept of a homogenised 'we' has been challenged in other areas by critical Black scholars (Fanon 1967) and Black feminists (hooks, 1987), and developed into concepts of intersectionality (Crenshaw, 2017), to which I return in [Chapter 10's](#) conclusions.

### **6.6.2 Ethical processes**

At the immediate, practical level, NHS Research Ethics Committee approval was obtained in advance of data collection (Nottingham 2 REC 17/EM/0401), as the study involved recruitment from NHS sites and of NHS service users. Data collection for this PhD was included in the ethics application, I was named as an ethics applicant, and contributed to the protocol development. All participants provided written informed consent.

I provided a Participant Information Sheet to participants in advance of interviews (presented in Appendix 5), which informed them about the research study, its aims, their role, and how information would be collected and stored. The information sheet included the option to request being interviewed by a researcher either with their own lived experience or without, and several participants requested a researcher with lived experience. During conversations with participants before the formal start of the interview, I made it known to them that I had my own lived experience, and therefore that the interview was being conducted by someone who had 'been there' to a certain extent.

Participants identified as having multiple and complex needs were given the information sheets by members of staff known to them, and had the opportunity to discuss any questions or issues with them prior to consenting to taking part.

All participants were informed both verbally and in written form that they were free to withdraw their participation at any time, without question or needing to give reason; and that all information and data collected would be treated confidentially and details kept anonymous, both in storage using an encrypted computer and in dissemination of information. It was made clear that only the research team and supervisors had access to the pseudonymised data and that anonymised quotations may be used in final analysis and journal publications. Opportunities were given to ask questions about the research prior to the interview and on the day itself.

I created wellbeing protocols, reviewed by other NEON researchers, to mitigate participant and researcher distress in recognition of the risks of retelling potentially traumatic experiences (Jaffe et al., 2015) and researching sensitive subjects (Nguyen et al., 2021). Signposting information to local and national support services was included in the Participant Information Sheet. It was made clear that breaks could be taken whenever required throughout the interview, and that the participant could end the interview at any time. The topic guide was flexible, with team agreement to minimise questions if the participant was experiencing distress at any point.

Given the additional vulnerabilities of participants with multiple and complex needs, only those accessing NHS secondary mental health care or the support of a voluntary sector organisation were recruited for this group. Furthermore, we recruited only via services where staff who were known to participants were available on the day for pre-interview support and a debrief session, should this be wanted by the participant. Mutual assessment on appropriateness to go ahead was carried out between participant and staff immediately prior to interview. Interviews took place in settings known to participants, with the option of being accompanied by a support worker if required. I drew on my professional background of working with people with multiple and complex needs and those experiencing mental distress to support participants during the interview.

For my own support and wellbeing, I had access to line-management and colleagues' support on the day of the interview or as soon after as possible. With the encouragement of my line-manager/supervisor, I booked at least an hour out following the interviews to decompress before writing up my field notes and continuing with my day, as the experience of listening to the stories was often quite intense. I found the impact of reading some of the transcripts of participants' stories which had been conducted by other interviewers could also be surprisingly strong, particularly when their experiences were similar to my own. With the rest of the research team we had an informal arrangement throughout the early analytical stages of proving spaces for each other to 'offload' and help process anything we were feeling in relation to participants' experiences. Based on our own experiences of this strong impact, we went on to develop advice and training on maintaining wellbeing for coders of the recovery narratives which comprised the NEON online intervention.

Given the narrative nature of the data, a concern in writing up this study was preserving participant confidentiality while retaining particularities of their lives and experiences. I took additional steps to destructively anonymise all transcripts rather than taking a simple pseudonymising approach.

## **6.7 Reflexivity**

Reflexivity is the process of reflecting critically on the self as researcher, the "human as instrument" (Denzin & Lincoln, 2018: 246). It is another of the indicators of high-quality narrative research noted by Andrews (2021); a crucial aspect since, in this approach "scholars are not just detached observers, but also narrators" (Hagström & Gustafsson, 2019: 398). As Andrews (2021) notes, "while it is important not to become overly engaged in a personal confessional, scholars should indicate the positioning of their own situated knowledge". This is the purpose of the 'locating myself' section of [Chapter 1](#). I also built ongoing opportunities for reflecting on my own positionality as co-creator of participants' narratives into the research process. I kept a research journal throughout, including reflections on puzzles, progress and positioning. I included a reflexive section within my field notes, enabling me to reflect on the ways in which I co-constructed each encounter, which informed my ongoing interviews and subsequent analyses. I discussed my positioning in relation to the data regularly during

supervision meetings, and have included sections on how this positioning specifically informed each analysis in [Chapter 8](#) and [Chapter 9](#).

## **6.8 Summary**

In this chapter I have given an account of the practical ways in which I went about translating a narrative inquiry methodology into appropriate methods, analytical procedures and ethical considerations.

## **Chapter 7: ‘Not the story you want, I’m sure’: what kinds of stories are people from marginalised groups telling?**

### **7.1 Introduction**

Chapters 7, 8 and 9 present my findings from the data co-created with 77 participants. These were generated using three forms of analysis, as described in Chapter 5’s Methodology and are presented here as three successive, linked studies.

In this chapter I present findings from a structural analysis, which addressed my first objective: to explore characteristics of recovery narratives told by people from marginalised groups, and whether they differed from the kinds of stories described in my systematic review. I preface the findings with some contextualising information and a description of the structural analytical process. I conclude with a discussion on the presented findings, their relation with existing literature and their implications.

#### **7.1.1 Background and aims of the first study**

To fulfil my first objective I conducted a structural narrative analysis of 77 recovery stories told by participants. I had created a preliminary conceptual framework for recovery narratives based on my systematic review and narrative synthesis (presented in Chapter 4, Table 1). However, the studies on which the conceptual framework was based collectively exhibited gaps in terms of narrators and narratives represented (listed in section 4.5). The framework may therefore have been inapplicable to narratives from more heterogeneous narrators, and may have omitted knowledge available from these more diverse groups. In previous research, this issue has been addressed through studies that assess the relevance, or ‘fit’, of an existing framework with a more heterogeneous group. For example, a systematic review of studies of recovery produced the widely-used CHIME framework, comprising five recovery processes: Connectedness, Hope, Identity, Meaning and Empowerment (Leamy et al., 2011). The original framework was based on published narratives describing past experiences of recovery, so its relevance for people currently using mental health services was unknown. The fit of the framework was assessed through deductive and inductive thematic analysis of focus group interviews held with current mental health service users (Bird et al., 2014). This analysis found that the CHIME processes were present in their accounts, hence ‘validating’ the framework’s relevance. It also



highlighted additional aspects of recovery for that population, hence refining the framework.

The aims of my structural analysis were therefore (i) to explore the overall fit of the preliminary conceptual framework with the narratives of people from marginalised groups and (ii) to develop a typology of recovery narratives, incorporating any identified refinements. The typology was intended to inform narrative-based practice, research and intervention development including the NEON intervention. The resulting paper was published in October 2019 and is available at <https://doi.org/10.1007/s00127-019-01791-x>

## **7.2 Method**

### **7.2.1 Structural narrative analysis**

Analysis was undertaken on the 77 narratives told in Part A of the interviews by me (n=20) and three other NEON researchers. The emphasis in structural narrative analysis (as outlined in [section 5.7](#)) is on the different elements used to construct the narrative, which play an important role in linking events and creating meaning for audiences (Bengtsson & Andersen, 2020). I created an analysis template based on my preliminary conceptual framework (presented in [Table 14](#)), to identify whether its dimensions and types could be applied to the interview narratives. I devised a two-stage structural narrative analysis process, analysed 20 of the narratives, provided analytical training and support for the other three researchers, and co-ordinated our analysis meetings.

In stage one, we coded narratives using the analysis template, analysing the narratives deductively to assess the *relevance* of the preliminary conceptual framework to the narratives of people from marginalised groups. Relevance was defined as assessing whether the nine dimensions of the framework were also applicable to these narratives.

In stage two, we undertook an iterative analysis to assess the *comprehensiveness* of the framework, through identifying areas of similarity in the interview narratives with existing types in each dimension, and exploring potential differences. After the initial coding by all four researchers, I drew on all contributions to generate findings. I identified potential refinements to the framework and discussed these with the three

other researchers, with members of the NEON Lived Experience Advisory Panel (LEAP) and with a wider analysis team with additional expertise in recovery research and digital health research. Decisions on refinements were made by consensus within the wider analysis team meetings.

Narratives where five or more dimensions appeared not to be relevant were discussed further within the team. Narratives to which it was agreed less than five dimensions applied are presented below as outliers, which demonstrate the limits of the typology.

## 7.3 Findings

### 7.3.1 Characteristics of participants

Seventy-seven interviews were conducted. Participant characteristics are presented in Table 13:

Table 13: Clinical and sociodemographic characteristics of interview participants (n=77)

Characteristic	Total	Group A (Psychosis experiences)	Group B (Minoritised ethnicities)	Group C (Under- served)	Group D (Peer roles)
n (%)	77 (100)	21 (27)	21 (27)	19 (25)	16 (21)
<b>Gender n (%)</b>					
Female	42 (55)	14 (67)	11 (53)	8 (42)	9 (56)
Male	30 (39)	6 (29)	9 (43)	9 (47)	6 (38)
Other/prefer not to say	5 (6)	1 (5)	1 (5)	2 (11)	1 (6)
<b>Ethnicity n (%)</b>					
White British	44 (57)	12 (57)	0 (0)	18 (95)	14 (88)
Black British	5 (6)	2 (10)	3 (14)	0 (0)	0 (0)
Black African / Caribbean	4 (5)	1 (5)	3 (14)	0 (0)	0 (0)
White Other	5 (6)	2 (10)	1 (5)	0 (0)	2 (13)
White and Black African /Caribbean	4 (5)	0 (0)	4 (19)	0 (0)	0 (0)
Asian / Mixed white Asian	4 (5)	0 (0)	4 (19)	0 (0)	0 (0)

<b>Characteristic</b>	<b>Total</b>	<b>Group A (Psychosis experiences)</b>	<b>Group B (Minoritised ethnicities)</b>	<b>Group C (Under- served)</b>	<b>Group D (Peer roles)</b>
Other	5 (6)	2 (10)	3 (14)	0 (0)	0 (0)
Prefer not to say	6 (8)	2 (10)	3 (14)	1 (5)	0 (0)
<b>Age (years) n (%)</b>					
18-25	4 (5)	0 (0)	0 (0)	3 (16)	1 (6)
25-34	16 (21)	3 (14)	6 (29)	4 (21)	3 (19)
35-44	16 (21)	5 (24)	4 (19)	4 (21)	3 (19)
45-54	30 (39)	8 (38)	9 (43)	6 (32)	7 (43)
55+	5 (6)	4 (19)	0 (0)	0 (0)	1 (6)
Prefer not to say	6 (8)	1 (5)	2 (10)	2 (11)	1 (6)
<b>Sexual orientation</b>					
Heterosexual	49 (64)	15 (71)	14 (67)	6 (32)	14 (88)
LGBTQ+	18 (23)	3 (14)	4 (19)	9 (47)	2 (13)
Prefer not to say	10 (13)	3 (14)	3 (14)	4 (21)	0 (0)
<b>Primary diagnosis</b>					
Schizophrenia or other psychosis	11 (14)	5 (24)	4 (19)	2 (11)	0 (0)
Bipolar disorder / cyclothymia	16 (21)	8 (38)	1 (5)	3 (16)	4 (25)
Mood disorder, e.g. anxiety, depression, dysthymia	15 (19)	1 (5)	4 (19)	4 (21)	6 (38)
Other, e.g. ADHD, personality disorder, substance abuse, autism	7 (9)	0 (0)	2 (10)	3 (16)	2 (13)
Prefer not to say	28 (36)	7 (33)	10 (48)	7 (37)	4 (25)

In all three findings chapters, ellipses in the quotations indicate pauses by the participant or interviewer. Ellipses in square brackets indicate that text has been omitted.

### **7.3.2 Relevance and comprehensiveness**

The preliminary conceptual framework comprised nine dimensions (Genre, Positioning, Emotional Tone, Relationship with Recovery, Trajectory, Turning Points, Narrative Sequences, Protagonists and Use of Metaphor), each of which contained between two and six types. For this study, it was operationalised as a preliminary typology.

I identified five or more of the nine dimensions within 75 (97%) of the 77 narratives. The analysis template and a completed analysis of one narrative which fitted existing dimensions and types is presented as Table 14. Although example quotes are supplied from the interview in support of each choice, in keeping with a structural analysis approach the narrative was considered as a whole when identifying dimensions and types.

Table 14: Structural analysis template and example

UID: A10      Researcher: JLB

#	Type	Definition	Rationale & examples
<b>Narrative form (what kind of story is this?)</b>			
<b>1</b>	<b>Genre</b>	<b>A literary kind, type or class of story</b>	
1.4	Enlightenment	Narratives of transformation and inspiration. Narrator views experience of distress/trauma as essentially positive, as a new perspective has been gained from it.	<p>This is an enlightenment story, as the narrator’s perspective transforms from one of illness/psychosis to one of spiritual opening and letting go. The result is a sense of new meaning/purpose through her work as a violin teacher. She goes from accepting others’ solutions (medication, hospitalisation) to her own solutions (peer support group, sessions of reliving &amp; letting go of unhelpful ideas like perfectionism &amp; competition). Her experiences are presented as positive rather than periods of illness, because of the emotional freedom gained from working through the distress.</p> <p>“So then I went into this really amazing space where I felt like I went back into my childhood again...physically I wanted to let go of loads of things ... as I went through that whole process it was like this massive opening, just kind of spiritual opening again”</p> <p>“I think I probably need to just do some sort of release work to move on from some of this and I think that’s what my depression’s about, and letting go of the children as well, allowing them to go and do their thing and finding out what my path is next”</p>

2	Positioning	Ways in which narratives are situated in relation to the mental health system	
2.2	Recovery despite the system	Narratives of protest in opposition to the biomedical model of mental illness.	<p>“[The psychiatrist] was like, you've got to keep taking it, you've got to keep taking it and I was just like, I can't...I don't want to take it.”</p> <p>“So it was horrible, I got very violently jumped on, injected with medication and afterwards I just took, I took all the medication that they told me to take because I didn't know what else to do”</p> <p>“He helped me to escape from hospital so I didn't stay there and after that time, because it was really, really violent, it was awful”</p>
3	Emotional tone	The overall mood or feeling of the narrative	
3.3	Reflective	Measured	<p>Numerous instances of reflecting on past experience through her changed perspective e.g.:</p> <p>“I feel like somehow my soul is showing me that that's not the right path for me and I'm not meant to go down that, trying to be somebody and trying to be oh, like look at me, big competition starts again, my parents come and watch, it's not about that and I know I've been shown so many times that life is not like that ... it's about love and it's about connection, going down that path would be the wrong one for me”</p> <p>Narrator speaks about times in the past where she's been angry, but she doesn't sound angry, or get angry again, in the current telling. So, did not include “critical” as a tone.</p>

<b>4</b>	<b>Relationship with recovery</b>	<b>How the narrator relates to the concept of recovery at the time of narration</b>	
4.2	Living well	Presents recovery as a process within which narrator is well-established	<p>"I think even now, like feeling depressed now, I think it's because there's stuff I need to let go of that I'm not letting go of"</p> <p>Even though the narrator describes herself as feeling depressed now, she has an explanation for this and a sense of what might help</p>
<b>Narrative structure (what shape of story is this?)</b>			
<b>5</b>	<b>Trajectory</b>	<b>The direction of a narrative towards its destination</b>	
5.1	Upward spiral	Describes an overall ascending progression towards recovery	The trajectory is <i>upward</i> from the POV of someone now <i>living well</i> – i.e. even though she still feels depressed sometimes, she sees her experience through an entirely different lens
<b>6</b>	<b>Turning points</b>	<b>Pivotal moments within the narrative which affect its overall shape. There may be one or more in a narrative.</b>	
6.1	Restorying	Turning point is the moment in which a narrator gains a new understanding of their experience.	"I guess the main – what I'm really saying is that going into the different reality, finding validation for that and taking it seriously rather than dismissing it as illness was my recovery, that was what helped me to recover, I think."
<b>Narrative content</b>			
<b>8</b>	<b>Protagonists</b>	<b>The major characters and/or forces at work within a narrative.</b>	
8.1	Personal factors	The force(s) working at micro or inter/intra-personal level within a recovery narrative. Most commonly the narrator him or herself. May also be a helping person or factor	<p>"I've been with [partner] for 10 years now and he has been really very grounding for me".</p> <p>"There was this guy who really took my side ... he really believed in me and he really validated me"</p>

8.2	Socio-cultural factors	Meso-level factors within a recovery narrative. Family, friends, groups or local organisations, mental health staff and services.	<p>"I just got my violin and I joined this service user group ... I wasn't an official service user in that setting, I was the professional"</p> <p>"Then I went to this festival, this rainbow gathering"</p> <p>"So then I was lucky enough to be able to go into a therapy group, full-time"</p> <p>"I find it very difficult because my childhood was so focused on being the best that it's difficult for me to let go of that kind of thing"</p>
8.3	Systemic factors	Macro-level factors within a recovery narrative. Wider community or socio-political systems including legal, healthcare, policy, political, religious and international factors	"So it was horrible, I got very violently jumped on, injected with medication and afterwards I just took, I took all the medication that they told me to take because I didn't know what else to do"
8.4	Other	Spiritual /supranatural factors	"And then I started feeling like something really wanting to come through me or something"
<b>9</b>	<b>Use of metaphors</b>	<b>Imagery employed by the narrator to depict states of being, relating to distress and recovery.</b>	
9.1	Distress metaphors	Focused on past distress or a future return to the experience of distress	"I was just at absolute rock bottom"
9.2	Recovery metaphors	Focused on past, present or future experience of recovery.	"It was as though a spiritual – an ancestral spirit entered my body and I, there was a kind of story in my ancestry that somebody lost their house.



**Notes**

It could be argued that this is an “up and down” trajectory story. I chose “upward” as, despite being currently depressed, the narrator is still framing this in terms of needing to let go of something – i.e. something she can handle, and an experience she views through her new perspective. “Upward spiral” still includes elements of difficulty, but there is no distinctive downturn in her tone or descriptions of her life here.

Not all dimensions were present in all narratives. Some stories did not contain a 'Turning Points' dimension, for example, attributing recovery to non-temporal factors instead, such as communities around them, as did this participant from group B (people with Black, Asian or other minoritised ethnicity backgrounds):

*I have got good people round me, so I guess that is the bulk of the story really, it is the people around me that have just been absolutely magnificent (B15)*

There was no 'Relationship with Recovery' dimension for one narrator from Group D (people with peer support roles), for good reason – she had rejected the concept of recovery, ironically while attending a recovery college. She reported that this gave her a sense of freedom:

*This [her story] is not really a good description of recovery I guess, but for me kind of being able to reject recovery...helped me in a way to – not feel better, but just to sort of feel 'me', and that I could make those decisions. I didn't have to get better if I didn't want to (D3)*

As she was now a peer support worker, she felt “two-faced” in her rejection of recovery as a concept. She appeared apologetic that her story didn't match what she thought was expected of her, saying to me that this was “not the story you want, I'm sure”.

I assessed that the types within five of the nine dimensions (Genre, Relationship with Recovery, Turning Points, Protagonists and Use of Metaphor) were comprehensively able to describe the narratives of people from marginalised groups – that is, I did not find further types of stories to be present in these dimensions. For example, all stories fitted one or more of the existing four types of Genre: 'escape', 'enlightenment', 'endeavour' or 'endurance'. I did however make changes to the other four dimensions (Positioning, Emotional Tone, Trajectory and Narrative Sequences) through the analytical process, as outlined below.

### **7.3.3 Refinements**

The 'Positioning' dimension refers to the way in which narrators position their recovery in relation to the mental health system, comprising three types: recovery 'within the system', 'despite the system' and 'outside of the system'. This reflected the language

used in studies included in the original systematic review. LEAP co-analysis identified that this was not sufficiently clear, as people experiencing mental distress may be accessing multiple systems, for example housing or employment as well as health. Types were renamed to refer to 'mental health services' rather than 'the system'. The 'recovery within mental health services' type was also extended to include two subtypes: (i) using services and (ii) delivering services, reflecting that delivering or advising on services was central to some participants' recovery, as this peer worker described:

*I was really taken aback when I learnt that actually having lived experience of mental health challenges was something that the NHS was interested in as an expertise. That was a real big turning point for me to realise that everything that I had gone through, could actually benefit both myself and other people (D8)*

The 'Emotional Tone' dimension describes the overall mood or feeling of the narrative. It originally contained six types ('buoyant', 'critical', 'disenfranchised', 'reflective', 'shaken' and 'tragic').

A further six potential additions to the framework were found in the data ('matter of fact', 'frenetic', 'agitated', 'confused', 'apologetic' and 'humble'). To increase comprehensiveness, all types were then synthesised into four overarching types: 'upbeat', 'downbeat', 'critical' and 'neutral'.

The 'Trajectory' dimension describes the overall direction of a narrative towards its destination. It originally comprised four types ('upward spiral', 'up and down', 'horizontal' and 'interrupted'). However, I found a different type in some of the narratives of participants identified as having multiple and complex needs, those from people accessing substance misuse services – 'cyclical' narratives, defined as 'cycling through sequences of distress, gradual recovery, a period of wellbeing and distress again'. My analysis indicated that these differed from the existing 'up and down' type, which also contained movement towards both recovery and distress. For example, narrators described a sense of going back to the beginning during distress periods. There was no sense of the narrator presenting themselves within what has been called a "crisis to resolution" progression (Toolan, 2012):

*I usually go through five year cycles where it starts off where I'll have everything, [then] throw it all away...burying my head in the sand, and then sort of like work through my own demons by blocking myself off, build myself back up again, get myself all the way back up there and then almost kick my own ladder from underneath me (C9)*

No benefits from previous periods of recovery/wellbeing were reported as being retained:

*I – mine goes in spells for quite a while, and then just come round, get myself clean again, get back to work and then...I've done it for the last 20 years, exactly the same thing (C8)*

There was little or no sense that the cycle could be exited:

*Because honestly I hate it, you know, every time I [use heroin]. It's like I'll do it. And I think well fucking hell, I've done it again. You know, I hate it – it's been like that for like ten years (C12)*

Cyclical narratives fitted the provisional definition of recovery narratives I had created based on studies from my systematic review, containing clear elements of strength, successes or survival as well as elements of adversity or struggle. The way in which success was represented appeared to be related to another dimension, the narrator's current 'Relationship with Recovery'. A narrative fitting the 'struggling day to day' type, i.e. relating to recovery as a process in which the narrator is tentatively engaging, described the cycle as:

*A continuous battle, and I think because of everything else that's going on it will be a continuous battle until the day I die (C9)*

In contrast, a 'making progress' type of narrative, where the narrator describes more confidence in their ability to tolerate distressing periods, described a cycle in terms of pride in moving through these times, for example:

*I have been that low. And that ill, I have been there and I have seen the light...and I have come back from it...I've been there, right there to the lowest of the low. And pulled myself back from it. And that's difficult to do (C12)*

I made two refinements to the 'Narrative Sequences' dimension, which describes component parts of a recovery narrative. First, the dimension originally comprised three types ('experiences of distress', 'turning point' and 'experiences of recovery'), each of which contained a number of sub-type sequences (for example, 'experiences of distress' contained five subtypes: 'life before distress/trauma', 'problems begin', 'problems worsen', 'impact of illness' and 'glimpses of recovery'). I renamed the dimension to 'Narrative Sections' for greater flexibility, as 'Narrative Sequences' suggested a linear progression through the types, whereas analysis showed that sub-type sections appeared in many different orders. Second, I renamed one 'Narrative Sections' type to better fit the data. The "Life before distress/trauma" section was identified in significantly fewer narratives than others (n=15, 19%); however, sections wherein narrators told of possible *origins* of their mental distress were more prevalent. For example, this LGBTQ+ participant:

*I didn't have a great home life. My dad was physically and emotionally quite abusive. My mum didn't leave him until I was about 18, so me and my brother were left in those circumstances... When I have been unpicking it in the many years of therapy I have had since, that seems to be the root of a lot of it, not having a great home life, not having a great start (C14)*

To better reflect this, the 'Life before distress/trauma' type was renamed to 'Origins', defined as a section containing 'possible roots or causes of later mental distress, or descriptions of life before illness'.

The results of my analysis of the 75 narratives for which the framework was assessed as relevant are presented as Table 15, incorporating all above changes:

Table 15: Characterisation of recovery narratives of people from marginalised groups (refinements underlined)

No.	Dimension	Types	Total	Group A	Group B	Group C	Group D
				(Psychosis)	(BAME)	(Under-served)	(Peer)
n (%)			75 (100)	21 (28)	20 (27)	19 (25)	15 (20)
1	Genre	Escape	6 (8)	2 (10)	2 (10)	0 (0)	2 (13)
		Endurance	21 (28)	4 (19)	6 (30)	7 (37)	4 (27)
		Endeavour	28 (37)	7 (33)	6 (30)	9 (47)	6 (40)
		Enlightenment	20 (27)	8 (38)	6 (30)	3 (16)	3 (20)
2	Positioning	<u>Within services</u>	37 (49)	6 (28.5)	10 (50)	12 (63)	9 (60)
		<u>Despite services</u>	18 (24)	9 (43)	5 (25)	1 (0.5)	3 (20)
		<u>Outside of services</u>	20 (27)	6 (28.5)	5 (25)	6 (31.5)	3 (20)
3	Emotional Tone	<u>Upbeat</u>	49 (65)	15 (72)	14 (70)	8 (42)	12 (79)
		<u>Downbeat</u>	8 (11)	0 (0)	3 (15)	4 (21)	1 (7)
		<u>Challenging</u>	15 (20)	3 (14)	3 (15)	4 (21)	1 (7)
		<u>Neutral</u>	7 (9)	3 (14)	0 (0)	3 (16)	1 (7)
4	Relationship with Recovery	Recovered	4 (5)	3 (14)	0 (0)	0 (0)	1 (7)
		Living well	36 (48)	13 (62)	10 (50)	5 (26)	8 (52)
		Making progress	21 (28)	5 (24)	4 (20)	8 (42)	4 (27)
		Surviving day to day	13 (17)	0 (0)	6 (30)	6 (32)	1 (7)
		Not applicable	1 (2)	0 (0)	0 (0)	0 (0)	1 (7)
5	Trajectory	Upward	46 (61)	14 (67)	14 (70)	7 (37)	11 (73)
		Up and down	15 (20)	4 (19)	3 (15)	5 (26)	3 (20)
		Horizontal	8 (11)	3 (14)	2 (10)	2 (11)	1 (7)
		Interrupted	1 (1)	0 (0)	1 (5)	0 (0)	0 (0)
		<u>Cyclical</u>	5 (7)	0 (0)	0 (0)	5 (26)	0 (0)

<b>6</b>	<b>Turning Points</b>	Restorying	14 (18)	6 (29)	2 (10)	2 (10)	4 (31)
		Change for the better	29 (39)	11 (52)	5 (25)	7 (37)	6 (38)
		Better and worse	29 (39)	3 (14)	12 (60)	10 (53)	4 (25)
		Not applicable	3 (4)	1 (5)	1 (5)	0 (0)	1 (6)
<b>7</b>	<b>Narrative Sections</b>	<u>Origins</u>	26 (35)	8 (38)	8 (40)	6 (31)	4 (27)
		Problems begin	70 (93)	20 (95)	18 (90)	18 (95)	14 (93)
		Problems worsen	70 (93)	20 (95)	18 (90)	19 (100)	13 (87)
		Impact of illness	56 (75)	16 (76)	12 (60)	15 (79)	13 (87)
		Glimpses of recovery	59 (78)	19 (90)	15 (75)	13 (68)	12 (80)
		Turning point	65 (87)	18 (86)	17 (85)	16 (84)	14 (93)
		Roads to recovery	71 (95)	21 (100)	19 (95)	17 (89)	14 (93)
		Life afterwards	64 (85)	19 (90)	17 (85)	16 (84)	12 (80)
<b>8</b>	<b>Protagonists</b>	Personal factors	72 (94)	20 (95)	20 (95)	17 (89)	15 (100)
		Socio-cultural factors	73 (96)	21 (100)	20 (95)	17 (89)	15 (100)
		Systemic factors	52 (68)	12 (60)	16 (76)	15 (79)	9 (60)
<b>9</b>	<b>Use of metaphor</b>	Distress metaphors	43 (57)	15 (71)	11 (55)	7 (37)	10 (67)
		Recovery metaphors	35 (47)	13 (62)	9 (45)	6 (31)	7 (47)

### 7.3.4 Outlier narratives

It was difficult to identify a majority of dimensions (five or more) within two of the 77 narratives. Both appeared to be relatively unstructured monologues, with few breaks or pauses and no discernible type of genre present. Notably, English was not the first language of either participant; both described significant experiences of trauma; and both expressed a preference in their stories for non-verbal ways of communicating. One narrator was a Black Caribbean man who began by graphically describing his multiple experiences of childhood sexual abuse. He then moved into an account of other life experiences interwoven with a series of visions he had experienced, which were difficult to differentiate into discrete narrative sections. He made several references to art being his preferred form of communication: “I couldn't think properly, I couldn't do

academic work okay right. I could paint". His art appears to have been central in helping him to construct a positive sense of identity:

*my ex-art teacher from [organisation] spoke very highly of me as well, okay – she said I was hard working and I could draw, I could do art work (B22)*

and in giving him a sense of purpose:

*I felt someone coming towards me but I couldn't see, [inaudible] I'm sorry [name] I didn't mean to, erm, God didn't mean to you to save the world okay, go back to England and become an artist (B22).*

Given the abuse perpetrated against him and the ongoing experiences of trauma he described, it is perhaps little wonder that the more conventional forms of storytelling described in the typology were inadequate in this case.

The second narrative was from an Eastern European white man, a peer support worker. His narrative was also largely without structured descriptions of events; instead consisting of descriptions of his anger at conventional psychiatry, delivered in a monotone. However, his tone changed when he began to speak about dance. He expressed his frustration with the focus in recovery services on *telling* stories:

*There has been so much focus as I said in the past [on] telling your story, telling your story, and the thing about dancing has been you don't have words...you are not supposed to talk during the dancing, so you don't get stuck in this cycle of 'this happened, this happened and then I did this and I feel so bad about this...I'm a terrible person' (D15)*

For this narrator, oral storytelling appears to reinforce a sense of personal inadequacy. Instead, as a peer support worker, he brings his experience of dance to the way he offers supports:

*the space where I am held when I go dancing, I try and bring that when I meet with someone. I try and allow the person to...express those things that they can't – don't feel they can, in other open places (D15)*



I concluded that these two narratives required a different set of dimensions in order to characterise them meaningfully, and so for the purposes of this analysis I assessed the framework as not relevant to them.

From the finalised framework I created a recovery narratives typology, including all refinements to types of narrative and to definitions. This is presented as Table 16:

Table 16: Characteristics of Recovery Narratives typology

#	Dimension/type	Definition	Description
<b>NARRATIVE FORM (What kind of story is this?)</b>			
<b>1</b>	<b>Genre</b>	<b>A literary kind, type or class of story</b>	
<b>1.1</b>	Escape	Narratives of escape from and resistance to abuse, threat, stigma and persecution.	Escape from oppressive beliefs, systems, services, treatments or negative identity as a result of maltreatment or stigma. May contain images of entrapment and/or of a fight for survival.
<b>1.2</b>	Endurance	Narratives of loss, trauma, difficult circumstances and/or seemingly insurmountable odds.	Endurance of losses, weathering storms or battering down the hatches. May contain haunting or chaotic elements or be in the midst of traumatic events. Successes may be expressed in terms of having survived, or kept going. Narrator's priority may be salvaging over restoring or transforming themselves.
<b>1.3</b>	Endeavour	Narratives of coping strategies and plans, with some continued difficulties and positive aspects.	Endeavouring to make changes and incorporate positive aspects, while accepting difficulties as an ongoing factor of recovery. Narrators may feel they are active agents of change, or may focus on doing things or keeping busy. Priority may be managing rather than transforming themselves.
<b>1.4</b>	Enlightenment	Narratives of transformation and inspiration, with experience of distress/trauma viewed as positive, as new perspective has been gained.	A journey of exploration or discovery leading to empowerment. May contain aspects of redemption or having been saved by something greater than themselves, either by spiritual or humanistic means.
<b>2</b>	<b>Positioning</b>	<b>Ways in which narratives are situated in relation to mental health services (defined as the dominant clinical mental health provision of the country involved).</b>	
<b>2.1</b>	Recovery within mental health services	Narratives incorporating positive experiences of the mental health system, either through using services or through delivering services (e.g. peer support)	Diagnosis or experience of being a member of staff or volunteer within mental health services may be experienced as empowering; and treatment, services or relationships with practitioners and/or colleagues and service users as enabling, positive or a salvation.

			'Within services' may include either or both of using and delivering services.
2.2	Recovery despite mental health services	Narratives of protest in opposition to the biomedical model of mental illness or associated myths (e.g. recovery is not possible) and/or in opposition to mental health services and systems.	Experiences of oppression. May include experience of maltreatment by mental health services, resistance to concepts e.g. 'myth of incurability', or recovering of voice/ agency.
2.3	Recovery outside of mental health services	Narratives of recovery in which mental health services do not feature, or feature only very minimally (e.g. visits GP). May not engage with psychiatric definitions and psychological concepts of individual personal growth.	Experiences of living a 'good life' beyond services. May incorporate social, political, spiritual, and economic elements, often with a focus on specific areas such as activism, adventure, relationships or spirituality. May contain elements of having a greater purpose: 'helping others in the same boat', or a changed understanding of what is most important in life.
<b>3</b>	<b>Emotional tone</b>	<b>The overall mood or feeling of the narrative</b>	
3.1	Upbeat	Positive tones	E.g. buoyant, content, hopeful, proud, optimistic, reflective
3.2	Downbeat	Negative tones	E.g. agitated, apologetic, frenetic, pessimistic, sad, shaken
3.3	Critical	Provocative or stimulating tones	E.g. angry, defiant, protesting
3.4	Neutral	Flat tones	E.g. matter of fact, monotone, disenfranchised
<b>4</b>	<b>Relationship with recovery</b>	<b>How the narrator relates to the concept of recovery at the time of narration</b>	
4.1	Recovered	Recovery as an outcome which has been achieved	Period of distress seen as being in the past. May be a clear split between past and present selves.
4.2	Living well	Recovery as a process within which narrator is well-established	Narrator is living well in either the presence or absence of mental distress and sees any continuing difficulties as things which they can overcome.
4.3	Making progress	Recovery as an ongoing process within which narrator is beginning to see progress	Narrator is confident in ability to cope, despite feeling relatively close to the disruptions of a mental health crisis.

4.4	Surviving day to day	Recovery as an ongoing process in which the narrator is tentatively engaging	Narrator may be in a new or difficult or ongoing situation where it may be difficult to realise their hopes, but they still express experiences in terms of recovery.
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### NARRATIVE STRUCTURE (what shape of story is this?)

<b>5</b>	<b>Trajectory</b>	<b>The direction of a narrative towards its destination</b>	
5.1	Upward	An overall ascending progression towards recovery	Narratives of revelation or purposeful suffering, or of evolution from darkness to light towards a better future, or of overall improvement.
5.2	Up and down	Continuing upturns towards health/wellbeing and downturns towards distress/struggle	May challenge the progressive trajectory of spiralling upward. May be experienced as dramatic, 'roller-coaster' narratives or more drawn-out 'progressive and regressive' stories.
5.3	Horizontal	An even narrative without significant upwards or downturns	Narrator may feel that they are currently stagnating, or taking one day at a time.
5.4	Interrupted	A narrative interrupted by an unexpected crisis or difficulty before resuming its former shape and direction	Narrator sees the crisis or difficulty as a blip, after which their life has returned to its prior state
5.5	Cyclical	A narrative cycling through sequences of distress, gradual recovery, a period of wellbeing and then distress again	Narrators describe a process of going back to the beginning, with no benefits from previous periods of recovery/wellbeing being retained during periods of distress. Narrators may describe cycle as frustrating (a continuous battle) and/or a source of strength (pride at ability to move through difficult periods).
<b>6</b>	<b>Turning points</b>	<b>Pivotal moment(s) within the narrative which affect its overall shape.</b>	
6.1	Restorying	Turning point is the moment in which a narrator gains a new understanding of their experience.	May be the moment a narrator resists being defined by a dominant discourse and takes over the authorship of their own stories.
6.2	Change for the better	Turning points described as moments of transition followed by sequences where things improve.	Positive events in themselves, such as a moment of self-acceptance or intervention from others, or difficult moments which prove to be a catalyst for positive change, such as realising that others couldn't help them.

6.3	Change for the better or worse	Turning points described as moments of transition followed by sequences where things either improve or get worse.	Narrator identifies both positive events and turns for the worse as turning points in their narrative
7	<b>Narrative sections</b>	<b>The components of a mental health recovery narrative.</b>	
7.1	Origins	Possible roots or causes of later mental distress, or description of life before distress	
7.2	Problems begin	Onset of difficulties, or a sense of going downhill	
7.3	Problems worsen	The central experience of distress	
7.4	Impact of distress	Effect on narrator's life, relationships etc.	
7.5	Glimpses of recovery	Positive changes which may lay the foundation for turning points	
7.6	Turning point	Getting involved in an activity, a new relationship, contact with services, a change of perception, hitting rock bottom	
7.7	Roads to recovery	A recovering period, or a sequence describing personal benefits, connections made etc.	
7.8	Life afterwards	Reflections, hope for a better future, inclusion of hopeful elements/triumphs to inspire others	
<b>NARRATIVE CONTENT (what resources have been deployed in the telling of this story?)</b>			
8	<b>Protagonists</b>	<b>The major characters and/or forces at work within a narrative.</b>	
8.1	Personal factors	The force(s) working at micro or inter/intra-personal level within a recovery narrative	Most commonly the narrator him or herself: the strong conqueror, the scarred survivor, the enlightened explorer. May also be a helping person or factor such as a helpful treatment or medication
8.2	Socio-cultural factors	Meso-level factors within a recovery narrative. Family, friends, groups or local organisations, mental health staff and services	These may be 'supporters or villains', exerting positive or negative effects on the narrative.

<b>8.3</b>	Systemic factors	Macro-level factors within a recovery narrative. Wider community or socio-political systems including legal, healthcare, policy, political, religious and international factors	These may affect the narrative either positively or negatively.
<b>9</b>	<b>Use of metaphors</b>	<b>Imagery employed by the narrator to depict states of being, relating to distress and recovery.</b>	
<b>9.1</b>	Distress metaphors	Focused on past distress or a future return to the experience of distress	May depict descent, spiralling out of control, disconnection, alienation, chaos
<b>9.2</b>	Recovery metaphors	Focused on past, present or future experience of recovery	May depict connection, bonding and integration: regaining control of life, partnership with others, victory in fight against mental distress

## 7.4 Discussion

In this study I assessed the relevance and comprehensiveness of a preliminary conceptual framework through a structural analysis of interviews with people from four marginalised groups. This produced a typology of recovery narratives. The study produced three key findings, which relate to existing literature in the following ways.

### 7.4.1 The diversity of narratives which can be defined as ‘recovery narratives’ is affirmed

First, I found the preliminary framework to be relevant to narratives of individuals experiencing diverse forms of recovery, involving many different factors. This finding supports research which presents recovery as a multidimensional process, involving components at individual, socio-cultural, political and structural levels (Williams et al., 2015). It strengthens my systematic review finding that there are multiple dimensions and types of narrative that can be described as recovery narratives. This is an important consideration for practitioners offering their own or others’ stories to support recovery, and for those who design and facilitate narrative-based interventions, such as courses within Recovery Colleges, or narrative-based public health or advocacy campaigns.

A key concern raised by those critiquing the use of recovery narratives in services was that narrow interpretations of recovery narratives may be operationalised for organisational rather than individual benefit (Costa et al., 2012, Voronka & Grant, 2021). Singular representations of recovery narratives, dependent upon “tight adherence to generic conventions” for their efficacy (Woods et al., 2019), may put pressure on narrators to conform to particular types of narrative depending on their context (De Wolfe & The Borderline Academic, 2019). This effect can be seen in the statement from an apologetic participant above, a peer support worker in a recovery college, who felt her story of resistance to the recovery model as operationalised in services was “not the story you want, I’m sure”. Her apologies provide evidence of the kind of pressure felt by narrators or would-be narrators, which may (unintentionally or otherwise) be exerted within storytelling contexts.

The typology presented in [Table 16](#) can be seen as speaking to this pressure by providing data which reinforces the multiplicity of forms, structures and content which are possible when recovery narratives are elicited in certain contexts. ‘Endurance’ and

'struggling day to day' narratives challenge the "compulsory positivity" (Carton, 2017) of some organisational agendas, while offering hope to people experiencing distress by, for example, reducing feelings of isolation. Socio-cultural and systemic factors within the typology challenge narrative-based interventions which may promote storylines "deflect[ing] attention from systemic inequalities and social injustice" (Woods et al., 2019). The presence of 'downbeat' and 'neutral' tones support the inclusion of stories which may not conform to a "genre of inspiration", required to be emotionally uplifting (Woods et al., 2019), but which may be experienced by the reader/listener/viewer as more authentic than entirely positive stories. Perception of authenticity has been found to be a key moderator of whether a recovery narrative had a positive or negative impact on those accessing them, and this perception was found to increase where narrators appeared not to have 'edited out' their experiences of adversity or struggle (Rennick-Egglestone et al., 2019b).

As both the benefits and harms of recovery narratives are further explored (Ng et al., 2019, Rennick-Egglestone et al., 2019a), it becomes increasingly important that narrative-based interventions and collections offer a variety of narratives, representing numerous 'templates' for recovery, to maximise their recipients' chances of experiencing connection and hope. For example, curators of a UK collection of recovery narratives, *Beyond the Storms* (Davidson & Lynn, 2013) found that its publication, though well-received, created a demand for other kinds of stories. The editor of the recent companion collection, *Riding the Storms* ([library.recoverydevon.co.uk/document/riding-the-storms/](http://library.recoverydevon.co.uk/document/riding-the-storms/)), reported that:

*the good intention of trying to give hope [in Beyond the Storms] was backfiring ... for some people, they were perversely making things worse and not offering hope. That's not to say that the stories in Riding the Storms don't offer hope but ... it's more about offering hope by helping people feel less alone" (Personal communication, 24.01.2019)*

By considering the multiple dimensions and types of recovery narrative identified in the typology presented here, practitioners and curators could build diverse collections which are more likely to have a positive impact on the widest possible range of recipients.



### 7.4.2 Typologies of narratives are ‘unfinalisable’

The second finding was that the typology needed to be refined to be more comprehensive, in order to fit the experiences of people from marginalised groups. For example, a new type of trajectory was identified. The stories of some participants identified as having multiple and complex needs (experiences of mental distress and substance use, homelessness and/or offending behaviour) were found to have more cyclical trajectories. For people with these cyclical experiences of distress and recovery, practitioners may have important roles as ‘holders of hope’ (Schrank et al., 2012) during periods of distress, when individuals may temporarily be unable to construct, hold onto or believe in their own previous narratives or experiences of recovery.

Another type was refined by changing its name to better reflect participants’ experiences. A ‘narrative sections’ type was originally titled ‘life before distress’. But many of the narrators from marginalised groups had not experienced or did not remember such a chapter of ‘life before’ their mental distress. Previous research has highlighted the overlap between experiences of childhood trauma and mental distress (Bentall et al., 2014, Cooke, 2017, Longden et al., 2016). The Power Threat Meaning framework, which provides an alternative to diagnostic categories in terms of understanding distress, gives a central place to the construction of narratives in an individual’s recovery (Johnstone et al., 2018). The renaming of this narrative section to ‘origins’ results in a more trauma-informed typology (Sweeney et al., 2016), while not excluding narrators whose origins may have been non-traumatic.

Constructing a typology is one of six ‘exemplars’ of dialogical forms of narrative analysis offered by Frank (2010). He describes some advantages of constructing typologies, including the acknowledgement that stories depend on other stories: “on recognisable plots, character types, conventional tropes, genre-specific cues that build suspense, and all the other narrative resources that storytellers utilise” (2010: 119). He reflects on responses of readers to his influential illness narrative typology, of restitution, chaos and quest types of narratives (outlined and built upon in [Chapter 4](#)), indicating that identifying types appeared to help people think about what stories they are telling, want to tell or may no longer want to tell. He also describes some disadvantages of constructing typologies, such as the risk of putting stories in boxes, therefore:

*allowing and even encouraging the monological stance that the boxes are more real than the stories, and the types are all that need to be known about the stories. In a world where simplification is a pretext for knowing, and knowing is a pretext for controlling, typologies are risky (Frank, 2010b: 119).*

He concludes that “typologies should never be considered final”. He expected other people to add types to his own framework, stating that “the methodological point is that a dialogical typology builder is always listening for another type’. From this perspective, no typology can ever be considered to be fully comprehensive.

### **7.4.3 Not all recovery narratives are expressible in conventional ways**

Third, the typology was found not to have relevance for two of the 77 narratives. In their less conventional forms, both can be seen as expressing the limits of “tellability” (Norrick, 2005, Ochs & Capps, 2009) making them less straightforward for analysts to comprehend. Indeed, for one of these narratives, a co-analyst wrote the following in the notes section of her analysis template: “Really not sure what to do with this narrative, particularly with limited time [...] really struggled, hope you fare better!” All other sections of the template were blank. This could be read as an expression of the incomprehensibility of the narrative to her, OR of how meaningless the categories of the typology appeared for this particular narrative. Yet it is often the narrators (that is to say, service users, patients, participants) who risk being dismissed if they do not conform to a professionally-generated typology, measure or framework. This can be seen, for example, in the ‘narrative coherence’ measure explored in [section 3.1.1](#), in which the participant rather than the typology is positioned as problematic. Using this measure, some narrators, perhaps particularly those with psychosis or trauma experiences, may be seen as producing meaningless ‘word salad’ in their stories (Mitchell et al., 2015) and may subsequently be judged incapable of ‘insight’ (Lysaker et al., 2002). This form of dismissal may particularly be the case in time-pressured situations – highly likely in current academic and health service settings – where there may be less opportunity to take the time needed to comprehend something more unconventional, as with the analyst quoted above. Rather than an inherent lack in the narrator, it may be that other forms of communication suit some narrators and some experiences better. For example, a conceptual review explored the potential of poetry to

support meaning-making for people with experiences of psychosis (Pearson et al., 2020). The review challenged the reductive notion that psychotic speech is merely an incoherent representation of a deeper pathology. Instead it proposed that psychotic speech could be considered as meaningful poetics – not as a glamorisation of psychosis, but rather reflecting the way that ‘poetic’ is used as axiomatic of an indescribable process, communicating something which otherwise might remain incommunicable (Pearson et al., 2022).

Narratives (and their tellers) at risk of being dismissed as ‘incoherent’ may instead require professionals and other audiences to rethink what may constitute a narrative (Baldwin, 2005). Narrow concepts of ‘tellability’ may reproduce what have been called sanist assumptions within mental health (Perlin, 2002, Poole et al., 2012). Such sanism can lead to testimonial injustice (Fricker, 2007), wherein a narrator’s credibility and capacity as a knowledge holder may be undermined by the listener’s prejudice. The primarily spoken and written narratives used within mental health practice may thus need to be extended to incorporate other forms of narrativity (Baldwin, 2005).

Approaches providing alternative narrative modalities within research and interventions include PhotoVoice (Sutton-Brown, 2014), participatory arts (Stickley et al., 2018), poetry (Pearson et al., 2022), dance (Ravelin et al., 2006), sport (Carless & Douglas, 2008) and games-based interventions (Kerr et al., 2019), in addition to the more established arts therapies already recommended by national guidelines for psychosis services (National Collaborating Centre for Mental Health, 2014).

## **7.5 Summary**

In this study I assessed the fit of a conceptual framework developed from my systematic review and narrative synthesis presented in [Chapter 4](#). The fit was assessed by undertaking a structural analysis of participant narratives. My findings demonstrate the overall relevance of the framework to the narratives of people from marginalised groups, and provide the basis for a refined, more comprehensive typology of recovery narratives. This typology demonstrates the diversity of existing types of recovery narrative across multiple dimensions, the impossibility of providing ‘finalised’ typologies, and the importance of offering and using non-prose based narratives. This underlines the importance for practitioners of offering narrative-based interventions

which provide access to diverse selections of narratives and/or possibilities of storytelling, which describe the multiple possible ways of recovering.

## **7.6 Reflexive pause**

At first, my overall aim of constructing and refining a conceptual framework which could be used as an evidence base for narrative-based interventions made sense to me. However, as my analysis progressed I had growing concerns about the ‘neatness’ of this approach and of how the resulting typology might be used in later research for normative purposes, regardless of any entreaties of mine to use them in pursuit of a plurality of stories. A marker of quality in narrative inquiry is ‘awareness of temporal fluidity’ (Andrews, 2021): the recognition that narrative research is built on shifting ground, and should reflect the fact that life does not stand still. A risk with developing a framework or typology which characterises narratives is that it provides a form of ‘frozen moment’ analysis which is ‘preserved in the hoarfrost of realist description’ (Les Back, cited in Andrews, 2021). This approach treats stories as “predetermined, universal categories and objects of analysis” (Fernandes, 2017) instead of co-constructed *processes*. Another important principle of the narrative inquiry approach is that the meanings of narrative will shift, depending on the context in which they are constructed and heard. I therefore turned next in my analysis to a focus on the contexts surrounding the telling of recovery stories.

## **Chapter 8: ‘Maybe I’d better not talk’: what is it like for people from marginalised groups to tell their recovery stories?**

### **8.1 Introduction**

In this chapter I present findings from a reflexive thematic analysis. This analysis further addresses my first objective, through taking what can be seen as a more three-dimensional approach to the ‘characteristics’ of narratives to include the effects of context on storytelling. The analysis also addresses my second objective of exploring participants’ experiences of telling their stories in formal and everyday settings.

I preface my findings with some background information and a description of the second analytical process undertaken, a reflexive thematic analysis. I conclude with discussion of the presented findings, their relation with existing literature and their implications.

#### **8.1.1 Background and aims of the second study**

In this second analysis, I shift my attention from the *characteristics* of narrative to the *doing* of narrative, which foregrounds the context within which particular narratives are produced (Phoenix, 2013). As I describe in [Chapter 5](#)’s methodology, in my chosen approach to narrative interviewing I saw participants’ narratives as stories of experience (Squire, 2013) rather than straightforward descriptions of events. This approach fits with what has been referred to as a ‘second wave of narrative analysis’ that has ‘moved from the study of narrative as text (first wave) to the study of narrative-in-context (Georgakopoulou, 2006: 123).

In making this division, Alexandra Georgakopoulou engages with a debate within narrative theory on whether a focus on ‘big’ or ‘small’ stories is more productive. ‘Big story’ approaches – or ‘life on holiday’, as Mark Freeman (2006) puts it – analyse the content of stories produced for an occasion, often an interrogative one, such as an autobiography, clinical encounter or research interview. These occasions can be useful for creating reflective opportunities for understanding that may not have been available in the immediacy of the moment (Freeman, 2006). ‘Small story’ approaches, in contrast, focus on the stories we tell “in passing, in our everyday encounters with each other”, also referred to as ‘narratives-in-interaction’ (Bamberg, 2004: 367). As Ann Phoenix

(2013: 73) notes, this approach allows insight into the dilemmas and troubled subject positions speakers negotiate as they tell their stories and so into “their understandings of current consensus about what it is acceptable to say and do in their local and national cultures”.

The two approaches of ‘big’ and ‘small story’ research can be seen as complementary. In this framing, my interviews take the ‘big story’ approach, as I elicited narratives within the context of a research interview. I was interested in the kinds of stories people from marginalised groups might tell when asked for their recovery narratives in this setting. But from a critical, emancipatory research perspective, I could not ignore the bigger picture in which participants might be telling their stories: the subject of mental distress is still shrouded in stigma and discriminatory practices, and thus stories of distress and recovery are told in a socio-cultural context that is inequalitarian. This led to my questions in part B of the interview, asking participants to reflect on their own experiences of telling their stories. Although not a small-stories approach in itself, as the data was elicited in a ‘big story’ setting (i.e. a research interview), my interest was informed by the small story approach and by its focus on engaging with the ‘troubled subject positions’ (Phoenix 2013) that participants might be negotiating as they told their stories elsewhere.

The perspectives of people experiencing mental distress and additional marginalisations on what it is like to tell our stories had not to my knowledge been explored at scale. Increased understanding of what it is like to tell such stories may sensitise mental health practitioners, policy-makers and researchers to some of the ‘complications, considerations and consequences’ (Voronka & Grant, 2021) that may exist for those undertaking the storytelling. My aim in this study was therefore to explore how stories of lived experience are told in various settings, from the perspectives of people from specific marginalised groups. The resulting paper based on this chapter was published in August 2022 and is available at <https://journals.sagepub.com/doi/full/10.1177/10497323221118239>.

## 8.2 Method

### 8.2.1 Reflexive thematic analysis

For this study I analysed Part B of the interviews of participants who had been asked the supplementary questions about how they had found telling their story in Part A, and how their own storytelling might vary in different settings (n=71). I selected a reflexive, inductive approach to thematic analysis (Braun et al., 2019), as an approach which reflects and is compatible with the assumptions of a qualitative paradigm (Braun & Clarke, 2019; 2006), including critical framings of language, data and meaning (Braun & Clarke, 2013). I used both semantic-level (descriptive) and latent (interpretive) approaches to coding and theme development; at first a largely semantic approach, to capture and stay close to participants' verbatim statements, with latent coding being developed in later stages (Terry et al., 2017).

I uploaded the transcripts to QSR NVivo version 12 and re-familiarised myself with the data by listening again to interview recordings and checking all transcriptions for accuracy. On first reading, I drew up a list of initial codes of interest, presented in [Appendix 6](#).

On subsequent readings, I generated initial themes through exploring possible relationships within and between codes. This led to my identification of factors which influenced stories at five levels, presented in [Appendix 7](#). I discussed and reviewed these initial themes with my supervisors to enrich my understanding, followed by an iterative process of re-reading transcripts and development of final themes, each based on one central organising concept. I asked several questions of my data: how do participants report varying their stories according to the setting? What reasons are people giving for varying their storytelling? What is at stake in each setting? What do participants report *not* speaking about?

Using Andrews' (2021) non-exhaustive checklist of quality indicators for narrative research as a guide, I provide information here about the study context, interview setting and other storytelling settings described by participants to *contextualise the research*. I provide extensive quotations and my findings at key stages of the analysis to enhance its *trustworthiness*; and I describe opportunities for *critical reflexivity* that were built in throughout the study. Sensitivity to *multi-layered stories* or the interconnection

of the micro and macro, *co-construction of meaning* and *attention to the untold* are central to my findings.

### **8.2.2 Reflexivity**

In addition to locating myself and my interest in recovery narratives in [Chapter 1](#), I provide here a reflexive account of the parts of my experience that specifically informed this thematic analysis.

I bring to this analysis my academic background in literature and sociology, and a professional background in community and youth work, including mental health service provision. Youth work is underpinned by a ‘pedagogy of the oppressed’ (Freire, 1970/2017), an educational approach based on the lived experience of people from marginalised communities. I also bring lived experience of intersecting marginalised identities, as a queer woman who has experienced and survived recurring mental distress, who is nonetheless relatively privileged educationally and as a white cisgender woman. I have known the power of stories to exclude or shame (for example, being on the receiving end of cultural stereotypes of lesbians), to liberate (for example, encountering LGBTQ+ ‘coming out stories’ as a teenager), and to exclude others in their turn, in Plummer’s “continuing paradox of othering” (2020: 64) – for example, witnessing the exclusion of trans people in some women’s and queer spaces. These understandings shaped my relationship with the accounts, for example heightening my awareness of issues of epistemic and testimonial injustice (Fricker, 2007).

## **8.3 Findings**

### **8.3.1 Participant characteristics for this analysis**

71 of the 77 participants were asked the supplementary questions about how stories might vary in different settings, and so were included in this study. Thirteen were not asked, due to time constraints or because participants had experienced some distress in the interview (either the participant indicated they wanted to finish, or the interviewer made a judgement to minimise supplementary questions in the light of distress).

Of the 71 participants, 39 were women, 29 were men, and 3 chose ‘prefer not to say’. All self-identified as experiencing forms of mental distress, with some using services and others not, either by choice or due to lack of availability. Four participants were aged under 25; 13 were aged 25-34; 13 were aged 35-44, 26 were aged 45-54, five were aged



55-64 and two were over 65 (eight preferred not to say). 25 participants identified as being from Black, Asian or other minoritised ethnic communities. 15 identified as being LGBTQ+. 39 had self-identified experiences of psychosis, and 28 had paid or voluntary peer trainer or support roles.

Four participants resisted the suggestion that they might vary their stories. One said “I just get far too effusive having the opportunity to speak”. Others linked the concept of varying stories with hiding parts of themselves due to stigma or shame, which they were committed to challenging. As one participant, a peer worker, said:

*Otherwise it's like there's something wrong, and there isn't anything wrong. It's just that stuff has happened in my life. That is unfortunate but it's not going to define everything about me, so I wouldn't change [my story] for anybody now*  
(A7)

### **8.3.2 Settings reported by participants**

Participants with paid or voluntary peer roles (hereafter ‘peer participants’) almost exclusively focused on how they told their stories in their peer work settings, including giving talks at conferences and to services, and when training practitioners and delivering peer support. Participants who did not have such roles (hereafter ‘non-peer participants’) focused on how they told their stories in everyday interactions, including formal settings (health, housing and employment services, support groups, on application forms for jobs, benefits and funding, and when completing questionnaires), and informal conversations (with family, friends, work colleagues, church members, others with similar lived experience and online). All participants were simultaneously producing *stories about their stories* in the research interview, and some offered thoughts about how the immediate research setting was shaping their telling.

Although I had asked for people to describe their ‘mental health and recovery experiences’ it was notable in this analysis that non-peer participants described telling stories of their lived experience more broadly, moving away from a recovery focus, whereas peers tended to report on their specifically recovery-focused storytelling.

### **8.3.3 Overarching finding: power dynamics affect how lived experience stories are told**

Questions of power differentials in the storytelling context were central to all participants' accounts of telling their stories. This finding first came to my attention when I noted that peer participants were reporting fundamentally different experiences than other participants. Peers, whether paid or unpaid, mainly described how their roles afforded them some authority to use their stories positively, to support or educate others. In contrast, non-peer participants mainly described their own relative lack of agency whilst telling their stories. They rarely reported using their stories to positive effect. This alerted me to ways that varying power dynamics in different settings were affecting participants' storytelling. Within this overarching finding, I identified four themes which further describe how questions of power affected the ways in which participants' lived experience stories could be told.

### **8.3.4 Challenging the status quo**

Peer participants reported opportunities for using their stories to challenge conventional assumptions and change attitudes. For example, this participant describes how she shared her own adverse childhood experiences with work colleagues, in order to challenge stigma and potentially judgemental attitudes:

*[The reason] I like to share is that I've somehow come to a point where people always think I'm posh, and there's so much power to sharing the parts of you that people don't expect. Because actually when I share my story, it changes the way that people perceive people that have those experiences [...]. It's easy for people to think [of those who] have grown up around heroin addiction and squats as lesser [...] But when you're making those judgements, you're making those judgements about me. When you are judging someone that's begging, I've been a child doing that. That's circumstance. And I think I have so much opportunity, in sharing my story, to make people really aware of circumstance, privilege, the fragility of the social status (B24)*

Delivering talks and training to the general public and other professionals offered opportunities to undermine or resist the dominance of biomedical narratives, through presenting different accounts:

*In sharing [my story] with a more broad audience, I have this conscious urge to still try and dispel any notions of disease or illness, because as a society I think we are becoming increasingly inculturated to all this stuff, so I will try and focus on experiences. In environments where I am teaching health and social care professionals, the purpose is slightly different. I am trying to help them be better practitioners. Part of that is about pointing out the vagaries of diagnostic terminology. So I will talk about the ontology, the epistemology, the history of the science. I will refer to philosophical underpinnings. And it might just go over the heads of some of them, but I know that sometimes I'm hitting home (A30)*

In supporting others with lived experience, peers described using their stories in ways that might inspire hope, normalise potentially shameful experiences and/or offer learning. They reported having opportunities to disrupt traditional power relationships within health services, through reciprocal exchanges of personal experience. These disruptions could have powerful effects, as can be seen in this account from a recovery college trainer:

*It's really lovely sometimes when people come to recovery college, and it feels like they have been through so many different parts of the service and they just don't know where they are and – "ok then, teach me something", arms folded, sitting back, here we go again. And oftentimes, even though we tell people that we're peers, the penny doesn't start dropping until they've been there a while and it comes out that we've got these stories. And it's almost like sometimes you can see people, their arms drop from in front of them and they start leaning forward, and they start looking at you differently and a barrier's gone. Not always but it's happened enough for me to realise how powerful it can be, to have somebody in front of you who knows the territory, still lingers in the territory, but works on it. (D8)*

Here, the fact that people in positions of authority also have “these stories” is reported as a welcome surprise for course attenders (“they start leaning forward”), who may have been in the system for a long time, and become disillusioned about what was on offer (“arms folded, sitting back, here we go again”).

### 8.3.5 Risky consequences

Peer and non-peer participants alike overwhelmingly reported or alluded to a strong sense of risk when telling their stories. Getting their story 'right' really mattered, because the consequences of getting it wrong were perceived to be, or had been, potentially serious for themselves or others.

Non-peer participants described how telling their stories in certain ways could exacerbate their own shame or distress, cause others distress, lead to being stigmatised by others, or result in unwanted clinical treatment or the potential loss of assets such as benefits, jobs or funding. Thus, fine judgements were made about what to share, when and with whom:

*I suppose, when I'm talking to a clinician I would be very wary I think, because if I say half the stuff that has happened in my head, they might go, 'right, lock you up'! (A2)*

There was a reported sense of watchfulness and a need for protection – sometimes protection of others, but mainly of themselves – due to the perceived damage that sharing some aspects of their stories might inflict. This sense of caution was echoed in the use of phrases such as 'sussing out' recipients prior to telling parts of their stories. Others described an in-the-moment process of gauging how to proceed, depending on cues perceived in their recipients:

*I do vary about it because you know, with communicating, with watching people's expressions and things like that [...] if I felt like somebody was going to be overly judgemental there might be things that I choose not to share. Or equally if I saw somebody was understanding and receptive and interested in what I was saying I might choose to share a little bit more (C3).*

Additional intersecting experiences of stigma and discrimination such as racism or homophobia could compound a sense of stories being risky to share. Participants from LGBTQ+ and Black, Asian and minority ethnic communities reported missing out elements of their experience entirely or not accessing services, to avoid having one more stigmatising label, as exemplified by this participant:

*I haven't talked about [mental health] in job applications, I have definitely not accessed NHS services because I felt – I guess when you have so many things stacked against you, so my life experiences, being a Black woman – do I want to stack against me the potential that I might reveal myself to a service that I then later want to work for or have colleagues from? [...] Maybe if I was a white middle class woman that didn't have any of those experiences, I might feel – or a white middle class man, if you really get down to it – I might feel like, oh you know what, I believe in non-discriminative legislation so I can do that. But I think that when you have got other things stacked against you, you don't want to then add another thing to the mix. So I haven't been to NHS services, at least in part for that reason (B24)*

Some participants expressed a desire to talk more freely, often described as being more open – “you do feel like you want to tell, because this is a big part of me” – but felt this was better avoided: “you want to say, but you – you hold back”. This participant had a stark example of the potential risks of talking openly:

*I didn't know who I could talk to, and who I was safe talking to [...] because, with my therapist, she was lovely and I trusted her, but then suddenly she brought on the psycho-blah person, and I just seized up and I was like, why are you here? And that's when they led to trying to lock me up, and I was just scared [...] I was being really open with my therapist because we'd got to a really nice, kind of trusting place [...] Also, because I wasn't saying a word, for ages, I felt like it really would help me to talk, so when I finally got comfortable enough to talk, then all that happening [being sectioned], it was like, oh shit, maybe I shouldn't talk (A2)*

A strong sense of betrayal was present in this account. The participant was aware of the risks (“I didn’t know ... who I was safe talking to”) and had shared her story only after building up trust over time with a specific professional. Yet choosing to tell her story in a particular way led directly to a loss of freedom and the onset of unwanted treatment. Perhaps unsurprisingly, she concludes that her previous strategy of *not* telling her story might have been less harmful to her.

One participant reported feeling naïve about her previous openness:

*I am always encouraged by not-so naive people that I should not say anything [...] My partner is a very strong believer that if they don't need to know, don't tell them, and my mum would probably say the same [...] A colleague once said to me, never give away too much [...] I think she's got a point. You know, it is very personal, and yeah, it's sort of the weaker part of you as well isn't it? (A14)*

Here, she is both judging herself for her previous approach and inviting the interviewer's endorsement of a view that her experiences of distress are a 'weaker' part of herself ("isn't it?").

As well as risk of judgement for describing distress, participants also described fear of judgement for describing their recovery:

*It's weird [...] you can't be too brazen about your [recovery], you can get unfortunately probably perceived as being a bit boastful; you know, 'I have had a psychosis but I have recovered'*

Peer participants also described a careful, considered process of 'tailoring' their stories; of gauging what might be relevant or useful to share whilst not being overwhelming. The risk in these cases was to those they were supporting:

*You've got to tell them in a way that it doesn't paint a dark picture, that they [think] 'Oh my God, is this what happened to him, I'll never...', you know. You've got to make sure that you tell a story as it is, to a degree, but also give them hope (B2)*

The fear expressed here is that telling their story "as it is" – presumably including difficult times as experienced by the peer – risks producing "a dark picture", the opposite of the desired effect incumbent on a peer worker, of embodying hope. A related, recurring concern was the potential to trigger traumatic memories for recipients – for example, where stories contained similar details. One peer reported the careful balancing this could sometimes require:

*It's a real juggling act as a peer to judge when the moment is right. And you can get it wrong. And when I get it wrong, I just go now, "I've got it wrong. I'm so sorry. I've really messed that up"(D2)*

This peer had previously described herself “shaking” as she began to tell the person she was supporting about an attempt to end her own life, in response to a direct question about whether she had ever been suicidal. She foregrounds twin yet potentially conflicting values of honesty with people she is supporting, and avoiding risk of harm, which she returns to repeatedly in the interview. Peer work differs significantly from other mental health professions, in that story exchange is often reciprocal rather than asymmetrical. This account, with its repeated stress on her awareness of risk, can be seen as addressing a fear based on the current unequal status of peer work within mental health practice; that peers may be perceived as somehow less professional than others through their disclosure, or even simply possession, of their own stories of distress. A peer trainer perhaps also speaks to this fear when she reports advising other peers to avoid sharing any potentially traumatic content:

*Generally speaking in my job I would keep away from 'hot button' issues, no matter what. We tell our students if you think about the emotional response to something you're talking about on a scale of 1 to 10, then we like to keep things in a 1 to 4 if we are sharing relevant experience, and keep away from big topics that we know are general triggers for lots of people. So, without saying it, we are talking about abuse stories, those sorts of things (D8)*

This account describes a paradoxical situation of being expected to provide support on the basis of shared experience, whilst being instructed not to include subjects which may have played a key role in experiences of mental distress.

### **8.3.6 Producing 'acceptable' stories**

Participants also reported a perceived or actual pressure to reproduce normative and acceptable stories in some settings, rather than authentic and possibly dissonant ones. This was experienced by some during the data collection process. One peer participant, for example, expressed a struggle between what he perceived I was asking of him in the interview and other ways he could tell his story:

*I could be ranting and raving...I could have a diatribe against psychiatry or mental health services, from my own experiences or generalising about things more broadly. I'm trying to focus on my own story for these purposes [the interview] but it's very hard for me to detach that from my political affiliations,*

*from my beliefs, from what I think are my understandings of the world and the way things work (D4)*

He perceived a need to “detach” his own story for the purposes of this research interview from his “understandings of the world” as a whole. The impact was perhaps to give a less emotional, more individualist account than he would have liked (the ‘trying to focus on my own story for these purposes’), whereas a more holistic account of his recovery might involve anger (“I could be ranting”), involvement in politics, and resisting dominant biomedical narratives (“I could have a diatribe against psychiatry”). His assumption seems to be that these parts of his story were not what I wanted.

Participants in settings which encouraged alternatives to dominant narratives also discussed experiencing subtle pressure to conform to acceptable narratives. For example, in a support group emphasising spiritual over biomedical interpretations of psychosis, one participant felt reluctant to share how difficult things were for her, because of other group members’ focus on good news stories:

*I go to a peer support group now, a spiritual mental health thing. I really struggle [to share difficult experiences] because I feel like I'm bringing the group down.*

People with psychosis experiences frequently reported that these were less acceptable than other forms of mental distress, and were often minimised in their tellings. For example, this participant described feeling that a certain amount of ‘losing it’ was acceptable in her field (the creative industries) but only within certain limits:

*You're allowed to say, 'I've been having a difficult time'. But, telling somebody that you've been sectioned? It does not go down well. It really doesn't. It's really hard, people just think, 'who are you?' And I've been in that situation where [I mentioned something about my story] and there's just this...instant judgement. And I don't mean it in a terrible way. It's just that you can see people go, 'Ooh. God. You've lost control of life'. You know, 'you couldn't keep it together'. It's almost like, you're allowed to have difficulties but you're supposed to do it in a really, I don't know, glamorous, interesting way. But to actually fall to pieces in a huge heap? No. That's ugly. So no [...] it's not something I advertise...at all (A8)*



Not “advertising” her experience of being sectioned was perhaps exacerbated for this participant by being a freelance worker whose employment depended on her reputation. She expresses fear of the consequences of straying away from a permissible narrative in her professional world, where “difficult times” can retain a sheen of glamour, towards an unacceptable narrative in which her life is viewed as out of control (“you couldn’t keep it together”), and “ugly”.

Intersecting experiences of stigmatisation and inequality again compounded the pressure for some participants. For example, a Black peer participant reflected to his white interviewer on how he had told his story thus far in the interview, comparing this to other occasions where his telling might vary:

*Interviewer: Have you ever felt that are parts of your story that you’re not allowed, unable or unwilling to tell in a certain context?*

*Participant: Yeah. So [...] if I was really going to be brutally, what I call, where I am right now, authentic, I’d mention more about global genocide on Black people. Yeah? All over Africa, the effect it has here, and the effect that still has ongoing as a society, has an impact – impoverishment, marginalisation, I’d expand on that more. And [...] there’d be more emotion loaded with that. So I’d have to watch my own level of resentment, while I’m doing that, do you see what I mean?*

*Interviewer: So that would depend on the audience, who you’re talking to?*

*Participant: Exactly, so when I do a BME [Black and Minority Ethnic] group – I don’t even like that term but that’s what we are at the moment – I do talk about the global genocide on Black people, you know. And it’s my belief, which might change going forward, but currently it seems to be that we’re, we’re being killed all over the world in one way, shape or form. And how that will affect your mental health. I mean, what? Really? [Laughs] Do you know what I mean, it’s a no-brainer (B4)*

His emotion at the often-unacknowledged links between living within racist structures and mental distress would not be acceptable to some audiences. Furthermore, it must be self-managed (“I’d have to watch my own level of resentment”). He raises the subject in the interview in response to a direct question, but still suggests he hasn’t said as

much as he would/could elsewhere, perhaps because the interviewer was white (“If I was going to be brutally... authentic, I’d mention more...”). And in another, structurally (even) more unequal position than that of research participant, he reports that telling his story from this perspective could result in serious loss of resources:

*Participant: For instance when I was going for some funding from [accounting company], that [the effects of racism on mental health] didn’t get mentioned [laughs].*

*Interviewer: So there’s something about structures here, that perhaps you’d avoid talking about?*

*Participant: Yeah [...] it wouldn’t be worth me...to be honest, it would be wasted energy, there’d be nothing positive that comes out of it (B4)*

The risk of losing funding, the emotional labour of having to explain links between racism and mental distress, and the risk of his experience being denied led to this participant being highly selective about when he would tell a more authentic version of his story. The interviewer asks how he decides in which contexts it is worth expending that energy. He responds:

*I’m getting better at it, I’m not brilliant at it. Sometimes [...] when someone gets killed on a ward or something, then it’s hard to contain the kind of, argh, you know. I’m getting better at just...you know (B4)*

He reports his anger and grief as responses that must be “contained”. Perhaps for his own mental wellbeing, or as a strategic decision to avoid damaging his own interests, he perceives that he must “get better” at how he manages this – even in situations where someone has died. Thus, people from marginalised communities can be in the dual role of absorbing the ongoing trauma of (in this case) racism, while also ensuring that their storied responses to this experience do not unduly trouble those around them.

### **8.3.7 Untellable stories**

Finally, some participants reported being unable to speak about certain traumatic parts of their stories, either at all, or at different points in their lives. Stories were described as containing “things that really scar us deeply and are really painful”, which were

subsequently not mentioned or brushed over. These included accounts of psychosis-like experiences, living through suicide attempts, sexual abuse and rape:

*Participant: Certainly being raped, I would [omit this]. That was one thing that, until recently I hadn't tackled [...]. I'm going to a men's group. And it allows me to talk about it fairly openly now, whereas I definitely wouldn't have done in the past*

*Interviewer: Because you felt that you just wouldn't have been listened to or...?*

*Participant: I think I just felt deep shame about it really. Yeah (A3)*

This participant's experience demonstrates how narratives can be a double-edged sword; either oppressive or liberating, depending on the balance of power in a given setting. Dominant social narratives about rape being a shameful experience, possibly exacerbated by being seen as something that happens to women, contributed to the silencing of this aspect of his story for many years. Conversely, it is hearing counter-narratives of similar experiences in the safe context of a group for male survivors which eventually 'allows' him to resist this internalised stigma and share his own story.

Sometimes, untellable aspects of stories were non-verbally demonstrated by participants, rather than being directly reported. It was striking how often sentences faded away when participants were broaching traumatic subjects such as childhood experiences of abuse:

*I've left some bits out, and I would never talk in real detail about... stuff that's been [indicates speech marks] 'done to me' by men, cos I just...you know, nobody needs...you just need to say, or something... (D2)*

One participant's speech appeared to dissolve almost entirely when returning to his experience of multiple incidences of organised sexual abuse as a child:

*Interviewer: Have you ever felt like there are parts of your story that you are not allowed, or unwilling, or unable to tell in a certain context?*

*Participant: Yeah. Those are deep dark, dark, dark, dark, don't, don't...that you don't do. Some things like pornography, okay, what happened with the pornography (B22)*

Another interpretation could be that the participant's speech, rather than dissolving, very precisely captures the splintering effects that such prolonged exposure to trauma can have. His account may also reflect findings in my structural analysis, that not all experiences can be sufficiently represented or reproduced in verbal form, perhaps traumatic experiences in particular.

This theme highlights an important form of risk inherent in telling lived experience stories, exacerbated by power differences in particular settings; that they can be re-traumatising for the narrator. They raise serious issues of whether, in what circumstances and for whose benefit people with lived experience should be asked to recount their stories.

## **8.4 Discussion**

My aim in this study was to explore experiences of telling lived experience stories in various settings, from the perspectives of people from marginalised groups who experience multiple, intersecting inequalities. My overarching finding was that differences in power dynamics affected how participants told their stories. Four themes describe this finding in more depth: personal stories could be told by peer participants in ways which might challenge and empower; while for peers and non-peers alike, their stories must be told carefully to avoid risk and remain acceptable within the constraints of particular settings, or not be told at all.

The concept of narrative power (Plummer, 2019) usefully summarises this complex interaction of the micro-level, individual stories of people with marginalised identities with the macro-level cultural narratives which exist about them, and 'people like them'. As my first theme *Challenging the status quo* demonstrates, narrators have some power or agency to challenge dominant narratives, producing beneficial effects for themselves and others through their stories. These findings support previous studies on ways in which peers can disrupt traditional clinician/patient power structures within health, where clinicians were always the experts and patients' opinions were less valid. Mancini (2019) describes how the 'strategic storytelling' of peers helped others create meaning, develop empowered and healthy identities, and learn what a 'recovery-oriented lifestyle' might look like. Sapouna (2021) explores the uses of lived experience narratives in social work education, finding that the inclusion of user narratives can sometimes provide transformative opportunities to model collaborative and dialogue-

based learning with students. Plummer describes this perspective as engaging in “a language of liberation, and the capacity [of stories] to do things” (2019: 31).

However, these studies also draw attention to the structural inequalities which limit peers’ capacity to effect change. Mancini (2019) notes that peer contributions continue to be minimised and misunderstood in mental health settings dominated by non-peer professionals. Sapouna (2021) highlights the continued power of recovery-oriented mental health and education systems to implicitly discourage expressions of distress that do not suit their aims. Plummer (2019) describes how dominant narratives can be a productive resource, but tend to favour the status quo, and are asymmetrical, favouring some forms of narrative and content more than others. They make some lives “abundant in capacity”, whereas others are “diminished, inferiorised, marginalised” (Plummer, 2019: 31).

Furthermore, as critics of anti-stigma campaigns have pointed out, those who do choose to disclose lived experience stories differ greatly in their individual capacities to withstand, resist or avoid the potential consequences of dominant narratives, depending on their social status: “there are substantive differences between a Prince or a pop star disclosing their struggles with mental health to the public, a precarious worker disclosing to an employer, or a mother disclosing to a social worker” (Tyler & Slater, 2018). The next three themes reflect these limitations on the power of storytelling, and problematise the use of lived experience narratives within services for three reasons.

First, the theme *Risky consequences* draws attention to the fact that people with lived experience are still largely telling their stories in contexts where narratives of stigma, deficit and inferiority prevail. The biomedical model of mental health – the dominant narrative within policy and practice in the Global North – defines mental distress in terms of individual dysfunction, deficit and/or disease – a ‘what’s wrong with you?’ (Harper & Cromby, 2022) diagnostic approach. This creates and reinforces narratives of inferiority. For example, a recent study on the recovery and identity narratives of people experiencing psychosis across ethnic groups highlights how diagnostic classifications may enhance the perceived ‘differentness’ of people with lived experience from the rest of the population, leading both to public and internalised stigma, particularly for those from already-marginalised populations (Lawrence et al.,

2021). Plummer describes this process as “narrative othering”, a process which creates ‘out groups’ and ‘outsiders’ who can become ‘the other’ and even ‘the enemy’ (2019: 72). These macro-level cultural narratives wield more power than the individual stories of people from marginalised communities may be able to counter. Moreover, valorising the use of individual stories constructed for specific pedagogical or therapeutic purposes within services can mask or divert attention and resources from the realities of telling lived experience stories and their consequences in everyday life which, as these findings show, continue to be fraught.

Second, the theme *Producing acceptable stories* gives examples of both peer and non-peer participants feeling pressure to suppress or minimise aspects of their stories. These aspects included their anger, experiences of abuse, political involvement, ongoing distress, less palatable types of distress (such as psychosis and being sectioned) and their perspectives on the contribution of systemic oppression such as racism to mental distress. These findings support concerns raised by studies discussed in [Chapter 3](#), that being asked for or required to produce narratives in mainstream contexts may constrain and restrict which experiences can be shared (Woods et al., 2019, Costa et al., 2012, Fisher & Lees, 2016, Heinemeyer, 2019, Russo, 2016, Sapouna, 2021, Voronka & Grant, 2021, Yeo et al., 2022).

By contrast, a recent study outlined processes by which experiencing stigma can lead to the formation of collective identities within ‘health social movements’ (Smith, 2020). It describes how social support networks *outside of mainstream services* facilitate interactions with others who share a stigmatised status. These interactions “transform personal problems into problems of the collective. In developing a positive collective identity, stigmatised individuals reject oppressive cultural and structural systems, and mobilise and engage in collective action to disrupt these systems” (Smith, 2020: 8). Thus collective narratives resist ‘narrative othering’ through normalising stigmatised experiences and, if the historical moment allows them to reach critical mass, ultimately functioning as tools for political change (Plummer, 2020). This process describes the original use of recovery stories within activist and survivor-researcher contexts (Rose, 2014). But, as Voronka and Grant suggest, the “meaning and value of such knowledge is inevitably recalibrated once reworked and incorporated within dominant mental health paradigms” (Voronka & Grant, 2021: 2).

A fundamental critique of the recovery paradigm, discussed in [Chapter 3](#), is that, as it has been formulated within mental health service policy (Harper & Speed, 2012), it returns the responsibility for becoming well to the individual, while denying, or taking as unalterable, the contextual root causes of mental distress (Heinemeyer, 2019). Thus the emancipatory origins of recovery, and its narratives, are at risk of being neutralised when transposed into the context of services operating from a paradigm which continues to be more likely to focus on, and encourage stories of, individual-level solutions to mental distress. To use Riessman's (2008) three-level model of narrative analysis, the recovery model and its accompanying narratives return the focus to individual/micro causes of mental distress, at the expense of understanding and addressing the socio-structural/macro causes.

Finally, the theme *Untellable stories* supports the findings of other studies, on the links between experiences of trauma and mental distress – see, for example, Sweeney et al. (2016). It highlights the potential costs to the teller of relating their experiences, and raises ethical questions about the circumstances in which people with lived experience should be invited to tell their stories. A move towards more trauma-informed approaches to mental distress may mitigate these concerns and provide a more inclusive context for all aspects of lived experience storytelling. Trauma-informed approaches are primarily focused on contextual understandings of human distress rather than individual pathology (Johnstone et al., 2018), which can be summed up as a shift from 'what's wrong with you?' to 'what happened to you?' (Harper & Cromby, 2022) – although it is worth noting that even accounts of 'what happened to you' may be fraught with hindrances, for example if the response is 'I don't know', as will be explored further in [Chapter 9](#).

Social factors such as poverty and racism can be considered forms of trauma; and traumatic experiences are more common for people from minoritised ethnicities and other structurally marginalised groups (Sweeney & Taggart, 2018). Topor and colleagues (2021) argue that emphasising themes of recovery within narratives risks forming a 'blind spot' in terms of the social and structural causes of mental distress. They state the necessity of paying attention to people's experience-based knowledge, not only about recovery processes, but also about the relationship between structural and social (as well as individual) explanations for mental distress. Yet social and

structural contributors to mental distress, such as abuse, violence, poverty and experiences of institutionalised racism, sexism and homophobia, are often infused with stigma, shame and unacceptability; and stories about these experiences are often met with denial. As these findings demonstrate, these aspects of stories are thus likely to be de-emphasised, minimised or silenced within people's stories of lived experience. This situation is likely to continue in settings which treat mental distress as illness or dysfunction, instead of as an embodied response to trauma and social injustice.

In this light, I might return to Harper and Speed's (2012) question and ask again, is the use of recovery stories recoverable within services? These findings do not deny the many positive as well as negative impacts that lived experience stories can have on individual recipients (Rennick-Egglestone et al., 2019a, Rennick-Egglestone et al., 2019b, Nurser et al., 2018), or the undoubted benefits of peer support (Gillard, 2019). However they do support ongoing work which calls for practitioners and researchers to be alert to the ways in which lived experience narratives may be misused by services (Yeo et al., 2022, Kaiser et al., 2020), and to be highly reflexive about how and why we are using them. Sapouna (2021) frames this in terms of a dual process of honouring what had been achieved by personal narratives, whilst problematising what may be lost. These findings reinforce the call of Voronka & Grant (2021) for frank conversations and environments that acknowledge the power dynamics associated with storytelling, particularly for those experiencing additional intersecting forms of stigma and marginalisation. The findings also draw attention to power differentials within the mental health recovery model. They may provide a platform for further, in-depth research on this issue of pressing importance, at a time of heightened worldwide attention to the links between mental distress and social justice. Being asked to tell one's recovery story, in particular by those in positions of greater power or aligned with a dominant narrative perspective, is never a neutral act.

## **8.5 Summary**

These findings contribute to a growing body of work on the 'politics and possibilities' (Woods et al., 2019) of recovery narratives, by taking a critical constructivist approach to my analysis which allows for attention to be paid to issues of asymmetrical narrative power. It draws attention to the macro as well as micro contexts within which mental health recovery narratives are co-constructed, and the way in which stories are shaped



and constrained by dominant cultural narratives, making any stories which deviate from these norms difficult or impossible to tell. It highlights the variable, evolving, selective and partial nature of the stories told in different contexts and circumstances, and describes a high level of vigilance on the part of narrators about the sharing of lived experiences. This may lead to a more sensitised approach to the complexities of eliciting and using lived experience stories within research and services, and a greater acknowledgement of the power imbalances which continue to problematise their use.

## **8.6 Reflexive pause**

This analysis has provided findings on the experiences of participants across the dataset of telling their stories in a variety of contexts. This led me back to consideration of the research context itself, and its (and my) role in shaping the stories that participants were presenting. Andrews' (2021) indicators of quality in narrative research include attention to the *co-construction of meaning*, or the principle that meaning does not exist in a pure form, but is created, recreated, contested and resisted throughout the research process. What possibilities for telling recovery stories were enabled by this particular research context, and what kinds of tellings might it have prevented? After a fruitful cross-case analysis, these considerations called for a return to a narrative form of analysis capable of investigating both the nuances of micro-interactions between researcher and participant, and the situatedness of participant accounts within dominant socio-cultural narratives.

# Chapter 9: ‘Nothing’s changed, baby’: what do the stories of people with multiple and complex needs tell us about mental health recovery research?

## 9.1 Introduction

In this chapter I present findings from a performative narrative analysis, which address my second objective: exploring participants’ experiences of telling their stories in formal and everyday settings, with a focus on the interview setting itself and the co-construction of ‘recovery’ stories between interviewer and interviewee.

I preface my findings with some contextualising information and a description of the third analytical process undertaken, a performative narrative analysis. I conclude with discussion of the presented findings, how they relate to existing literature and their implications.

### 9.1.1 Background and aims of the third study

Up to this point my focus has been on what participants have directly reported in their accounts. I asked questions relating to lacunae in their narrative tellings, such as whether participants ever felt unable to tell parts of their stories in certain contexts. But my findings have been based on what participants have reported directly. A good-quality narrative inquiry will also pay *attention to the untold* within the interview context (Andrews, 2021), including the possible kinds of telling that the interview context itself might enable and prevent.

Since “even the most intimate of stories bears a relationship to the external world” (Andrews, 2021: 364), a quality narrative inquiry will also investigate *multi-layered stories*, or the coexistence of different levels of storytelling, and the interconnectedness between the micro and macro. Stories always exist in relation to other stories, which may be identified by the narrator but, as Andrews points out, are often – and most powerfully – un-named.

In this final study I undertake a ‘deep dive’ into two stories from the group of participants identified as having ‘multiple and complex needs’, to explore more deeply this relation between the micro and macro in participants’ accounts, including that which may be unspoken. ‘Multiple and complex needs’ is a commonly-used phrase in UK

substance misuse services to describe co-occurring issues of mental distress with homelessness, substance use and experience of the criminal justice system (Harland et al., 2022). People with multiple and complex needs experience particularly poor health outcomes compared with the general population (Perry et al., 2021). A 2015 study found that in England over 250,000 people a year have contact with at least two of the homelessness, substance misuse and/or criminal justice systems, alongside almost universally present mental distress and poverty (Bramley et al., 2015). This figure is likely to have risen in a post-COVID landscape (Sher, 2021), and in the context of austerity measures introduced by European and US governments to reduce public spending on, for example, welfare, health and social care (Altermark & Plesner, 2022, Harland et al., 2022, Aldridge, 2020). The COVID pandemic has focused attention on the extent to which socio-economic and ethnicity-based inequalities influence health (Public Health England, 2020) and reinforced that physical and mental health inequalities will not be reduced without action on social and structural determinants (Stansfield & Shah, 2021). Focusing on the narratives of people with multiple and complex needs provides me with an opportunity to explore the effects of such determinants on individual lives. Structural causes of mental distress may be harder to discern in individual narratives, but may be observed in what are often conceptualised as subjective experiences, such as negative self-concept, hopelessness, self-neglect, passivity and dependence (Karadzhov, 2021a).

In this last findings chapter I therefore aimed to explore the narratives of participants defined as having multiple and complex needs, while being informed by (i) the literature explored in [Chapter 3](#) which problematises the uncritical solicitation of recovery narratives and (ii) an analytical approach which attends to both immediate (micro-level) and structural (macro-level) contextual factors shaping narrative accounts. I sought to explore the kinds of recovery stories people with multiple and complex needs may tell, how micro and macro-level contextual factors may be shaping their accounts, and what ethical and other issues might arise when eliciting recovery stories from people facing multiple socio-structural inequalities.

## 9.2 Method

### 9.2.1 Performative narrative analysis

For this study I analysed the ten interviews which were conducted with participants identified as having multiple and complex needs. I selected a performative narrative analysis approach, which is alert to both the immediate and structural contexts of storytelling (Bengtsson & Andersen, 2020, Riessman, 2008). Recovery research based on narratives has largely used thematic (Brown & Kandirikirira, 2007), structural (Thornhill et al., 2004) or visual (Doroud et al., 2022) forms of analysis. These approaches focus on *what* is being told, and *how* narrators are telling their stories. A performative approach explores *why* particular stories may be told (Riessman, 2008, Frank, 2010b). It examines storytelling in its immediate, socio-cultural and historical contexts, which provide specific opportunities and limitations for the teller (Bengtsson & Andersen, 2020).

I re-immersed myself in the data by re-reading the ten interview transcripts and field notes. I discussed candidate narratives for selection within supervision. I selected four for further analysis, and chose two to present as case studies. These were chosen for two reasons. First, they were illustrative of structural determinants of mental distress faced by narrators with multiple and complex needs. Second, they provided illustrative examples of problems that can occur with the elicitation of recovery-focused narratives, and two contrasting ways of responding to them.

I devised a narrative analysis process using questions drawn from Bamberg's (2020) integrative approach and Bengtsson and Andersen's (2020) performative approach (presented in [Appendix 8](#)). Using Bamberg's (2020) identity navigation practices, I explored how each participant marked themselves as the same as or different from others and as relatively agentic or passive in relation to events. Second, I asked six performative questions, based on a combination of Bamberg's (2020) and Bengtsson and Andersen's (2020) approaches. In relation to immediate contexts: (i) how do participants position themselves in relation to the interviewer/wider audience?; and (ii) how does the interviewer actively participate in the production and ongoing interpretation of narrative? In relation to socio-cultural contexts: (iii) how do participants position themselves in relation to meta-narratives?; (iv) how is the immediate context linked to broader historical/socio-cultural contexts?; (v) how do

these have an impact on expectations of what must be explained and what is self-explanatory?; and (vi) what does the participant not explain?

### **9.2.2 Reflexivity**

As with [Chapter 8](#) I provide here a reflexive account of the parts of my experience that specifically informed this analysis. This is important to revisit at this stage, since “the investigator becomes an active presence in the text” in particular within performative analysis (Riessman, 2008: 105).

I brought to this analysis my experiences as a queer woman growing up in a working-class community in the 70s and 80s. I was able to disengage from internalised meta-narratives of shame and unacceptability through engaging with counter-narratives of resistance and pride available within LGBTQ+ communities (such as ‘coming out stories’, see Plummer, 1994/2002), thus bringing to the analysis a positive experience of the power of stories to transform the effects of internalised oppression. My perspective was also informed here by my professional community and youth work, including supporting people with multiple and complex needs in substance misuse services, and by my own lived experience of recurring depression during my teenage years and into adulthood, during which I sought out mental health narratives (including articles, memoirs and friends’ experiences) for support, inspiration and insight into lived experiences of moving on from despair.

## **9.3 Findings**

Eight of the participants were male and two were female. Nine identified as white British and one as white Irish. Six identified as heterosexual, one as a gay man, two did not provide responses, and one preferred not to say. Interviews ranged from 18-65 minutes. Findings are presented as follows: a summary of each narrative and my initial reflections at the time of the interviews in 2018; analysis of macro and then micro-level narrative co-constructions; and possible alternative readings.

### **9.3.1 Paul: “Things just seem to happen. And I’m not sure why”**

#### **9.3.1.1 Story summary & initial interviewer response**

Paul is a white British man aged 45-54, a long-time drug user recruited through a substance misuse service, where the interview took place. At the time of the interview

he was homeless and living temporarily with a friend, having just emerged from what he described as his latest 'bender' (UK slang for prolonged period of heavy drug or alcohol use). The first extract (Table 17) is taken from the beginning of the interview:

*Table 17: Paul's story (Extract 1)*

- 
- 1 I: Could you tell me about your experiences ... of mental health, or emotional issues, and of  
2 your recovery, or of your ... ways you coped, or however you want to phrase it basically? Can  
3 you tell me that as if it was a story, so as if it had a beginning, a middle, and then kind of like  
4 where you are at, or stuff about the future? Thank you!
- 5 P: Mine is ... I get fed up sometimes. I don't know if you call it depression or not, I don't  
6 know, and all the time I've always gone onto drugs for that, and it just makes it worse, but it  
7 just seems a lot better at the time. And I – mine goes in spells for quite a while, and then just  
8 come round, get myself clean again, get back to work and then ... I've done it for the last 20  
9 years, exactly the same thing. I just get fed up with the job I'm doing or ... anything, anything  
10 really. But the only problem is now I'm getting a bit too old for it. So I've just been talking to  
11 the staff in here, sorting [a] drug substitute prescription, trying to get myself sorted out that  
12 way really. I mean it started when erm ... just working as normal, and then I split with my  
13 wife, got fed up from then. It was already ... messy anyway, dragging out for a long time, and  
14 I've never actually been treated for depression, but I don't know if it is or not. I don't know if  
15 fed up's a, you know, a part of depression, I suppose it would be, I'm not really sure. At the  
16 moment ... I'm not too bad, I've had somewhere to stay for a while, been staying at my  
17 friend's house ... I'm just hoping that it will go the right way. And then once – because I will  
18 get myself sorted, it's just staying that way, that's the difficult one, that's the biggest problem  
19 I find. Just stopping ... normal. I don't know if there's an answer to that or not. Bit tricky  
20 really. [Long pause]. With working, I always seem to work my way up the companies quite  
21 well, and then I mess that up sort of thing, just – I get fed up, don't turn up. I mean people  
22 have said this, it's some sort of mental health – but I've never been diagnosed, so I'm not  
23 really sure. But everything I do is always my fault. You know, I always mess 'em up myself,  
24 and I can never understand why I do that either. Tricky really.
- 25 I: Mm, sounds it, yeah.
- 26 P: Yeah. I don't really know what to say now.
- 

Paul presents his experiences as “spells” of getting “fed up” with work or with “anything really”; he is unclear whether this is depression, but uses drugs to cope with this (line 6). Things seem to get better for a while, but get worse, before he starts “get[ting] myself clean again” and back into work for a while. He describes getting fed up once more and “exactly the same thing” happening again, continuing for 20 years. His sense of getting “too old for it” appears to have prompted his approach to the service. He says he will be able to “get himself sorted” because he has in the past; but the problem is “staying that way”. He is not sure if his feeling fed up is depression or not, and identifies

it as beginning after a messy split with his wife. He stresses that “everything I do is always my fault”.

After describing these spells, Paul comes to a halt. I start asking some prompt questions. However, they don't seem to 'help' Paul to continue, and although he does say more he keeps returning to 'not knowing', in what I initially perceive as frustration at not being able to understand his own story. In my field notes, I write that I “fear” this isn't a recovery story, as there seem “so many blanks and unknown things” about it.

### **9.3.1.2 Macro-level context**

I identified three socio-cultural meta-narratives which could be seen as co-constructing Paul's personal account. The first may be summarised as 'get clean first', and speaks to the way that different services in England may fail to interact. Paul is accessing substance misuse, not mental health, services; these are often separated in England. He refers throughout his narrative to uncertainty about whether his being 'fed up' is depression, and says he has never been diagnosed or received treatment for it. Later he comments that “there's got to be some mental health issue somewhere there, there's *got* to be, I mean it's insanity” [i.e. his repeated return to drug use]. In their report on homelessness in the UK, Bramley & Fitzpatrick (2018) describe mental ill health as 'almost universally present' among people with multiple and complex needs. However, they are often treated based on what is judged to be their main need ('primary diagnosis'), with services often “designed to deal with one problem at a time and to support people with single, severe conditions” (Making Every Adult Matter coalition, 2015: 7). Substance use can be deployed as an exclusion criteria for mental health services (House of Commons Home Affairs Committee, 2015). For Paul, these structural factors may be preventing him from accessing mental health support and contributing to a narrative of confusion.

Second, another recurring thread is Paul's description of hiding that there is anything wrong from the people around him. After saying that things started to go badly for him after his marriage ended, and commenting that his drinking probably masked his low mood, there is a long pause before he adds: “I'm always so – very good at making out there's nowt wrong either” especially to people close to him, “my mam, people like that”.

This extends to clinical encounters:

*My doctors have asked me, like [about his mental health] – I just say I'm all right, I always have done. Which, I don't think that's a good thing either really, just bottling everything up, but that's what I've always done.*

He later says he doesn't like to "pass things on", a phrase suggesting he may see difficult feelings as contagious, or which may be a more palatable way of presenting a reluctance to discuss such feelings with others. Here his individual narrative may be influenced by hegemonic meta-narratives of masculinity, characterised by emotional control and a lack of vulnerability (Emslie et al., 2006), adherence to which has been associated with depression (Parent et al., 2019) and the inhibition of help-seeking, (Seidler et al., 2016). A narrative of being too old for continued "benders" may be more acceptable to him than a narrative of "depression", which can be associated with powerlessness and the uncontrolled expression of emotion (Emslie et al., 2006).

A third thread relates to a moral meta-narrative; namely, that the problems of substance-users are self-inflicted and their suffering is deserved. This prevailing attitude is demonstrated, for example, in Atkinson & Sumnall (2020)'s discourse analysis of substance use in the UK reality show *The Jeremy Kyle Show*, which found that users were blamed for their substance use and resulting problems, and held fully responsible. Paul can be seen here as offering just such a narrative. He returns repeatedly to a stance that "everything I do is always my fault". He marks himself as different from other people, saying "whenever I hear of mental health, I know that most of mine's all my own fault" and "I do see things where people are suicidal, won't go out or anything, and that must be ten times as bad as mine. Because I know mine are all self-inflicted". By contrast, he is the one who messes things up – he has brought "it" on himself. These 'narratives of self-responsibility', strengthened by neoliberal health policy discourses and associated welfare reform strategies, have been shown to "inflict, sustain and exacerbate" mental distress and suffering for people from low-income communities in a form of "narrative violence" (Thomas et al., 2020: 1125). Paul's story can be seen as evidence of Thomas and colleagues' findings: that such policy discourses can become naturalised and normalised by individuals themselves, and by the health professionals seeking to support them; and that those with less access to material resources may be less likely to be able to resist such narratives.



This combination of meta-narratives may be seen as creating a ‘narrative deadlock’, with a materially negative effect on Paul’s life. An internalised narrative that feelings are to be bottled up, exacerbated by a belief that his distress is his own fault, makes it substantially less likely that Paul would seek support from family, friends or frontline professionals. He is thus unlikely to gain access to mental health services, and even if he does, his drug use may exclude him. Thus the problems he faces remain situated within his own person, and the cycle continues – in Paul’s case, for 20 years.

Alternatively, Paul may be shrewdly taking part in his own form of narrative resistance, deploying these meta-narratives to his own ends in exchange for something of benefit to him (perhaps the cash on offer, or the opportunity to be heard). He may be presenting exactly the kind of ‘narrative of lack’ which Lawler (2005) describes as ubiquitous in the media and other discourses when describing working-class existence – a lack not simply of material resources but of “the right ways of being and doing” (Bourdieu, 2018). Paul might reasonably assume such a narrative is required of ‘people like him’ (white working class, substance-using, homeless) in the context of a mental health study conducted by a university researcher in a substance misuse service.

### **9.3.1.3 Micro-level context**

I identified three factors related to the interactional role of the interviewer and study context which may also be contributing to Paul’s ‘narrative of lack’: (i) my request for an explanatory story; (ii) my choice of opening question and prompts; and (iii) my focus on a personal sense of transformation or resilience.

First, the request for an *explanatory* story (line 2) seems to result in Paul feeling at a loss. He presents his cycling through “spells” not as an active choice, but as something that puzzles him. The phrases “I don’t know” and “I’m not sure” are repeated throughout (for example in Table 17 at lines 5, 6, 14, 15, 19, 23 and 24) in relation to his mental health, drug use, what sustains him and why he continues to “mess up”. In a performance auto-ethnography of anxiety and physical activity during Covid-19 lockdowns, David Carless (2022) unsettles the idea that we can always know what aids recovery. He describes his own struggle to say with confidence what works for himself, to say nothing of a whole population. He cautions: “let nobody forget that *stuff* happens that cannot be put into words” (Carless, 2022: 311, his italics). Ultimately Carless is able, as an educationally and economically resourced individual, to use narrative to

“transform myself ... choosing a better story for myself”. However, if a narrative researcher in the field of mental health can struggle to tell stories of his own recovery processes, it may be a lot to ask of someone currently without the most basic ontological security of a home.

Paul’s stance of not knowing could also be a resistance to the meaning-making process at the heart of a narrative epistemology – as he says, “things just seem to happen. And I’m not sure why”. Critics of narrative approaches have rejected its central premise that all humans typically see their lives as a narrative, or that narrative is an especially distinctive form of human behaviour, and the normative conclusion that conceiving one’s life in such a way is consistent with a well-developed sense of identity (Atkinson, 2010). In relation to narratives of health and illness, Angela Woods (2011) echoes philosopher Galen Strawson (2004) in cautioning narrative practitioners to guard against the risk of isolating or distressing people who may not fit this way of conceiving oneself. Tore Dag Bøe and colleagues (Bøe et al., 2021) refer to this tendency within narrative-based interviews as a ‘qualitative fallacy’, a blindness that may accompany qualitative explorations if they neglect aspects of life that resist being represented in narrative structures, with well-organised meanings and well-composed stories. Here the experiences of the interviewee may fall victim to a ‘narrative reconstruction’ (Bury, 2001) in order to fit the researcher’s aims. Whilst something may be gained by this, the “reality of life with its complexity, unresolvedness, contradictions, indefiniteness, and myriads of connections and interruptions” may be lost (Bøe et al., 2021: 5).

It is also possible that Paul may not see his experiences as being ones of ‘recovery’, or even of coping. Our recruitment strategy involved a gatekeeper; it was a member of staff who identified Paul as having a ‘recovery story’, not Paul himself, and this singling out to tell such a story may be adding to a sense of confusion or puzzlement.

Second, my questions and prompts are inviting a specific type of narrative, which did not occur to me until this analysis and a discussion within a supervision session, four years after the original interview. In the opening question, I use a version of Riessman’s (2008) open-ended question designed to elicit a narrative: “could you tell me about your experiences of...?” Next, however, I add some guidance, based on McAdams (2013)’s Life Story Interview: “can you tell me that as if it was a story”, suggesting to participants that this would consist of a beginning, middle, and thoughts on the present

and future. However, this phrasing of “tell me...*as if* it was a story” implies that some tellings are not story-like. This introduces unexplored epistemological assumptions, effectively closing down Riessman’s stipulation of an ‘open-ended’ question and setting up a model template for the participant. For those whose stories do not necessarily follow such a trajectory, this model could be problematic, and may be contributing to Paul’s sense of his story being somehow lacking. He apologises several times for what he may see as his inability to present his experiences in the desired way: he is “sorry it isn’t really in a story” and concludes “I just wish I could put it more into a story for you”. As other studies have found (see, for example, Nurser et al. (2018)), participants in narrative-based interventions or research may have negative experiences if they feel their stories do not align with what a recovery story *should* look like, an ideal which may be imposed by the way a course or, in this case, an interview question is structured. This ideal may also be imposed by an interviewer’s unexplored normative assumptions. An inclusive definition of ‘recovery narratives’ was an important NEON study team principle. However, when I considered my interview prompts to Paul separately (Table 18), they show a tightly-defined idea of the key components of a recovery narrative:

Table 18: Paul’s story (Extract 2)

Line	Prompt question
33	Where do you think it started for you?
43	What would you say helps you?
53	So what does it look like when things are going well for you?
61	Does it feel like there are tipping points that tip you towards feeling “self-destructive”?
68	Why do you think that might be [bottling up difficult emotions]?
86	What sort of things have helped you to be in a slightly better place?
93	What do you do [for work]?
107	Okay, so it feels repetitive to you, because if it was a story – what sort of shape would it be?
114	What I’m really struck by is that you keep going and you seem quite optimistic, and that’s amazing to me [...] do you know what helps you to feel positive?
134	If you look to the future, what would you want?
165	Do you know what it is that changes – that gets you from one place to that next place?
173	What is next for you? What would you hope for?
216	Are there other things apart from work that you think, I would give that advice to somebody else in a similar position to me?

These prompts suggest that Paul's story should contain content about what helps (line 43), some turning points (61) and a clear shape (107). The focus should be on what helps him feel positive (114) or move on from distress (86, 165); on the future (134) and on advice for others in similar situations (216). Two factors were driving this line of questioning. One, some un-noticed ontological assumptions derived from my own experiential 'use' of stories. They mirror my own past seeking for relief from despair through stories offering personal insight into moving on from distress (lines 43, 86, 165 and 216), and maintaining a sense of hope (114 and 173). They also conform to archetypal ideals. However broadly a study may define 'recovery' narratives, the meta-narrative of the 'hero's journey' (Campbell, 2003) of overcoming the odds and triumphing over disaster remains influential as the ideal narrative of recovery from illness in the Global North (Frank, 1995/2013), despite critiques by narratologists (for example, Mäkelä & Meretoja, 2022). Two, an important study principle was to leave stories unedited to minimise curatorial control (Yeo et al., 2022), should the participant opt to donate their story to the NEON intervention, This is shaping my attempt to elicit a sequential story with clear advice for others, in the belief this will be most beneficial. The "fear" recorded in my field notes implies concern that there is nothing in Paul's story that might be valuable for others, and an assumption that the stories we were eliciting needed to be 'useful' in this way in order to contain valuable knowledge.

My fear reflects critiques that, by creating a genre of 'recovery narrative' and ascribing it particular characteristics, such as inspiring hope and offering practical strategies to individuals, stories which do not fit these requirements will be excluded or not considered worthy of sharing with wider audiences (Kaiser et al., 2020). In their critical review of the mobilisation of recovery narratives in services, Woods and colleagues (2019: 231) find that self-expression in these contexts is "highly circumscribed, goal-directed, and carefully crafted to fulfil larger imperatives". Here, this form of mobilisation is transported to the research context. A pragmatic concern with 'what works' may function to suppress other experiences of distress, suffering and recovery which do not conform to such templates (Pascal & Sagan, 2018). This matters not least because, as perhaps with Paul, such pragmatism can render a person's narrative of their own experience "yet one more thing at which service users can fail" (Rose, 2014: 217). Furthermore, the stories which are available socially and culturally affect how others may imagine and shape their own experiences (Plummer, 2019). Analysis of my implicit

assumptions demonstrate how some stories may routinely become excluded from narrative interventions and research studies, if the gatekeeper (researcher, editor, curator) does not examine their assumptions about what may constitute a recovery story.

This is problematic for at least two reasons. One, there is evidence that other forms of stories are also helpful for people experiencing distress. Findings from a process evaluation of the NEON study suggests for example that some participants expressed a desire for and found value in narratives which did not shy away from the 'messy stuff' (Ali et al, in preparation) rather than the 'compulsory positivity' (Woods et al., 2019) which is often recommended or implied in recovery narrative guidance.

Two, there is also concern about what may be lost. As Sapouna (2021) reflects in a discussion of her inclusion of lived experience narratives in social work education:

*Do I only include articulate narrators in education? What about people who struggle to share their stories? What about the incoherent and overwhelming stories? What about people who refuse to share their stories [...]? What about those who identify as 'unrecovered' and in need of long-term support? Do we privilege certain types of narrative-generated knowledge over others? (Sapouna, 2021: 10).*

Analysis of my implicit expectations show how some stories may routinely be excluded from narrative-based interventions and campaigns (Yeo et al., 2022) if the gatekeeper (researcher, curator, editor) does not examine their epistemological assumptions about what a recovery story might be, or if the narrative does not fit the agenda of the curator or researcher.

A third factor co-constructing Paul's narrative is that my expectations of recovery stories are shaping how I hear his story, such that my questions rarely respond to what Paul is actually presenting. His story includes such potentially rich areas to explore as the break-up of his marriage, his currently positive relationship with his mother, his "bottling up" of feelings with family and clinicians, his drinking to mask feelings and his father telling him that the "only good thing" was that Paul had a trade. With a more inductive focus, my interview prompts may have drawn more directly on the story he

was telling. But in pursuit of an archetypal 'recovery' storyline, these cues were missed, and with them the opportunity to build a more contextualised picture of Paul's life.

Moreover, my line of questioning means I miss something that Paul does clearly present – that it is his employment and economic situation that helps him (Table 19):

*Table 19: Paul's story (Extract 3)*

---

165	I: Do you know what it is that changes – that gets you from one place to that next place?
166	P: [Pause]. To be honest, no. Sorry! I wish I did really. It must be something!
167	I: Sure, yeah, because to me that's amazing that you don't stay there, that there is something
168	that moves you from that point to a point where you, sort of ... start doing things again. And
169	it's fine if you don't know what it is.
170	P: I really don't know, that's the thing.
171	I: No, completely fine.
172	P: I don't really know, I'm sorry.
173	I: No worries at all. What would you say is next for you? What would you hope for?
174	P: Well, next? I've done this a few times as well, what I keep doing is I keep wandering
175	around the companies where I worked, one of them will see me and they'll drag me in for a
176	coffee... and then it'll really go from there, sort of thing.
177	I: Go from there, as in offer you some work?
178	P: Yeah. I've done it three times, exactly the same thing. Or I'll just turn up at the pub where I
179	know they will go for a drink every Friday. But like I say, the only good thing was, I'm good
180	at it, and that helps, so ... and also, where I work, a lot of them have, in their own frame of
181	mind, what you do out of – when you're not at work, you do what you like. Which is, you
182	know, which is fair enough sort of thing, as long as you come to work and do your work,
183	that's – yeah.
184	I: Yeah, it's nobody's business what happens after work is it?
185	P: Yeah, so that's what I'll do next.
186	I: Right. Yeah.
187	P: Sorry, it isn't really in a story –

---

In response to a question about personal change, Paul repeats that he does not know what helps him to move on. Influenced by my professional background, I am attempting a positive reframing for Paul around what I see as his resilience over so many years (line 167). But this questioning appears to back him further into a corner – “I really don't know, that's the thing”, and again, “I don't really know, I'm sorry”. Yet when asked what's next for him, Paul is clear. What he “keeps doing” is going to places he knows potential employers will be. He thinks being “good at it” (his job) is what helps him to secure re-employment, and mentions another factor, almost as an afterthought – that in his field, there is an attitude of “when you're not at work, you do what you like”. His employers and colleagues do not judge or stigmatise, but provide supportive

employment conditions, where gaps are not treated as signifying a problematic employee. This is the factor he identifies as helping him to move on repeatedly from his phases of drug use. Thus, Paul's story can be framed as one which indeed contains important information about recovery – but at a structural level, which I am not expecting.

### **9.3.2 Cheryl: “Nothing's changed, baby”**

In contrast to Paul's *narrative of lack* (whether internalised or strategic), the next story can be read as an agentic *narrative of resistance* to framing the participant's experience as 'recovery'.

#### **9.3.2.1 Story summary and initial interviewer response**

Cheryl is a white British woman in her fifties, recruited through a rights and support organisation for sex workers, where the interview took place. Immediately prior to the interview, she and her support worker had a long discussion about whether or not to go ahead with it. Cheryl was not in a good place, having visited a self-harm support organisation for the first time the day before, which had involved completing a lengthy questionnaire about her experiences. She concluded she was happy to proceed with the interview as long as it wasn't "like yesterday", and opted to have her support worker present throughout. It was a hot day and there were many distractions in the interview, including loud noises from outside, insects which were bothering Cheryl, and two phone calls from her daughter. The first extract (Table 20) is taken from the beginning of the interview, and contains themes that recur throughout:

Table 20: Cheryl's story (Extract 1)

- 
- 1 I: Okay, so if you're happy to start then I'll just ask you the first question, which is  
2 that – just – erm, could you tell me about your experiences of mental health issues?  
3 And kind of how you've survived everything that has happened to you? And could  
4 you –  
5 C: When I –  
6 I: Sorry Cheryl, could you tell me as if it is a story? So like where you think it might  
7 have started for you? So you were just mentioning about stuff when you were little  
8 for example. And then what happened after that –  
9 C: Well, sex ... sexual and mental abuse from the age of five until 11 sexually, but  
10 mental health and the physical abuse went on till when I was 16. I was sectioned  
11 when I was 16 for three years till I was 19. I had electric shock treatment that  
12 turned me into a zombie, I was on that many tablets. And they [...] [anon name], he  
13 said to me, he's only ever heard of two occasions that they've had electric shock  
14 treatment, and I'm one of them. And they only do it when you're that traumatised  
15 there's nothing left for them to do. So ... I think it's shit, mate – back in them days  
16 they used to have tablets in your food and everything. And when I went on [anon  
17 ward] they just wanna fucking sedate you, if you don't do what they want, they  
18 take your own room off you and put you in a cubicle. And it's right next to the men  
19 and [inaudible].  
20 I: Right yeah, so you didn't like that.  
21 C: Nah. Not at all baby [pause while participant has a drink]. But that's about it,  
22 and I think mental health is shit to be honest. The police don't understand still. I  
23 don't think anyone understands mental health problems
- 

Cheryl appears keen to get on with the interview (line 5), perhaps unsurprisingly in light of her experiences the day before, but I interrupt to again request that she tells it *as if* it is a story. Cheryl moves directly into describing the abuse she experienced from early childhood and her hospitalisation in her late teens. She is angry about her hospital treatment, which she contends turned her into a sedated “zombie” and which appears to have involved inappropriate accommodation for a woman who has survived male sexual violence. She thinks mental health is still “shit to be honest”, and that the police don't understand it; that no-one does. Her comment “that's about it” indicates there is nothing more to say; her story is summed up as a blunt presentation of multiple trauma and her view of poor treatment by services. Prior to recording, Cheryl spoke about the extent of her abuse and some of its consequences, including not being able to talk about it for years and continuing to experience sensory flashbacks some 30 years later. During



my explanation of the recovery context of the study, Cheryl responded by saying that she will never be able to recover; it is too late for her. In my field notes I describe being again unsure “if this will be a story we’ll consider to be a recovery narrative, by Cheryl’s terms”.

### 9.3.2.2 Macro-level context

Two contrasting meta-narratives of mental health can be seen as threaded through Cheryl’s story:

*Table 21: Cheryl’s story (Extract 2)*

---

35	P: I start counselling this month on [day], about it.
36	I: Have you had any counselling before?
37	P: Yeah, but I didn’t open up.
38	I: Yeah, right. Do you know why that was?
39	P: Too painful, babe.
40	I: Yeah. Yeah. Sure.
41	P: But I’ll do it, cos that’s the only way I’m gonna move on, <u>innit?</u> I can’t keep living
42	like that, it’s – but I know I’ll always have depression, I know I’ll always cut myself,
43	because it’s release. I don’t do it for sympathy, I don’t do it when anyone else is in
44	the house, but as soon as I see that blood it’s like the whole world’s been took off
45	my shoulders.

---

Arguably, Cheryl employs the vocabulary of personal resilience common to recovery accounts here, seeing herself as needing to “open up” and “move on”. She will participate in counselling despite anticipating a painful process (line 39). On the other hand, a narrative of resistance can also be seen as present – she will “always” have depression and thus cut herself. She says it is not sympathy she wants from her self-harm, but release.

Before the interview, Cheryl actively refutes her story as one of recovery. She has experienced formal, coercive mental health services, which she reports have not helped. She may want, at least in part, to access the counselling at the self-help charity, but Cheryl does not see herself as mentally ill or mad, as indicated by her later distinguishing of herself from other inpatients: “the second time I was sectioned, if I didn’t do what they said, they took my own room off me and put me in a cubicle with a lunatic”. This is not a story of seeking a diagnosis. Her account can be seen as one of

trauma and abuse; her self-harm a reasonable response (rather than an absence of recovery), which requires no further explanation.

Nor is Cheryl's story a moral tale about escaping sex work. There is no mention of Cheryl's current life circumstances, perhaps indicating her active selection of topics to share or that she considers relevant for the purposes of the interview. Her focus can be seen as remaining with the structural causes of her distress as she sees it: childhood abuse, coercive mental health services, treatment by uncomprehending police, and ongoing intimate partner violence. Her agentic responses to ongoing trauma include self-harm and suicidal thoughts, and a willingness to try therapy and to continue accessing the support she is positive about receiving from the rights organisation. This shaping of her experience mirrors a meta-narrative of a trauma-informed approach to mental health, wherein mental distress is constructed not as an illness or disorder located within a person, but a rational response to, and communication about, structural injustice (Johnstone et al., 2018, Sweeney et al., 2016). Cheryl's narrative is co-constructed in the context of support from a rights-based organisation, working to challenge inequality as well as provide immediate support. Ironically, her resistance to a recovery discourse arguably returns 'recovery narratives' to their original focus, of attention to human rights and the structural causes of distress.

### **9.3.2.3 Micro-level context**

Three immediate-context factors can be seen as shaping this narrative. First, my discomfort with a recovery framing in this context. Following Cheryl's pre-interview description of continued trauma, I make an active choice to drop the word 'recovery' from my opening question, as it seems inappropriate. My discomfort with this phrasing can be seen in my hesitation and slight stumbling before asking if Cheryl can talk about her "experiences of mental health issues" (Table 20, line 2), and the subsequent phrase "how you've survived everything that's happened to you" rather than 'your recovery' or similar. In response, Cheryl repeats the details of her abuse without hesitation. The ease and free sharing of intimate details with a stranger may suggest she is accustomed to sharing her story with others, and is adept at doing so. She may be used to giving of her intimate self to professionals; as a sex worker she may not be afforded the luxury of privacy in many parts of her life.

Her readiness to provide such information may also indicate that she does not want to prolong the experience of telling her story. In contrast with Paul, she is agentic within the interview. She has already been asked two questions (Table 20, lines 1-3) and does not need the framing “tell me as if it is a story” before she begins. She appears confident in her responses and in selecting what she tells, as well as dictating the terms and length of the interview. She focuses on what she may assume is required – the traumatic details. Given her weariness from the day before, she may also want a no-nonsense exchange of her story as quickly as possible for the promised cash.

A second immediate-context factor shaping the narrative is my pursuit of a personally transformative turning point, which elicits an embodied refutation from Cheryl. I attempt to prompt a linear account of Cheryl’s earlier life:

*Table 22: Cheryl's story (Extract 3)*

---

82	I: Do you remember what happened next in your life after being in the hostel?
83	P: Nothing's changed, baby. I still feel the same, I still <u>wanna</u> kill myself every day.
84	I still self-harm, I done that a couple of weeks ago [shows scars]. It's always deep,
85	when I do that down my arms, it sends electric shocks. Because I've damaged the
86	nerves in my arms, cos that's how deep I cut.
87	I: Deep, yeah right –
88	P: Get me, nothing's changed mate ... not nothing, no one understands –
89	[participant's phone rings]. Can I answer that please? Cos it's probably one of my
90	daughters.

---

As with Paul, I am pursuing a traditional story arc with a turning point, but this does not resonate with Cheryl. Nothing has changed, she says; she still wants to kill herself every day. She shows me the vivid scars on her arms (84) and emphasises the nerve damage they have caused due to the depth of her cutting (85-86). It is as if, having told what she thinks she is expected to share, she does not elaborate further but instead embodies her trauma – a physical demonstration of the depth of her distress. The academic literature around self-harm, despite widely seeing it as a response to trauma, generally portrays it as a failure to develop healthy coping mechanisms (Nock, 2009, Favazza, 2011).

However Cheryl’s open-ness about her self-harm can be read in another, more agentic way. Kesherie Gurung (2018: 35) suggests that “those who engage in self-harm practices are performing embodied, socially situated acts of healing, survival, and self-creation in a physical attempt to retell complex, fragmented stories of abuse, existential

angst, trauma, and loss of self". Cheryl's physical embodiment of her trauma may illustrate this, in what can be seen as an act of resistance to cognitively 'sanitising' her story (Costa et al., 2012), with linear plots, defined turning points and neat, happy endings.

Third, my positive reframing into resilience, which clashes with versus Cheryl's continued sense of violation. The tone of the interview changes after I attempt to reframe Cheryl's suicide attempt:

Table 23: Cheryl's story (Extract 4)

---

140	P: Maybe that was God's will, you get me? Maybe not to jump.
141	I: Yeah, maybe – yeah.
142	P: And I don't – I don't understand anything anymore.
143	I: <u>Mmmm</u> . But you're still here.
144	P: Life's just a bitch, isn't it? I've had nothing but violent relationships, apart from
145	[partner] and then he died when he was 35 through the alcohol, that'll be twelve
146	years at end of August. He's the only guy what's <u>tret</u> me right, in my – since I was a
147	kid. [Inaudible] I've always fallen for guys that abused me, hit me. Always. And
148	then, I have to move on from that.
149	I: <u>Mmmm</u> .
150	[Long pause. Participant cries, interviewer offers tissues]
151	I: Shall we stop?
152	P: Move on to the next question please.

---

In noting that she chose not to kill herself, I am offering affirmation of Cheryl's ability to survive (line 143). But this does not land with Cheryl, as she reflects on the violence in her adult relationships. Her voice and body language soften as she talks about "the only guy what's tret [treated] me right", and quietly starts to cry. I move on as requested (line 152), asking whether other people's stories have ever helped. She says no, they upset her, and repeats that she hasn't got long. I ask if other people's stories have ever been *unhelpful* for her. She replies "baby, no-one's been through my life". She shows other scars on her arms, not of self-harm but from her childhood abuse, and describes who and what made them. In response to my continued questions about the relevance of stories to her life, she returns to the physical evidence of her abuse, co-situated with her own sites of self-harming; an embodiment of her trauma and survival when stories may be irrelevant and language perhaps inadequate.

I end the interview when Cheryl says that she continues to feel violated “by everything”. Cheryl’s tonal shift from instructional and matter-of-fact to sadness and tears raises a number of questions on the nature of the exchange. Why did Cheryl consent to the interview, after her experiences of the day before, and given that she does not consider hers to be a story of recovery? An obvious incentive was the cash on offer. As is considered good ethical practice (Heney & Poleykett, 2021), participants’ labour was recompensed by offering £20 cash or vouchers as an honorarium – no small amount for someone struggling financially, as Cheryl was. Although the alternative seems worse and has been critiqued as exploitative of lived experience narrators (Yeo et al., 2022), payment may run the risk here of rendering the exchange straightforwardly transactional; cash for trauma; cash for ‘recovery’ stories. Other participants of the ten who were identified as having multiple and complex needs were direct about this – “honestly? The cash” was one person’s straightforward response about his motivation to participate. In light of the financial incentive, is Cheryl giving me what she thinks is required as quickly as possible, despite the cost to herself, thereby mirroring her sex-working relationships? Or is this a reductionist analysis?

Whatever her reasons for participating, what I had seen immediately post-interview as a sparse narrative becomes rich with significance when viewed as an embodiment of the fractured and stark nature of her trauma, and a refusal to sugar-coat ongoing experiences of distress in the face of continued structurally unjust conditions.

## 9.4 Discussion

My findings from this performative study can be discussed at two levels. Firstly, I explored the kinds of recovery stories people with multiple and complex needs may tell. Paul can be seen as constructing a *narrative of personal lack* in which he blames himself for his situation and apologises for his inability, as he sees it, to give a storied account. In contrast, Cheryl can be seen as constructing a *narrative of resistance*, rejecting a label of mental illness and rejecting any possibility of recovery. Instead she presents her past abuse and trauma, her survival of it, and an embodiment of its continuing effects. Paul and Cheryl give very different accounts, but ‘recovery’ appears to have little meaning for either of them in their current situations.

Both are experiencing multiple inequalities. Mental health inequality is a complex phenomenon, with interacting macro (structural) and micro (agentic) components

(Karadzhov, 2021a). Previous research shows how multifaceted the relationship between structural and agentic factors is for the potential recovery of people with multiple and complex needs. Numerous studies suggest that the issues they face are progressive, rooted in childhood and linked to underlying social and structural factors outside of individual control, many resulting from social exclusion (Harland et al., 2022, Mabhala et al., 2017, Bramley & Fitzpatrick, 2018). As I explored in [Chapter 2](#), recovery-based research has been criticised for its over-focus on the personal, agentic level of identity transformation or resilience, at the expense of structural factors (Padgett et al., 2016, Harper & Speed, 2012). As explored in [Chapter 3](#), critics of the ‘recovery narrative’ point to the same issues with their elicitation and reception (Voronka, 2019, Woods et al., 2019).

My findings provide empirical evidence of this over-emphasis in action, demonstrating how the elicitation of recovery narratives can mirror this focus on individual resilience and attempts to ‘overcome’. This over-emphasis may function to occlude the structural causes of mental distress (including, in these cases, homelessness, poverty, child abuse and intimate partner violence), as well as the heterogeneous ways in which people endure or carry on without expectations or experiences of transformation. Attention to structural factors within narratives of lived experience is vital to ensure that recovery research does not continue to maintain a ‘blind spot’ in this area (Topor et al., 2021). Offering decontextualised, reductionist forms of recovery narrative which pay insufficient attention to the economic, institutional and political injustices that people experiencing mental distress may systematically endure (Karadzhov, 2021a, Morrow & Malcoe, 2017) does little to address the needs of the most vulnerable (Karadzhov, 2021a, Morrow & Malcoe, 2017).

Secondly, and ironically, my findings function as a critique of the very process of eliciting and using ‘recovery narratives’ as a source of knowledge. Like others, I am “leveraging the methodology I am questioning”, as Jay Burkette (2022) describes in a performative reinterpretation of the research interview. Narrative researchers can think of ourselves as the ‘good guys’, dealing with meaning, purpose and attempting to counter society’s dominant narratives (Costa et al., 2012). However, adopting a narrative approach is not inherently enough to ensure genuinely emancipatory research. As survivor/narrative researcher Kathryn Church warns, we may be the ones

who by our own self-reflexivity have figured out how to be *really* effective at stealing stories (Church, 2013). Nor is being a researcher with lived experience sufficient in itself to ensure an emancipatory or epistemically just approach. As survivor researcher Jasna Russo states, other structural inequalities “affect the aspiration to such a ‘we’” (Russo, 2016). She cites Patricia Hill Collins who, in advocating for an intersectional approach to scholarship, reminds us that knowledge “cannot be separated from the power relations in which it participates and which shape it” (Collins, 2012: 453). I may have attempted to show solidarity with Paul and Cheryl as someone who also had lived experience of distress. But I also had intersecting privileges of education and access to economic resources which puts me in a different world to their current situations. This set of circumstances do not undermine the severity of my own experiences of distress. But they did put me in a position in which, for me, recovery has been a possibility.

Church reminds us that research is about power, in the mundane practices too (Church, 2013). The ‘big stories’ of the research proposal and ethics protocol provide the context for the more intimate encounter of the interview, and shape how these will be understood (Church, 2013). By adopting a critical and reflexive standpoint, it was possible to examine my own epistemological assumptions at all levels of the study, revealing ways in which a pragmatist approach to research (Rorty, 1999) can result in unacknowledged assumptions being embedded into its design. Like other colleagues, I have found that my research methods, despite social justice-oriented intentions, were here inadvertently reproducing a neoliberalist agenda (Pascal & Sagan, 2018). The recovery model – that is, the personal recovery approach as it has become mainstreamed within research and services – is epistemologically individualist. It appears to be neutral and accessible to all, but it is not, and cannot be so, until the structural determinants of mental distress and wellbeing are equally addressed.

## Chapter 10: Conclusions

In this chapter I summarise my findings, situating their overall significance within the global context of what has been described as a 'storytelling boom' across multiple spheres of public, private and political life. In the light of this wider context, I go on to suggest implications of this study for narrative-based research and practice, and explore some ways of addressing issues of power imbalances at analytical and methodological levels. Lastly I offer concluding reflections, while attempting to resist the narrative urge to finalise accounts into tidy endings.

### 10.1 Summary of findings

My aim for this thesis was to conduct a narrative inquiry into the possibilities and problems afforded by the 'recovery narrative' as a distinct genre within mental health research and practice. My objectives were (i) to explore characteristics of recovery narratives told by people from marginalised groups; and (ii) to explore their experiences of telling recovery stories in formal and everyday settings. Data was co-created with 77 research participants, and I conducted three types of narrative analysis.

**Preliminary conceptual framework:** Through a narrative synthesis of findings from papers included in my systematic review, I developed a preliminary conceptual framework describing characteristics of recovery narratives as explored in the academic literature to date. Narratives were characterised as being diverse and multidimensional across structure, form and content, incorporating multiple subgenres, positionings with regard to the mental health system, emotional tones, relationships with the concept of 'recovery', trajectories, types of turning point, sequences, types of protagonist/antagonist and uses of metaphor.

**Chapter 7** demonstrated that, when asked for their narratives of recovery in a research interview context, 75 of the 77 participants with experiences of marginalisation provided accounts which could be described using the nine dimensions of the conceptual framework. Their stories were more diverse in type than the original framework accounted for. This affirmed the heterogeneity of storytelling which is possible within the genre of 'recovery narrative', suggested the 'unfinalisability' of



typologies, and highlighted that not all recovery narratives can be adequately expressed by conventional formats.

**Chapter 8** moved from exploring stories as static, bounded objects to seeing them as processes, co-created and embedded in the contexts of their telling. It found that questions of power differential in storytelling contexts were central to all participants' accounts of telling their stories of lived experience, affecting the kinds of stories it was possible for them to tell. Participants with a peer role focused on how they had shared their narratives of recovery, and described their ability in some circumstances to *challenge the status quo* and conventional assumptions, through telling their stories in contexts such as professional training and public speaking. Participants who did not have peer roles described what it was like to tell stories about their lived experience more generally, shifting from a focus on recovery aspects. Their experiences of storytelling were characterised by the *risky consequences* of sharing their stories, by a pressure to produce '*acceptable*' stories in some contexts, and by the *untellability* of some of their stories.

**Chapter 9** shifted the storytelling focus to the research interview context itself. I found that, for participants identified as having multiple and complex needs, being asked for their recovery story could result in (i) *narratives of personal lack*, wherein narrators blame themselves for their inability to overcome vast structural inequalities; or (ii) *narratives of resistance*, wherein the embodied effects of such structural inequality refute paradigms of illness or recovery altogether. Micro-level analysis exposed the epistemologically individualist assumptions of the recovery model – i.e. the personal recovery approach as it has become mainstreamed into services – and showed how these may translate into the eliciting of recovery narratives of a highly constrained type. Macro-level analysis demonstrated ways in which dominant cultural narratives may serve to reinforce this focus on individual responsibility, whilst obscuring the greater socio-economic factors at work in individual experiences of distress.

These findings suggest that it is possible in certain contexts for people to tell stories of recovery from mental distress which are indeed diverse, taking many different forms and types. However, the findings also suggest that, in the current socio-cultural context, diverse forms of lived experience storytelling are less likely to be possible for people

with additionally marginalised positions in society. Meta-narratives of stigma, discrimination and individualisation are affecting the ability of these participants to tell stories which give full pictures of their mental distress, and of what changes they might need at societal as well as individual level to enable their recovery. Experiences which are particularly challenging to dominant socio-cultural narratives, such as the role of racism (and the widespread denial or minimising of its effects) in the mental distress of people from racially minoritised communities, are likely to be softened or omitted for mainstream audiences. Researchers and practitioners working in a recovery model context, despite any personal commitments to social justice perspectives, are at risk of replicating the individualist assumptions inherent within the model, unless we are open to challenging ourselves to deconstruct them through, for example, critically-informed, reflexive practice (LeBlanc & Kinsella, 2016). Such assumptions may leave participants and service users apologising for their stories (“not the story you want, I’m sure”); regretting sharing them (“maybe I’d better *not* talk”); or, since the conditions which caused their distress have not substantially changed in their lives, simply refusing to tell them (“nothing’s changed, baby”).

Where does this leave me at the conclusion of this thesis, in terms of my own position on the value of recovery narratives? My findings, and a recently-discovered global perspective on trends within storytelling practice, leaves me more convinced than ever of the need to engage in mental health research which takes a critical reflexive approach. As I began to write this chapter at the end of 2022, I came across details of the biennial ‘Narrative Matters’ conference, which in 2023 will take place in Tampere, Finland. The conference is entitled “Instrumental Narratives: Narrative Studies and the Storytelling Boom”, and the blurb describes a global picture of changing storytelling practices in the context of a broader shift to neoliberal, free-market economies. Although mental health contexts are not mentioned, this description had eerie parallels with the critical literature I have engaged with throughout this thesis. It places accounts of the co-option of mental health recovery narratives into a global context, wherein other storytelling practices with roots in political activism are being similarly appropriated for organisational and governmental purposes, obscuring the violence of structural inequalities.

## 10.2 A global picture: the storytelling boom, 'instrumental' and 'curated' stories

My findings can be seen in the light of this global 'contemporary storytelling boom' (Mäkelä et al., 2021) described by narrative theorists as taking place across multiple spheres of life, from social media platforms (Georgakopoulou, 2022) and non-profit fundraising campaigns (Macrae, 2022) to cultural diplomacy, legislative processes and election campaigns (Fernandes, 2017). Critical scholars argue that this boom has been facilitated by a proliferation of storytelling manuals and workshops offered by business consultancies, storytelling strategists and the self-help industry, encouraging individuals, businesses and institutions to 'instrumentalise' and commodify stories of personal experience to achieve particular goals (Mäkelä & Meretoja, 2022). In these contexts, the injunction to 'Tell your story!' has become an inspirational mantra, in a marked parallel with the way that 'telling your story' courses and guidelines can be presented, for example, in recovery college prospectuses and on mental health non-profit organisations' websites. As with narrative-based research, storytelling in these fields is often presented as a universal human characteristic and an inherent good. But a growing number of narrative theorists are questioning this stance, calling for a more 'story-critical' approach to the storytelling boom (Mäkelä & Meretoja, 2022). Story-critical scholars do not treat the 'instrumentality' of storytelling, i.e. utilising stories to achieve a particular goal, as inherently negative. But they highlight that, in the global shift towards neoliberal politics, personal stories have come to be configured more closely on the model of market principles (Fernandes, 2017), in a commodification of personal experience that can be to the detriment of narrators, and can downplay the limits of popular story formats (Mäkelä & Meretoja, 2022).

This commodification of storytelling, and the effect it can have on the stories of marginalised people around the globe, is explored among others by Sujatha Fernandes (2017) in her study of global storytelling practices, *Curated Stories: the uses and misuses of storytelling*. Although Fernandes does not discuss storytelling in mental health contexts, her arguments sound strikingly familiar. In her review of the 'storytelling turn' of recent decades, she presents a wide range of studies. They track how, as social movements went into decline and neoliberal free-market policies were imposed across the globe, political modes of narration (such as the *testimonios* of radical social

movements in Latin America and the consciousness-raising groups of the women's movement) were abstracted from the goals of building mass movements that confronted power and structural inequalities, and reoriented towards transactional, therapeutic and then market-based, individualised modes of storytelling.

For example, studies of the truth commissions of Central and South America and South Africa describe the commissions' focus as being on promoting therapeutic models of national healing, which prioritise individual reconciliation and forgiveness over achieving collective justice for atrocities committed by armies and dominant groups. In a vivid example of how contexts and methodologies can proscribe the kinds of stories that can be told, Fernandes discusses studies of the South African Truth and Reconciliation Commission. In the beginning, there were few constraints on the ways testimonies could be related, with initial testimonies including detailed descriptions of the context surrounding particular incidents (Castillejo-Cuéllar, 2007). However, investigators grew frustrated by the slow pace of data collection, with statements taking hours to complete. As Fernandes observes, "the kinds of knowledge that were produced by open-ended narratives could not be easily processed by a commission that had defined its mission as fact-finding in the service of truth recovery" (Fernandes, 2017: 24). A year after it began, the protocol for soliciting stories had gone from being a series of open-ended questions to a highly specific questionnaire that the respondent was expected to answer concisely. One question was: "Briefly describe what happened to you or the person you are telling us about. Who got hurt, killed or kidnapped? When did it happen? Who did it?" (Bonner & Nieftagodien, 2002: 177). The protocol made available 40 lines for responses to their questions. Ultimately, the 'truth' offered by the Commission has been critiqued as being of limited value (Stanley, 2001, Avruch, 2010), with people's accounts being used, not to achieve social justice, but as a means through which "the nation was to be purged or cleansed of the 'sins' of its violent past in order to found a future reconciliation" (Moon, 2008: 92).

Fernandes also presents her own three case studies of 'curated storytelling', defined as the compressed stories of individuals wherein macro-level "histories, ambiguities and political struggles are erased in an effort to create warm and relatable portraits of others who are 'just like us'" (Fernandes, 2017: 2). For example she examined the US-run online Afghan Women's Writing Project (AWWP), a series of online creative writing

workshops which sought to 'give voice' to 'silent' Afghan women who shared their own stories of abuse and hardship with readers across the globe through the project website. She analysed 300 online stories and the comments made on them, and found that, by disconnecting the personal experiences of Afghan women from the broader geopolitical context of war and military invasion, the stories tended to reinforce Orientalist stereotypes of traditional patriarchal culture as responsible for their situation. Rather than enabling an exploration of structural conditions leading to atrocities, including the US's own role in Afghan military history, solutions in the stories are presented by the women as possible only through individual empowerment, self-esteem, and uplift through education.

Thus, Fernandes suggests, through this and other case studies, how storytelling has been reconfigured in a neoliberal era; in the case of the AWWP project to show how 'curated stories' were part of broader efforts to absorb and redirect global anti-war opposition. She describes these 'curated stories' as a means of "producing subjects who are guided by principles of upward mobility, entrepreneurship and self-reliance." Yet crucially, and despite the desire for personal advancement, "the majority of those who tell their stories are not able to improve their conditions" (Fernandes, 2017: 11). Thus, in a mirroring of the critiques of recovery narratives presented in this thesis, 'curated stories' may shift the focus away from structural problems and defuse the confrontational politics of social movements. Fernandes asks "rather than being the magical elixir we imagine, might curated stories actually inhibit social change?" (Fernandes, 2017: 3).

### **10.3 Implications for narrative research and practice**

What, then, for narrative-based research and practice in the field of mental distress? How can we ensure that our stories, and our work with stories, can promote the social change required to address the causes of mental distress? At the very least, how can we ensure that the way that we present and use stories of lived experience does not avoid the structural contexts of mental distress and continue to perpetuate an unjust status quo? I now turn to exploring various suggestions from narrative researchers on working with narratives in ways which preserve what I continue to believe to be their

emancipatory potential when shared in conducive contexts and aligned with other collective action for social justice.

Sapouna suggests that a sensitive approach to the use of lived experience narratives in healthcare is one which remains alert to the nuanced relationship between lived experience narratives and the operation of power in the contexts where they are shared and heard (Sapouna, 2021). Survivor and narrative researcher Kathryn Church offers six thoughts on what ‘politically alert researchers’ can do: (i) take a stand: drop ideas of objectivity and bias and engage in the fight against marginalisation; (ii) question dominant narratives: conceptualise studies outside of the dominant narratives, question diagnostic categories; (iii) be as participatory as possible: work with strong leaders from politicised organisations; (iv) be as reflexive about our own positions as possible: be aware, be upfront about who we are as researchers; (v) listen as well as tell – we will miss many other vital storylines if we listen only for ‘the lived experience’ of individuals, and only for processes of illness and recovery, as demonstrated in my case studies of Paul and Cheryl; and finally (vi) find the collective in the individual: learn to perceive and reveal the “bones of large social institutions that shape the flesh-and-blood experience characteristic of personal stories” (Church 2013: 29).

However, those who benefit from existing power relations are unlikely voluntarily to give up their power, even as they may pay lip service to the acknowledgement of power. As my findings illustrate, a critical orientation to one’s practice, whether that is based in the academy, the clinic or the recovery college, is the paradigm most likely to provide alertness to the power and politics inherent in mental health settings. Critical approaches to practice are fundamental to social work and youth work professional training, and the increased involvement of people with lived experience within mental health practice settings could be a route for a more critical approach to practice to be embedded in healthcare training. At the same time, a decrease in what has been referred to as the “othering representational practices” (Grant, 2016) within healthcare settings may enable practitioners who do have their own experiences of distress to feel more able to speak openly about this. How might narrative researchers go about combatting such ‘othering’, as and in solidarity with people with lived experience? I explore potential responses to this question at analytical and methodological levels.

### 10.3.1 Addressing issues of power at analytical level

Any practice rooted in an emancipatory paradigm needs to consider the equalising of power relationships. A central power relationship within research contexts is that of the analyst and participant. As Russo reminds us, “survivor authors have already undergone classification and interpretation of their experiences in the course of receiving psychiatric diagnoses and prognoses” (Russo, 2016: 220). She holds that this makes any further processing of published survivor accounts and interview-based narrative research a highly complex and delicate matter.

Qualitative researchers have used tools such as ‘respondent/participant validation’ or ‘member checking’ to address issues of analytical power, wherein the participant is given opportunities to respond to the analyst’s interpretation of their account. However, these approaches are contentious. Critical theorists warn of epistemological conundrums and a variety of practical and philosophical pitfalls associated with these approaches (Motulsky, 2021). Within mental health research, survivor and service user researchers have long since noted the often-tokenistic level of ‘involvement’ this can represent (Beresford & Evans, 1999).

Russo’s (2016) review of studies based on published survivor accounts was informed by her experience of being *interpreted* instead of *heard and responded to* in the course of psychiatric treatment. She advocates for dialogical approaches to working with the analysis of lived experience narratives, in which as sole analysts we give up any “aspirations to interpretive dominance” (Russo, 2016:225), or having the final say within the analytical process. She echoes Frank (2010: 100) in seeing interpretation instead as an ongoing dialogue with the story which “does not speak *about* ... but *with*” the other person, and recognises what she refers to as the other person’s ‘unfinalisability’. I have attempted to resist finalising, particularly within analysis of Paul and Cheryl’s stories, by presenting my findings as plausible possibilities rather than objective and verifiable ‘truth’, and by providing alternative readings.

Other methods of equalising the balance of power between analysts without lived experience and their research participants have been suggested. In their study questioning the professionalisation of recovery, Clara De Ruyscher, an academic, and Peter Tomlinson, a service user, adopted a collaborative case-study design wherein they

co-analysed Tomlinson's experiences of recovery and treatment using a bricolage approach as a more egalitarian process of knowledge production (De Ruyscher et al., 2019). Kristina Dernbach suggests the emancipatory potential of collective auto-ethnography, such as her own and others' stories of suicidality (Dernbach, 2022). Auto-ethnography has the benefit of dispensing with 'top-down' or 'outsider' analysis of individual lived experience, although this does not inherently guarantee an emancipatory positioning.

The question of whether to involve participants in the analytical processes of this study was a recurring ethical issue for me. I initially felt that my position as a researcher with lived experience meant that, since my research was 'user-controlled' (*by us, not about us*), this was sufficient to guarantee an emancipatory analysis of findings which would be 'on the side of the participant'. Informed by a Queer theoretical paradigm, Alec Grant (2016) maintains that the binary apparent in 'researcher-researched' and 'professional-patient' arguably contributes to maintaining an "indefensible cultural binary between 'mental illness' and 'wellness'" (Grant, 2016: 294). For Grant, this binary can be undermined when the researchers and the researched are the same people, who celebrate a postcolonial *hybrid* identity status as both mental health researcher professionals and people with lived experience of service use and of mental distress.

But as my own analysis demonstrated, possession of one's own lived experience does not automatically lead to an emancipatory perspective. Such thinking can lead to false assumptions of similarity based on one essentialising characteristic, which may serve to cover over important structural differences. As previously noted in my discussion of ethics in [Chapter 6](#), quite apart from the well-established critical theory critiques of 'experience' as a foundational category (Rose, 2017), any concept of a homogenised 'we' has been challenged by intersectionality theory (Crenshaw, 2017), wherein it becomes impossible to talk about an individual's experience of mental distress without talking about their other identities (Smith, 2019). Despite the pervasiveness of mental health injustices, not all people who have been labelled as 'mentally ill' experience the same degree of societally induced harms. Our positions in prevailing social hierarchies – organised by shifting boundaries of race, gender, social class, sexuality, physical ability, age and so on – profoundly shape those experiences (Morrow & Malcoe, 2017).



Researchers (and others) who do not take these multiple and intersecting identities into consideration may fail to recognise the complexity of their participants' experiences.

Russo distinguishes between ambition to *interpret* the knowledge of people with lived experience, and the aspiration to *connect with* and *advance* our knowledge. This calls for methodologies that enable “*everybody* involved in the research to take part in the process of making meaning of experience”, which in turn reveals an urgent need “to revisit prevailing research values and principles” (Russo, 2016). Attention to power within mental health research is required not just at analytical, but at methodological level.

### **10.3.2 Issues of power at methodological level**

Within the mental health system, injustices have occurred and continue to occur. Furthermore, the chances of experiencing mental distress are distributed unequally among population groups. Given this context, my findings lead me to conclude that conducting qualitative research in a default positivist paradigm will not be sufficient to ensure the transformation of the mental health system that is required. Like pioneering disability scholar Michael Oliver (1992), I found that replacing this paradigm with an interpretivist one was not enough. Interpretive research still has a relatively small group of powerful experts doing work on a relatively large group of powerless research subjects (Oliver 1992: 106), who are too often seen as in some way fundamentally ‘other’ from the ‘experts’. In this vein, Oliver holds that “interpretive research is just as alienating as positivist research” and calls for a shift to research methodologies built on participation and reciprocity (Oliver 1992: 107).

In the intervening years, intersectional, decolonising, indigenous, feminist, post-structural, transgender, queer and critical realist approaches have all been employed to question the manifestation of power relations in mental health systems and its impact on people with mental distress (Morrow & Malcoe, 2017). All seek to disrupt research from a positivist or interpretivist paradigm which adheres to normative biomedical and cultural structures of ‘ill health’, ‘pathology’, or ‘deviance’, which “functions in the service of maintaining cultural hegemony and normativity to the disadvantage of some people and populations” (Grant, 2016: 294).

The risks of ‘allowing’ the circulation of lived experience stories within mental health research and practice, and thinking that this is enough, may be worse than silence itself from a social justice point of view. Paul Gready (2013) summarises research on testimony and social justice, stating, in parallel with Fernandes (2017), that “the struggle now is less over the articulation of the marginalised and subaltern voice than for greater control over voice, representation, interpretation and dissemination. Voice without control may be worse than silence; voice with control has the capacity to become a less perishable form of power because ... it allows voice to enter into a more genuinely reciprocal dialogue”

Grant (2016) likewise suggests that representational practices in much of qualitative inquiry collude with the idea of locating mental health difficulties exclusively with individuals:

*The act of ignoring the world, as though it could go away, and pretending to a supposedly limitless capacity of agency and lived experience to transcend and overcome social and material structures, or ignoring the importance of these structures relative to the assumed significance of lived experience, feeds back into curricular and other practices in mental health which perpetuate the normative and the oppressive (Grant, 2016: 296).*

This attention to structural conditions resonates with Lois Weis and Michelle Fine’s (2012) call for a ‘critical bifocality’ in all qualitative research; or a “dedicated theoretical and empirical attention to structures *and* lives” (Weis & Fine, 2012). Thus an emphasis on the ‘social life of stories’ (Chase, 2018), directing attention to the social conditions surrounding narrative activities such as truth commissions, has become increasingly important within narrative inquiry and is perhaps a contribution that is vital to maintain within narrative-based mental health research. Like Fernandes, “rather than taking stories and the prototypical story forms as givens”, as narrative researchers we can continue to “interrogate the conditions of production of both narrative and genre” (Fernandes, 2017: 163).

## **10.4 Closing reflections**

Jan Pascal and Olivia Sagan (2018) call for making the ‘outlier’ narratives our core business as narrative inquirers. In this thesis I have chosen to foreground, not omit,

stories which do not fit the neat template of 'recovery narrative'. In doing so I hope to have contributed to the continued hearing of a plurality of voices which are at risk of being silenced in this field – including those who feel they have to apologise for their story not being the right kind; those who have learned through bitter experience that telling their story in good faith can lead to unwanted consequences; and those for whom recovery remains largely irrelevant – and thus to the further complicating of the concept of recovery. Research on 'recovery narratives' which is simplified and stripped of context risks reinforcing neoliberal ideas of individual responsibility for their own wellbeing for some of the most structurally disadvantaged people in society, while leaving living conditions, and ongoing situations of social injustice, unchallenged and unchanged.

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## Appendix 1: MEDLINE search strategy

The following search terms were used, identified from the title or abstract of papers:

1. Mental Disorders/
2. Behavior/
3. Psychological Phenomena/
4. Mental Health/
5. (Mental\* or psych\* or mad or madness or trauma\* or distress\* or 'lived experience').ti,ab.
6. 1 or 2 or 3 or 4 or 5
7. Mental Health Recovery/
8. Psychiatric Rehabilitation/
9. Resilience, Psychological/
10. Hope/
11. Quality of life/
12. (Recover\* or transform\* or resilien\* or surviv\* or thriv\* or endur\* or rebuild\* or hope\* or conquer\* or reclaim\*).ti,ab.
13. 7 or 8 or 9 or 10 or 11 or 12
14. Personal Narratives/
15. Narration/
16. Narrative therapy/
17. (narrat\* or story or stories or storytelling or telling or tale\* or restory\* or counter-narrative\* or disnarrat\* or memoir\* or testimon\* or biograph\* or autobiograph\* or auto-biograph\* or autoethnograph\* or auto-ethnograph\* or photovoice).ti,ab.
18. 14 or 15 or 16
19. (typol\* or classif\* or genre\* or theme\* or structur\* or categor\* or framework\* or dimension\* or format\*).ti,ab.
20. 6 and 13 and 18 and 19.

## Appendix 2: Summary of quantitative findings (systematic review)

<b>Length of recovery narrative</b>	<b>#5 Alisic et al. (2016)</b>	
	<b>Characteristic</b>	<b>Definition</b>
	Elaboration	No. words in children's versus parents' recovery narratives

<b>Linguistic categories</b>	<b>#5 Alisic et al. (2016)</b>	
	<b>Characteristic</b>	<b>Definition</b>
	Mental state language	Proportion of cognitive process & emotion words used (anxiety, anger, sadness & optimism)

<b>Dimensions of discursive features</b>	<b>#38 Shohet (2007)</b>	
	<b>Characteristic</b>	<b>Definition</b>
	Certainty	Strong cognitive verbs (realise, know)
	Affiliation with institutional narratives	Weak cognitive verbs (guess, think)
		Hedges and mitigations (but, almost, just, sort of)
	Past and present selves	Continuity adverbs (always, still, whenever)
	Linearity/experientiality of narrative	Progressive tense verbs
		Experiential nouns and verbs (feel-conjugations)
		Direct reported speech and thoughts
Subjective constructions (maybe, if)		



## Appendix 3: Interview Topic Guide

### PART A (UP TO 45 MINS)

1. Can you tell me in your own words about your mental health and recovery experiences please? For this first part of the interview, I don't have any set questions to ask you – could you tell me about your experience as if it were a story with a beginning, a middle and how things might look in the future? There's no right or wrong way to tell your story – just tell me in any way that feels most comfortable.

*Prompts: (only if narrator comes to a stand-still): Can you tell me more about that?  
What was the experience like for you?*

*Is there anything else you'd like to tell me about your recovery story?*

### PART B (UP TO 45 MINS) – when the participant has finished telling their story

2. How was that experience for you, telling me something about your story today?  
*Prompts: is it something you're really familiar with doing, or not?*
3. How do you vary how you talk about your experience, depending on the context?  
E.g. who you're talking to, where you are, how you're feeling that day?  
*Prompts: Have you ever felt that there are parts of your story that you're unable to share in a certain context?*
4. As you know, we're interested in how stories might affect people who hear them, and we're aware that sometimes it might NOT be helpful to hear a story of someone else's experience. Can you think of examples of times when people sharing their experiences have been unhelpful to you?  
*Prompts: Can you tell me more about this? What was unhelpful?*  
*Prompts: What were your personal circumstances at the time?*
5. And can you think of examples of stories that have been helpful to you?  
*Prompts: Can you tell me more about this? What was helpful?*  
*What was it about the person or story that had the impact? / What were your personal circumstances at the time?*

Has this changed the way in which you give your own accounts in an attempt to help others?

*Prompts: Can you tell me more about this? What was helpful?*

## Appendix 4: Field notes template

### Field notes

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**STUDY:**

**CI:**

**PARTICIPANT ID NUMBER:**

**Researcher:**

**Date:**

#### 1. Descriptive

**Physical setting:** *[location; type of setting; weather]*

**Participant:** *[overall appearance/demeanour of participant;, non-verbals; age; background; personal circumstances etc.]*

**Summary:** *[responses to interview as a whole, stand-out points etc.]*

**What was the tone of the interview?**

**What will you take away from it?**

**What was central to the recovery narrative?** *[most notable characteristics/themes, turning points etc.]*

**What did you learn about the impact of stories on the interviewee /others?**

## **2. Reflexive**

**Reflection on own role as an interviewer:** *[reflection on feelings, possible biases etc., immediate context for self, prior to interview]*

**Reflection on own role as a participant in the narrative:** *[own responses to participant, changes in questions, any additional questions asked]*

**Impact on interviewer as recipient**

# Appendix 5: Participant Information Sheet

## NEON Phase 1. Participant Information Sheets. Activity 1. V3.0. 31st January 2018. IRAS reference: 234535.

**1. Research Study Title:** NEON: Narrative Experiences Online

**2. Research Team:**

**Peer Research Assistant: Joy Beardsley.** Telephone: 0115 748 4289. Email: [joy.beardsley@nottingham.ac.uk](mailto:joy.beardsley@nottingham.ac.uk)

**Research Assistant: Dr Kate Morgan.** Telephone: 0115 748 6344.  
Email: [kate.morgan@nottingham.ac.uk](mailto:kate.morgan@nottingham.ac.uk)

**Chief Investigator: Prof Mike Slade.** Contact through Lee Edwards-Kelsall: [lee.edwards-kelsall@nottingham.ac.uk](mailto:lee.edwards-kelsall@nottingham.ac.uk)

**3. Invitation for participation in a research activity**

You are invited to take part in a research activity organised as part of the NEON study. The following information has been provided to help you understand the purpose of the research activity and what the research will involve. Please take your time in deciding whether to participate, and please get in touch with the research assistants listed above if you have any questions.

**4. What is the purpose of the NEON study as a whole?**

The purpose of NEON is to understand how recovery stories (personal stories of mental health problems) can be of benefit to people with mental health problems, and to design and trial a clinical intervention built around recovery stories. "Recovery" here refers to the process of learning to live as well as possible, either with or after a mental health problem.

**5. Why have I been invited to participate?**

In research activity 1, 120 participants are being recruited who have experience of mental health difficulties, to help us understand how they tell their stories of recovery, and how and why they might share them with others. Participants can also offer their story for future use in the NEON study, meaning it could be viewed by others during and after the NEON Study. However, this is optional, and you can still take part in this research activity if you do not wish to offer your story to the study in this way.

## **6. Do I have to take part?**

Participation in this research is entirely voluntary, and there will be no negative consequences for you (e.g. for your care if relevant, for your employment if relevant) if you choose not to participate. You can discontinue participation at any time, and if you do, any data that has been collected about you will be destroyed. If you do choose to take part, you will need to sign a form indicating your consent for taking part in the research.

## **7. What will I be involved in if I agree to take part?**

If you agree to take part, please contact the research team, using the details provided at the top of this information sheet, to organise a venue and a time for an interview. The interview will last for an hour, and you will be paid £20 plus reasonable travel expenses as a compensation for your time and effort. At the start of the interview, you will be asked to share your recovery story with the researcher. You will then be asked some follow-up questions about it. Your story and interview will be recorded using either an audio or a video recorder (your choice), and will be analysed by the research team.

## **8. What are the possible benefits of taking part?**

The NEON study will design and test an intervention built around recovery stories, and the knowledge developed through this process will have an impact on future clinical practice. Making a contribution to this process, through taking part in an interview, might be perceived as a benefit, as might the experience of sharing your story with a trained listener.

## **9. What are the possible disadvantages and risks of taking part?**

For some participants, talking about their own experiences can be distressing, and the distress that this causes could be perceived as a disadvantage of participation. You can stop at any time.

## **10. What happens after the interview?**

Your story and your interview will be transcribed. Any names of people and places in it will be replaced with fictional ones to protect your identity and the identity of others. The research team will analyse both the story and the interview, and will produce analysis reports and publications which summarise what has been learnt. This learning will feed into later work in the NEON study. Quotations from your story or your interview might be used in study publications, but any published data will be thoroughly anonymised, e.g. details will be changed to ensure that you cannot be identified through it.

## **11. What will happen if I withdraw from the study?**

Your participation is entirely voluntary and you are free to withdraw at any time, without giving any reasons, and without your legal rights being affected. If you withdraw, then any identifiable information held about you will be destroyed, including transcripts in which names have been changed. To withdraw, please contact a member of the research team listed above, providing your name, and stating that you wish to withdraw. To allow for withdrawal, we will keep a master file, linking your name to your data. Access will be strictly controlled by the chief investigator.

## **12. Will my taking part in this project be kept confidential?**

All identifiable information collected through this study will be held confidentially, with access to third parties strictly prohibited. Digital data (including audio or video recordings of your story and interview) will be held on secure servers owned by the University of Nottingham, whilst physical data (such as signed consent forms) will be held in locked cabinets in the Nottingham Institute of Mental Health. Our project sponsor (Nottinghamshire NHS Foundation Trust) may audit data, but only under terms of strict confidence, with disclosure to a third party strictly prohibited.

Please note that confidentiality may be breached if your interview suggests that you are at risk of harming yourself or others, or if it suggests that you or others have engaged in criminal activities that require notification (e.g. relating to protection of children). Decisions to breach confidentiality will be made in collaboration with the investigator.

### **13. When will my data be destroyed?**

Digital recordings of your story and your interview will be deleted after six months, unless you have offered your story to the NEON study, in which case we will keep it, in which case it could be viewed by others during and after the NEON Study. Transcripts will be deleted after five years, and only destructively anonymised data will be retained, e.g. data where sufficient information is removed so that an individual cannot possibly be identified through it. The master file will be deleted by the end of the NEON study.

### **14. What will happen to the results of the research project?**

Findings will be disseminated through academic, practitioner, consumer and carer articles and presentations. If you would like to keep track of these, then details will be provided through the project website, accessible here: <http://www.researchintorecovery.com/NEON>. If we include any quotes from your interview in project publications, then they will be sufficiently anonymised that it will not be possible to identify you through them.

### **15. What should I do if I feel distressed?**

If you feel distressed during the interview, please tell us, and we will offer to pause or conclude the process - you can stop the interview at any time. If you continue to feel distressed after leaving, you might wish to consult the following services which are available in Nottinghamshire and nationally for confidential emotional support and information:

#### **Nottingham Wellness in Mind**

**Web:** [www.wellnessinmind.org](http://www.wellnessinmind.org)

**Tel:** 0800 561 0073 – information and advice helpline, available 7 days a week 9 a.m. – midnight.

**Drop-in:** Nottingham Wellbeing Hub, 73 Hounds Gate, NH1 6BB. Drop-in available Mon-Fri 9-5.

Offers free mental health and emotional wellbeing support to people living in Nottingham, either online, face to face or by phone. Staff will reply to messages left online within 24 hours. There are also self-help guides and resources available the website.

#### **Nottingham Local Information Online (LION) directory**

**Web:** [www.asklion.co.uk](http://www.asklion.co.uk)

Community directory of local services, including a dedicated “mental health” section of available groups, activities, services and support - scroll down to the “Health and Self Care” section and then click on “Mental Health”).

### **Saneline**

**Web:** [www.sane.org.uk/what\\_we\\_do/support](http://www.sane.org.uk/what_we_do/support)

**Tel: 0300 304 7000.** Available every day from 4.30 – 10.30pm (local rate number – included in inclusive/free minutes on mobiles).

**Textcare:** confidential text support sent at specific times, set up via an online form (see link above).

**Support Forum:** [www.sane.org.uk/what\\_we\\_do/support/supportforum](http://www.sane.org.uk/what_we_do/support/supportforum)

National mental health charity offering specialist emotional support and information to anyone affected by mental illness, including family, friends and carers, via an out-of-hours helpline and online support forum.

### **Samaritans**

**Web:** [www.samaritans.org](http://www.samaritans.org)

**Tel: 116 123**

**Email:** [jo@samaritans.org](mailto:jo@samaritans.org)

**Nottingham Drop-in:** 18 Clarendon Street, Nottingham, Nottinghamshire, NG1 5HQ.

Available Monday, Tuesday, Thursday, Friday, Saturday 9.30am - 9.30pm. Wednesday

11.30am - 9.30pm and Sunday 9.30am - 2.00pm.

National confidential listening service offering a safe space to talk.

### **16. What if something is going wrong?**

If you have any concern about the study, you should first speak to one of the researchers (details in Section 2 above). You can also contact the programme coordinator Stefan Rennick-Egglestone on 0115 82 30926 or through [stefan.egglestone@nottingham.ac.uk](mailto:stefan.egglestone@nottingham.ac.uk). If you remain unhappy, and wish to formally complain, you should contact the Research and Innovation office at Nottinghamshire Healthcare NHS Foundation Trust, who are the sponsor for the study, by email to [Randlenquiries@nottshc.nhs.uk](mailto:Randlenquiries@nottshc.nhs.uk) or phoning 0115 9691300 extension 11903 or 11904.

Alternatively, you can contact your local Patient Advice and Liaison Service in the following ways:

Phone: 0115 993 4542

Email: [complaints@nottshc.nhs.uk](mailto:complaints@nottshc.nhs.uk)

Write to:

Patient Experience Team

Moorgreen House

Highbury Hospital

Nottingham

NG6 9DR

### **17. Who is organising and funding the research?**

The project is funded by the National Institute for Health Research, as part of their Programme Grants for Applied Research stream of funding.



## **18. Who has reviewed the project?**

All research in the NHS is reviewed by an independent Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the Nottingham 2 Research Ethics Committee ((nrescommittee.eastmidlands-nottingham2@nhs.net). The project has also been reviewed by the Health Research Authority, and by the Research and Innovation Team at Nottingham Healthcare NHS Foundation Trust, who are sponsoring the project.

## Appendix 6: Initial codes (thematic analysis)

1	Uses story to challenge stigma about mental health
2	Includes more of story to help get own needs met
3	Uses story when training mental health professionals to emphasise difficulties of living with mental health issues
4	Expresses preference for openness but there are barriers
5	Gauges likely response of recipient(s) and varies accordingly
6	Uses story to inspire hope
7	Omits parts of story – has had negative responses from recipients in the past
8	Omits parts of story – anticipates negative response from recipients
9	Omits traumatic events – too painful to think about
10	Omits traumatic events – too shameful to include
11	Omits traumatic events – has had previous unhelpful responses from recipients
12	Would omit past experience of sex working to daughter
13	Varies to avoid causing distress to recipient
14	Omits family trauma in a public narrative because inappropriate to share their story
15	Expresses wariness about sharing parts of story with clinicians – has led to unwanted treatment in past
16	Will go into more detail in a close relationship
17	Emphasises how medication makes them feel with psychiatrists because they're unable to understand how it affects life
18	Support group helped them to talk more openly about rape than in the past
19	Includes more with people who've had the same experiences because it's normalising
20	Would tell story from a more anti-institutional perspective with others with lived experience
21	Would be more explicit about extent of the effects of racism with other BAME people
22	Emphasises parts they have in common with recipient(s) – so they can relate to story more
23	Omits psychosis because it's less understood than other mental health issues
24	Omits having had mental health issues when filling in questionnaires
25	Wants to protect self but will share if it helps recipient
26	Doesn't go into details of own experience with class students, in order to keep story positive (teacher)
27	Would disclose abuse with male partners
28	Omits spiritual perspective with atheists because they wouldn't get it
29	Perspective and story has changed over time from a blaming/victim narrative because compassion has grown
30	Includes more today because it's a research interview context
31	Needed to tell story more in the past than now
32	Omits negative talk about others in public narratives because of potential negative impact on them
33	Would include mental health as spiritual crisis perspective when training psychiatrists but not as a client
34	Uses humorous perspective w friends but stresses the involuntary & scary aspects w mental health professionals
35	Omits mental health issues in job applications – fear of not getting job
36	Gives talks on past elements of story but omits current issues because not yet processed
37	Depends on own mood and wellness

38	Depends on how well recipient is at the time
39	Doesn't vary story because having the opportunity to speak is too good (i.e. so includes all)
40	Omits own mental health experience with her daughter's partner – has own mental health issues
41	Omits own mental health experience with her sister because it's a difficult relationship
42	Less open than in the past because wants privacy and doesn't want mental health to define her any more
43	Depends how much it's appropriate to share within the narrator-recipient relationship
44	Wants to be useful to others but not boastful about own experience of recovery
45	Would be more open with siblings now older, to help them avoid risk
46	Careful about expressing Muslim views because they might come across as extreme
47	Doesn't talk about some experiences because they are very personal
48	In the past didn't mention own mental health issues – now gives talks on it
49	Omits ADHD experience because still coming to terms with it
50	Would vary less than in the past because able to be more open now
51	Would be careful about sharing his sexuality within African community of origin, for his own protection due to stigma
52	Would tailor it differently for people without lived experience to increase insight
53	Gives less mental health background detail in interview – not needed
54	Omits extent of effects of racism when applying for funding
55	Omits mental health issues when at adoption support group
56	Varies because different services want different approaches to the story
57	Monitors what they share in support groups because doesn't feel they're as bad as some people
58	Cautious about what is shared to protect self
59	Omits mental health issues with alcohol recovery keyworker because they have related it all to alcohol in the past
60	Gives secular or Christian perspective depending on context
61	Omits details to avoid shocking recipient and having to deal with their reactions
62	Omits mental health experience as a Black woman to avoid further potential discrimination
63	Omits parts because still embarrassing to share about mental health
64	Uses humour to make it possible to talk about difficult subjects like suicidal ideas less emotively
65	Varies depending on time constraints – shared more in research interview but at GPs only have 10 minutes
66	Omits traumatic events – still processing them
67	Doesn't vary the important things because they don't need to change
68	Doesn't talk with people he knows – sees his mental health issues as his own fault – but would/does talk to strangers (e.g. in research interview)
69	Doesn't vary – seen as less honest
70	Wouldn't tell anything to a police officer or social worker
71	Hesitates to mention sexuality within services because they've focused unhelpfully on it in the past
72	More anxious talking about mental health than physical health at work
73	Shares more than in past because there's a more open culture around mental health
74	Shares more with others with same lived experience – they understand
75	Talks about mental health but doesn't tell everyone the extent of the distress
76	Hard to tell people about scary thoughts because didn't know how they'd react

77	Wouldn't go into details of intrusive thoughts because you have to be careful and trust the people who you tell
78	Careful about sharing details of own experience within peer support – would for some recipients as it's normalising
79	Varies talking about own experience within peer support to prevent triggering
80	Would never be specific about having been abused, within peer support
81	Sometimes feels the need to share more, to explain behaviour that might seem strange to others
82	Reframes own suicide experience as a tool to help recipient within peer support
83	Creates narrative to suit own ends when recipients holds power – e.g. psychiatrist
84	Omits criminal activities
85	Will reveal and conceal different things even in a supportive service
86	Own beliefs and political affiliations will shape what is shared
87	Just tells mums in the playground what they want to hear – it's like having two faces on
88	Doesn't tell whole story within peer support because it would be inappropriate role reversal
89	In a health appointment would only include what's wrong, not the positives
90	Wouldn't talk about discrimination and poor treatment on the wards when training current service users
91	Omits parts of story which might disempower recipient
92	Would share more about abuse with women to avoid embarrassing men
93	Only shares things within peer support that are relevant and helpful to recipient
94	Would share details of poor service experience if others want to talk about it
95	Doesn't vary – would be hard to maintain different stories
96	Has to emphasise the worst parts of themselves to gain benefits
97	Doesn't tell story much
98	Expresses resistance to openness
99	(Implicit code) Concept of 'oversharing', or that saying too much about own mental health is a negative thing
100	(Implicit code) Lapses into silence, leaves gaps or speech dissolves when talking about difficult subjects

## Appendix 7: Initial themes (thematic analysis) – factors influencing storytelling at five levels

Theme	Sub-theme	Definition	Exemplar quote	Code #
<b>1. Intrapersonal level (factors relating to or impacting on the narrator themselves)</b>				
1.1 Narrator's own mood and wellbeing	n/a	How (or if) a story is told will vary depending on narrator's mood or state of wellbeing on that occasion. Telling may vary in a number of ways, e.g. telling less or nothing if having a bad day, or telling more if very distressed	And some days I'm not feeling like it. My story isn't 'we all lived happily ever after' because it's life isn't it, we all get stuff in life. So some days I do struggle with depression and I won't be as, well, interested in talking about things so I limit it like that. I just gauge it.	37
1.2 Narrator's communication preferences	1.2.1 I prefer to be open and honest if it's possible	Narrator has a preference for including as much of their story as possible, but indicates this is not always, or has not always been, possible	I kind of have to brush on stuff, but I'd – I'd rather be open and say like, this has happened.	4, 25, 45
	1.2.2 I resist the (perceived or actual) pressure to be fully open	Narrator resists a self- or other- imposed perspective that inclusion of everything is desirable; either because of risk, their right to privacy, or because they don't see it as the natural way that stories are told	I always think as a peer, using your lived experience, all you're really – so like, my label, which used to have 'peer recovery trainer' on it, all that would say was I have limited experience of recovery. Anything else I share beyond that is completely up to me in the moment. Nobody has the right to say what or when or how I share that. And I don't have to share any more than that actually, if I don't want to.	47, 98
	1.2.3 I sometimes use humour strategically	Narrator reports varying by sometimes using humour to achieve something – e.g. relief for self, a new perspective for recipients, or to make talking about difficult things more possible or bearable. They also refer to times when humour is not appropriate, or can backfire.	I often use humour to kind of – either, it can be used in two ways, it sometimes masks it, which isn't particularly helpful, and then at other points it makes it funny and it makes it bearable. And I have found also when I tell things, even when it's quite serious, to friends, they do sometimes end up laughing and I don't feel like I'm being taken seriously so it's – Yeah but it does mean I can talk openly with my friends.	34, 64

Theme	Sub-theme	Definition	Exemplar quote	Code #
	1.2.4 I don't vary my story	Narrator rejects the concept of varying the telling of their story e.g. seeing this as less honest, or expressing desire to include everything when given the opportunity	I wouldn't [vary the way I tell my story]. I don't. I have a big problem with the truth. And I don't like lying...One time, one way only and that's it and that's the truthful way. Yeah, I will not embellish or add to anything.	39, 67, 69
1.3 Narrator's beliefs and politics	n/a	How a story is shared, in terms of content, perspective and tone, is connected with the narrator's beliefs (spiritual or other) and political affiliations, and whether or not the recipient may share or be interested in them	It's how you say what you say, or how you get across the meaning that you want to communicate, because I could be ranting and raving...I could have a diatribe against psychiatry or mental health services, from my own experiences or generalising about things more broadly. I'm trying to focus on my own story for these purposes [the research interview] but it's very hard for me to detach that from my political affiliations, from my beliefs, from what I think are my understandings of the world and the way things work. And all about them will colour what you share.	28, 86
1.4 Avoidance of negative experiences or consequences for narrator	1.4.1 I may vary the way I tell my story due to my embarrassment or shame	Narrator describes varying, such as omitting parts or 'over-explaining', in some contexts due to their own or family shame about a traumatic experience (e.g. rape, sexual abuse, suicide), or embarrassment about mental health issues themselves	Certainly being raped, I would [omit this]- that was one thing that I – until recently I hadn't tackled that[...and so I'm going to a men's group. And it – it allows me to talk about it fairly openly now, whereas I definitely wouldn't have done in the past. [I: Because you felt that you just wouldn't have been listened to or -?] I think I just felt deep shame about it really. Yeah.	10, 63, 68, 81
	1.4.2 I may vary the way I tell my story to avoid negative reactions from the recipient(s)	Narrator describes omitting, exercising more caution than in the past or choosing not to share some parts at all, with family, friends, in health services, online and at work, either due to past experience of negative responses, or because they anticipate them or can't rule them out. Negative responses specified included being judged, stigmatised, disbelieved, rejected, not understood or taken	I work in the arts, so – you know, we're supposed to be the feeling people. And we are...[pause] we are...but[...] it's like – you're allowed to say 'I've been having a difficult time'. But, telling somebody that you've been sectioned? It does not go down well. It really doesn't. People just think, 'who are you?' And I've been in that situation where [...]it was with a group of actors, and there's just this – instant judgement. And I don't mean it in a terrible way. It's just that you can see people go, 'Ooh. God. You've lost control of life'. You know, 'you couldn't keep it together'. It's almost like, you're allowed to have difficulties but you're supposed to, sort of, do it in a really, I don't know, glamorous, interesting way. But to actually fall to pieces in a	7, 8, 11, 24, 58, 76, 77, 87

Theme	Sub-theme	Definition	Exemplar quote	Code #
		seriously, or being seen as less competent or weaker	huge heap...no. That's ugly. You know. So no, I don't. I – a couple of people obviously know, that I was, you know...they do know. Er...but I wouldn't ... it's not something I advertise – at all.	
	1.4.3 I may omit painful or traumatic parts to avoid causing myself distress	Narrator reports omitting parts of their story, because they don't feel ready to share them, haven't yet got the words, are still processing parts, don't want to give those parts impetus, or because parts are too painful to think about. Or narrator implicitly demonstrates this through leaving gaps in their account, trailing off, or their speech dissolving within the interview when recounting traumatic events	Yeah, I think we all do really [vary how we tell our stories]. I mean there's some things that really scar us deeply and are really painful, and you know, when we're talking about experience we either don't mention them or brush over them. A bit like the sexual abuse that I previously talked about – it's probably something that is quite deep in me that is an issue that needs to be unfolded, that impacts on my mental health – quite difficult. However because of what – what was in that experience it's not easy to talk about, so I say 'sexual abuse' but not actually what that contains, because by doing that – would – would make it really painful for me to talk about.	9, 36, 49, 66, 75, 100
	1.4.4 I may vary potentially shocking parts, to avoid recipient's own shock and unwanted sympathy	Narrator may omit or minimise parts of their story that may feel too much for the recipient, e.g. multiple traumatic events or particularly extreme trauma in order to avoid unwanted sympathy or having to deal with the shock of the recipient	Often when I talk to people I want to warn them, 'oh sorry I hope you don't find this too...I hope this isn't too traumatising for you' [...] I was with someone and they didn't know my mum was dead yet and I said oh my mum was dead, and then they were like, 'oh gosh I'm gonna have to leave the room, can I just take a minute? I feel so sad about what you have said' and it was just genuinely like – they didn't expect that, so they were like, I need to leave. And so much of my experience of sharing little things here or there – is that people kind of, well people just react with like too much sympathy, they're just like 'oh my gosh', like 'I'm so sorry', like 'I cannot believe -'. And you're like, okay, I don't really need you to find my life this shocking [laughter]. It is pretty shocking, like. I just reel it off, like 'yeah, I know, my dad raped my mum and I was born and then someone threatened to stab me, and then -' you know, whatever. So I get it's shocking but [...] my mum's death is not – this is the tip of the iceberg!	61
	1.4.5 I vary my story to avoid negative	Narrator either omits parts in general (e.g. criminal activities), or with particular professionals (e.g. with police or social workers) or feels obliged to emphasise	Sometimes I've had to emphasise more things in my latest DWP for example. You know, having safety, financial security, to be able to	70, 84, 96

Theme	Sub-theme	Definition	Exemplar quote	Code #
	consequences within services	parts they would rather not share in order to receive services	recover – it means I have to show the worst part of myself to DWP[...]I have to pump up the worst part of myself in order to be accepted.	
<b>2. Interpersonal level (factors relating to or impacting on the recipient)</b>				
2.1 Narrator's assessment of recipient's wellness	n/a	How (or if) a story is told will vary depending on narrator's perception of the wellness of their recipient(s), e.g. by shaping the story to fit recipient's current needs, changing the tone or focus, or not telling it at all	If you have a friend or a relative who's mentally ill as well, you have to be sensitive to how you talk to them about yourself, so, I think mostly I would tailor how I share that stuff around someone who's vulnerable.	38
2.2 Narrator's consideration of what is appropriate to share within relationships with power imbalances	n/a	Narrator reports omitting parts or specific details or being careful about what they share, according to what they gauge as appropriate within the boundaries of specific relationships where they hold more power, for example, mother-daughter, teacher-student, within peer support, researcher-participant	I told my story to my tutor group but I left many things kind of under the radar. Like I told them I was in uni, tried to achieve too many things, I got ill, my body shut down and I ended up in the hospital for a few weeks, but I never went into details as to why [...] I wanted to just keep it really positive, and – not positive as in, 'be positive and smile!', no, more like a nice tone.	12, 26, 43, 78, 80, 88, 94
2.3 Narrator's assessment of recipient's likely or	n/a	Narrator describes an in-the-moment process of gauging what or how much to tell, or what tone to take, depending on recipient's response, e.g. degree of openness or attentiveness, how much	I do vary about it because you know, with communicating, with watching people's expressions and things like that, and, you know, if I felt like somebody was going to be overly judgemental there might be things that I choose not to share. Or equally if I saw somebody was –	5



Theme	Sub-theme	Definition	Exemplar quote	Code #
actual response		understanding is demonstrated, how genuine their interest or, within training, how trainees are contributing to discussions	was understanding and receptive and interested in what I was saying I might choose to share a little bit more about that.	
2.4 Avoiding risk to recipient(s)	2.4.1 I may vary how or what I tell to avoid negative effects on the recipient	Narrator reports limiting or being careful of what they share to avoid recipient feeling threatened or distressed – e.g. by talk of mental health itself; a particular topic such as hearing voices; worry or pain about what’s happened to the narrator; hurt about their own role in narrator’s distress; becoming more worried about their own mental health issues; or feeling brought down or disempowered by someone else’s recovery, including sometimes within support groups	I think that is why I’m not working in the mental health system because having people that I already know, sometime I will make them feel – instead of feeling empowered, they feel bad on themselves – ‘oh, they haven’t recovered, look at all these, doing all this for us’ – so I would be sensitive to them.	13, 41, 44, 57, 91, 92
	2.4.2 I may vary how or what I tell as a peer support worker, to avoid triggering a recipient	Narrator is a peer support worker and either omits parts or changes details, e.g. specifics of events or relationships, in order to avoid triggering the recipient’s own trauma or distress	Generally speaking in my job I would keep away from 'hot button' issues, no matter what. We tell our students if you think about the emotional response to something you're talking about on a scale of 1 to 10, then we like to keep things in a 1 to 4 if we are sharing relevant experience, and keep away from big topics that we know are general triggers for lots of people. So, without saying it, we are talking about abuse stories, those sorts of things.	79
2.5 Benefitting the recipient	2.5.1 I may vary how or what I tell as a peer support worker to	Narrator is a peer support worker and tells story in ways which convey hope and model the possibility of recovery, by e.g. emphasising positive aspects, incorporating practical ideas, or emphasising how difficult thing had got,	You’ve got to tell them in a way that it doesn’t paint a dark picture that they [think] ‘Oh my God, is this what happened to him, I’ll never -’, you know. You’ve got to make sure that you tell a story as it is, to a degree, but also give them hope.	6

Theme	Sub-theme	Definition	Exemplar quote	Code #
	inspire hope	to demonstrate what may be possible even in extreme circumstances		
	2.5.2 I include or emphasise the parts I have in common with the recipient	Narrator is a peer support worker and chooses to include or focus on parts only if in common with the recipient, e.g. professional training, experience of substance use, suicide, trauma or weight gain, emotional versus physical effects of ME – in order to be more relatable, or because this is seen to be the most relevant and helpful way to use one's own story in a peer context (e.g. reframing own experience as a learning tool)	But if I am talking to a group of psychiatrists and psychologists, I would emphasise more [my] training in psychology as a way to try and heal myself. If I am talking to people that have experienced homelessness, I focus more on my own experiences of homelessness. And if I was talking to people who had experienced a lot of trauma, I would focus more on that.	22, 82
	2.5.3 I omit anything that isn't going to be helpful for the recipient	Narrator is a peer support worker and omits parts they gauge will be unhelpful e.g. traumatic experience of services to those still within them, or specific details because of generational difference, or	[I alter my story] all the time. And it is all true, but – it's kind of how I arrange the truth. Like that thing about my practice, I haven't shared that with anyone, yeah? In my work [...]and the reason for that is I think it is traumatising. Yeah? For people using the services now, yeah? I wouldn't share that. I only share things that are relevant I think and helpful.	90, 93
	2.5.4 Varies when talking to people without lived experience,	Narrator is a peer support worker and varies story with people without lived experience, to increase insight into lived experience, for example emphasising some parts, using humour to challenge stereotypes	With the student nurses I want to, the bit that I share more is the – the whole challenges, so that's when I would be speaking quite clearly about how difficult it was.	3, 52

Theme	Sub-theme	Definition	Exemplar quote	Code #
	to increase insight			
2.6 Relationship with some recipients makes some parts more possible to tell	2.6.1 I include more parts or details within close relationships	Narrator will include more parts or more detail with their partner, close family members or friends	Yeah absolutely it varies I think, it really depends on who I'm talking to, if it's someone I know very well or a close friend then I can pretty much be completely open with them about everything that has happened in my life. But if it's a stranger or someone new, like this interview, I'm not going to go into as much depth.	16, 27
	2.6.2 I tell my story differently to recipients with the same lived experience	Being more able to include more of their story, or particular perspectives, with people with the same lived experience, e.g. survivors of abuse or rape, mental health service users, BAME people, those with same spiritual perspectives. Reasons given include because these parts are more likely to be validated, understood or believed, or because the effect of a number of people sharing the same experience normalises something that would usually be taboo to speak about (e.g. being a survivor of incest, or the full extent of the effects of racism)	So if I was really going to be brutally, what I call, where I am right now, authentic, I'd mention more about global genocide on Black people. Yeah? All over Africa, the effect it has here, and the effect that still has ongoing as a society, has an impact, impoverishment, marginalisation, I'd expand on that more. And that'd be more, there'd be more emotion loaded with that. So I'd have to watch my own, as I said, level of resentment, while I'm doing that, do you see what I mean? [I: So that would depend on the audience, who you're talking to?] Exactly, so when I do a BME group – I don't even like that term but that's what we are at the moment – so I do talk about the global genocide on Black people, you know. And it's my belief, which might change going forward, but currently it seems to be that we're – we're being killed all over the world in one way, shape or form, you know. And how that will affect your mental health. I mean, what? Really? [Laughs] Do you know what I mean, it's a no-brainer, you know.	18, 19, 20, 21, 52, 60, 74

Theme	Sub-theme	Definition	Exemplar quote	Code #
<b>3. Immediate context (factors addressing the narrator's immediate setting)</b>				
3.1 Within health services	n/a	Narrator reports varying their story in health settings (therapists, psychologists, psychiatrists), due to previous negative experience or treatment, the power imbalance, time constraints, or the focus of a particular service. Reasons given include: to ensure their own needs are met, and to avoid unwanted treatment, being misinterpreted, misunderstood, or one aspect being inappropriately focused on (alcohol, sexuality)	I wasn't saying a word, for ages, I felt like it really would help me to talk, so when I finally got comfortable enough to talk, then all that happening [being involuntarily hospitalised], it was like, oh shit, maybe I shouldn't talk.	15, 17, 33, 56, 59, 65, 83, 85, 89
3.2 Within the research interview	n/a	Narrator reports telling their story differently within the research interview e.g. telling the whole story, giving more detail, being more open or including more stigmatised subjects (psychosis, abuse), due to having more time, being asked an open question, because it was anonymous and because it was important to include more for education/research purposes. Conversely, omitting some things here as elsewhere, or not including details of a family trauma because the story would be made public	Yeah its interesting I've never really told it in that way before. So, a lot of friends and things know different aspects, or the GP knows a certain bit of it, but it's interesting saying it all the way through and thinking about how it intersects with, say my dyspraxia and disability and my sexuality and things like that, it's quite interesting.	14, 30, 32, 53
<b>4. Societal context (factors addressing wider cultural narratives)</b>				
4.1 Challenging	4.1.1 I tell my story to challenge mental	Narrator reports including more or all of their story in order to challenge mental health stigma, including rejecting the	I am realising it more and more at work [in the NHS], I wouldn't lie, I wouldn't sort of say that this has not happened to me, oh I would absolutely say[...]for me personally it's part of my process that, otherwise it's like there's something wrong, and there isn't anything	1

Theme	Sub-theme	Definition	Exemplar quote	Code #
dominant narratives	health stigma	concept of varying their story at all for this reason	wrong, it's just that stuff has happened in my life and that is just how it has turned out. Yeah, that is unfortunate but it's not going to define everything about me, so I would be- I wouldn't change it for anybody now. I wouldn't do that.	
	4.1.2 I use my story to challenge the biomedical model of mental health	Narrator tells their story from a different perspective (e.g. experiential, spiritual) in order to challenge a wholly diagnostic or illness-focused perspective	In sharing it with a more broad audience, I have this conscious urge to still try and dispel any notions of disease or illness, because as a society I think we are becoming increasingly inculturated to all this stuff, so I will try and focus on experiences. In environments where I am teaching health and social care professionals, the purpose is slightly different. You know, I am trying to help them be better practitioners. Part of that is about pointing out the vagaries of diagnostic terminology. So I will talk about the ontology the epistemology, I will talk about the history of the science, I will refer to philosophical underpinnings. And it might just go over the heads of some of them [laughs], but I know that sometimes I'm hitting home. I think that stuff is really important for professionals to understand – because the vast majority of my teaching these days, the ultimate aim, is about providing more genuinely person-centred support. Focus on a disease, you're not focusing on a person, you're focusing on a label that's described in a text book. Focus on the person in front of you.	1, 33
	4.1.3 I use my story to challenge other prejudices	Narrator shares more stigmatised parts of their experience (e.g. childhood poverty) to challenge recipient's assumptions and judgements	The other reason I like to share is that, I know that I've somehow come to a point where people always think I'm posh, and there's so much power to sharing the parts of you that people don't expect. Because actually when I share my story, it changes the way that people perceive people that have those experiences [...]it's easy for people to think that [people who] have grown up around heroin addiction and squats and whatever, as – kind of lesser [...] but that's me – when you're making those judgements, you're making those judgements about me. When you are judging someone that's begging, I've been a child doing that. That's circumstance. And I think I have so much opportunity, in sharing my story, to make people really aware of circumstance, privilege, the fragility of the social status and all those things.	1

Theme	Sub-theme	Definition	Exemplar quote	Code #
4.2 Avoiding prejudice and stigma	4.2.1 I may omit or minimise parts about lived experience to avoid mental health stigma	Narrator would vary parts or details with some recipients to avoid mental health stigma, e.g. omitting mental health issues entirely when applying for a job; omitting details such as being sectioned to colleagues; emphasising a positive perspective with colleagues when working as a peer.	You see one thing I have learnt on this journey is, it's a stigma, it really is. No matter how much people say it's not, even when you are working in the field and they know, it's a stigma. So therefore, for me I had to learn to put myself in this positive...how can I put it, be a positive person, even when you are with colleagues and certain things. Because they know your history as well.	35, 55, 72
	4.2.2 I make sure I don't share too lengthily or inappropriately	Narrator addresses unspoken stigma by emphasising that they don't share their story excessively or inappropriately, or by expressing concern about this	I think you have got to be careful, but – I think in context, then yeah, I would say. If it seemed right [I:  Yes, depending on the person and their situation] Yeah, I don't think I would just randomly start blurting out well [laughs] – [I: on the bus or-] No!	99
	4.2.3 I omit psychosis experiences as they are more stigmatised	Narrator may include having experienced other mental health issues but omits psychosis due to additional stigma, or less understanding of it	Especially at work, I've never really felt comfortable telling people I'm on antipsychotics, or like I suffer with psychosis. I would rather say depression [...] in my last job I was having sleep problems and I wanted to tell them I was on antipsychotics, but on the same hand I didn't want to tell them? And they asked me what medication I was on and I just said antidepressants.	23
	4.2.4 I omit talking about my sexuality	Narrator may omit their LGBTQ+ identity e.g. within their community of origin due to additional stigma, or within services because they have unhelpfully focused on it as a problem in the past, or may share more of their story with women than men due to increased fear of homophobia	The thing with being gay that's still a stigmatising subject in the African community [...]unfortunately because some of the violent homophobia that I witnessed back in [country] it did taint my own attitude towards being gay and that led to struggles with self-acceptance, so I think it will always be – a sore subject and maybe I would suss out, you know, for my own protection, and maybe for others around me, when is it the right time for me to bring that up, and, you know, where can I bring it up? So I think that's something	51, 71

Theme	Sub-theme	Definition	Exemplar quote	Code #
			that, for a long time within my community of origin, I would, erm, think about a lot.	
	4.2.5 I omit parts due to racism	Narrator may omit lived experience entirely or minimise parts of their story, to avoid compounding the effects of racism	I haven't talked about [mental health] in job applications, I have definitely not accessed services, NHS services because I felt – I guess when you have so many things stacked against you, so my life experiences, being a Black woman, do I want to stack against me the potential that I might reveal myself to a service that I then later want to work for or have colleagues from? [...] Maybe if I was a white middle class woman that didn't have any of those experiences, I might feel – or a white middle class man, if you really get down to it – I might feel like, oh you know what, I believe in non-discriminative legislation so I can do that. But I think that when you have got other things stacked against you, you don't want to then add another thing to the mix. So I haven't been to NHS services, at least in part for that reason.	21, 46, 54, 64
<b>5. Temporal context (factors relating to passage of time)</b>				
5.1 Changes in perspective over time	n/a	Narrator tells story from a different perspective than in the past due to growth in compassion	I've definitely changed – I look back and see my developmental journey through – because I think I used to be quite a victim of it to be honest [...] and maybe told it more from that perspective whereas now it's, I don't- there's no blame at all, it's not my parents' fault, it's not, you know anyone's fault, And – not even the system's fault to be honest because they're just doing what they know is right at the time. And so my, I think as my compassion's grown – the way I tell my story is different.	29
5.2 Confidence growth over time	n/a	Narrator feels more confident about including more of their story than in the past, due to own career success, getting support, meeting others with mental health issues, gaining more experience of telling it, understanding own needs more,	So as I became more confident in myself, that changed as I met more people with mental health problems, that really made a difference because you start openly talking about things. I just think there's a big difference. I don't know whether it's my stage of life or that things have actually changed in society, probably a bit of both.	2, 48, 50, 73

Theme	Sub-theme	Definition	Exemplar quote	Code #
		getting older or society becoming more open		
5.3 Less relevant over time	n/a	Narrator tells story less than in the past due to it no longer affecting them, feeling less need to tell it or a desire for closure	It's not a way that I want to define myself [...] And although I don't feel shame as such, I do feel a certain desire for privacy – and also closure that actually having put that to one side, I was able to have such a different life and a very happy life.	31, 42, 97



# Appendix 8: Performative narrative analysis template document

*Based on Bamberg's (2020) integrative approach and Bengtsson & Andersen's (2020) performative approach. Produced by Joy Llewellyn-Beardsley and Alison Edgley in 2022. Permission to re-use this template is given, under the terms of the Creative Commons CC-BY license.*

## **Stage 1 analysis (Bamberg's identity navigation questions)**

1.1 How does the participant present themselves in the interview?

1.1.1 SAMENESS/DIFFERENCE: How does the participant present themselves as different, similar or the same with respect to others?

1.1.2 AGENCY/PASSIVITY: How does the participant navigate between agency (capable of producing and changing things in their world) and/or passivity (recipients of biological/natural or social forces) in how they presents their story?

1.1.3 CONTINUITY/CHANGE: How does the participant navigate aspects of continuity and/or change in their story?

## **Stage 2 analysis (Bamberg/Bengtsson & Andersen questions combined)**

### **2.1 Immediate interpersonal context**

2.1.1 How does the participant position themselves in relation to the interviewer/ wider audience?

2.1.2 How does the interviewer actively participate in both production and ongoing interpretation of narrative?

### **2.2 Socio-cultural context**

2.2.1 How does the participant position themselves in relation to dominant discourses?

2.2.2 How is the immediate context linked to broader historical/socio-cultural contexts?

2.2.3 How do these have an impact on expectations of what must be explained and what is self-explanatory?

2.2.4 What does the participant *not* explain?