

**A qualitative exploration of Telling My Story in mental health recovery.**

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## Thesis Portfolio Abstract

**Purpose:** The aim of this thesis project is to explore the role of personal storytelling in mental health recovery.

**Design:** The project is presented in portfolio format, including the following sections: a brief introduction to the portfolio, a systematic review of the literature on storytelling interventions for mental health recovery, an empirical paper exploring the qualitative experience of storytelling in a UK mental health recovery context, an extended methodology chapter, and an overall discussion and critical evaluation.

**Findings:** The systematic review identified some preliminary evidence for the usefulness of storytelling in mental health recovery, but identified a need for inductive exploration of this in a UK mental health context to guide future developments of storytelling approaches. The empirical paper used Interpretative Phenomenological Analysis to explore the experience of storytelling for individuals who had attended the Telling My Story course offered at a UK recovery college. Findings showed that storytelling has the potential to have a profound impact at the individual level, at the same time as being a social act where the role of the listener(s) is central to the experience. Five key themes were identified: *a highly emotional experience, feeling safe to disclose, renewed sense of self, two-way process* and *a novel opportunity*. The group environment of mutual storytelling was perceived as beneficial for most, although not all, participants.

**Originality/value:** Storytelling can be a highly meaningful aspect of one's recovery journey and more time could be dedicated to individuals telling their story within UK mental health services. The findings of the empirical paper offer insight into how storytelling is experienced by those who use it, which can be used to guide future developments and provide direction for measurement of outcomes. Areas for further research are considered.

# Contents

<b>Chapter One – Thesis Portfolio Introduction</b> .....	5
Definitions of key terms.....	5
What is meant by “recovery” in mental health?.....	5
Recovery colleges.....	6
The Telling My Story course.....	7
Outline of portfolio .....	8
<b>Chapter Two – Systematic Review</b> .....	9
Title page and abstract.....	10
Introduction.....	11
Method.....	13
Inclusion/exclusion criteria.....	13
Search strategy.....	14
Assessment of quality and risk of bias of included studies.....	15
Data analysis.....	16
Results.....	16
Narrative Enhancement and Cognitive Therapy.....	19
Coming Out Proud.....	22
Anti-Stigma Photovoice.....	24
Recovery Narrative Photovoice.....	25
Tree Theme Method.....	26
Playback Theatre.....	29
Discussion.....	30
Core components of storytelling.....	31
Distinguishing factors.....	32
Summary of current evidence and implications for future research.....	33
Limitations.....	35
References.....	37
<b>Chapter Three – Empirical Paper</b> .....	43
Title page and abstract.....	44
Introduction.....	45
Method.....	47
Study design.....	47
Participant recruitment.....	47
Data collection.....	47
Analysis.....	48
Validity and rigour.....	48
Results.....	48
Theme one: a highly emotional experience.....	49
Theme two: feeling safe to disclose.....	50
Theme three: renewed sense of self.....	51
Theme four: a two-way process.....	53
Theme five: a novel opportunity.....	54
Discussion.....	56
Limitations.....	58
Implications for practice.....	59
Acknowledgements.....	60
References.....	61
<b>Chapter Four – Extended Methodology</b> .....	65
Qualitative methodologies.....	65
Lead researcher context.....	65
Reflexivity.....	66
Reflective journal.....	66

Interpretative Phenomenological Analysis (IPA).....	67
What is IPA?.....	67
Theoretical underpinnings and epistemological framework.....	67
The lead researcher’s theoretical framework.....	69
Method.....	69
Ethical approval.....	69
Study design.....	69
Lead researcher’s attendance on the TMS course.....	71
Development of the interview guide.....	71
Participants.....	72
Data collection.....	74
Ethical issues.....	75
Transcribing.....	76
Analysis.....	76
Write-up and dissemination.....	78
<b>Chapter Five – Discussion and Critical Evaluation.....</b>	<b>79</b>
Reflections from the lead researcher.....	79
Further discussion of findings.....	80
Clinical implications.....	89
Strengths, limitations and considerations for future research.....	92
Overall conclusion.....	95
<b>References.....</b>	<b>96</b>
<b>Appendices.....</b>	<b>102</b>

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## Chapter One – Thesis Portfolio Introduction

This thesis was undertaken as part of the lead researcher's Doctorate in Clinical Psychology at the University of East Anglia.

### Definitions of Key Terms

Definitions for some of the key concepts of this project are given below, to offer the reader clarity in what is being referred to within each term.

#### What is Meant by “Recovery” in Mental Health?

The emergence of the recovery movement followed on from the period of de-institutionalisation and the anti-psychiatry movement of the 1960s and 70s, when mental health “survivors” began to find their voice and speak out about their experiences. This first took place in the USA in the 1980s by influential writers such as Patricia Deegan and Judi Chamberlin, with key figures such as Ron Coleman and Alison Reeves following suit in the UK in the 1990s. The writings outlined a transition away from focusing on problems, diagnosis and symptoms towards concentrating on regaining a sense of personal identity and control.

Below are two well-referenced definitions of personal recovery that neatly summarise its key components.

Recovery is described as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life even with 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, p. 15)

It involves making sense of, and finding meaning in, what has happened; becoming an expert in your own self-care; building a new sense of self and purpose in life; discovering your own resourcefulness and possibilities and using these, and the resources available to you, to pursue your aspirations and goals. (Perkins, Repper, Rinaldi & Brown, 2012, p. 2)

As outlined within the above definitions, mental health recovery (also termed “personal recovery”) promotes a focus on the individual's experience and finding meaning in life beyond the limitations of their mental health difficulty. It therefore differs from traditional approaches to clinical recovery, which have followed an illness-based model and have therefore been guided by psychiatric diagnosis and a focus on eradicating symptoms (Slade, 2013). There is contention around the use of the term “mental illness” in mental health recovery, because it sits within the medical model and indicates some kind of

deficit or state of abnormality. The Mental Health Foundation (2017), for example, proposes that the term “people with a mental illness” suggests a need for medical treatment, whereas “people with a mental health problem” offers a broader definition that acknowledges the person first and highlights how mental distress may be experienced as a “problem” but not necessarily an “illness”.

What is key to both terminologies above is the idea of “person-first” language. Although it is acknowledged that some people may choose to define or label themselves according to a diagnosis, there has been a general movement since the 1990s towards the use of person-first language that emphasises that individuals are not solely defined by their difficulties (Ohio State University, 2016). A recent study by Granello and Gibber (2016) has researched the impact of language in this context and found that participants displayed greater tolerance towards those with a mental health difficulty when the phrase “people with mental illnesses” was used as compared to the phrase “the mentally ill”. Their conclusion was that we should be using language that honours the personhood of the individual by separating their identity from illness or disability.

The lead researcher aligns to this ideology and believes it to be fitting with the recovery approach to mental health. Much of the literature drawn upon within this portfolio uses the term “severe mental illness” to describe samples of participants who have an identified mental health difficulty. The lead researcher has retained the terms used within the respective studies when describing existing research in order to give a sense of how they present their research. However, effort has been made to promote person-first use of these terms (for example, “people diagnosed with severe mental illness” as opposed to “mentally ill people”). Outside of discussion of the existing literature, however, the lead researcher has used recovery-focused descriptions that move away from the “illness” model of mental health, such as mental health “problem”, “challenge” or “difficulty”. It is hoped that this acknowledges the suffering that a mental health problem brings for an individual, but in a way that conveys common humanity (Neff, 2003) and relatable human suffering as opposed to abnormality or medicalisation.

### **Recovery Colleges**

In the UK, the Implementing Recovery through Organisational Change (ImROC) organisation is pioneering the development of recovery-oriented services and interventions. Other influential organisations include The Scottish Recovery Network and the Centre for Mental Health. One way of promoting the recovery movement is through mental health organisations and charities that already exist, and many of these within the UK are working hard to bring a recovery focus to the approach that they already offer. ImROC offers guidance for how this can be done. A second approach is to set up new services that are specifically for recovery-oriented practice. Recovery colleges are one

such service, and their development is currently one of ImROC's key initiatives for promoting the recovery vision within the UK.

Recovery colleges are a central resource for driving forward recovery initiatives and there are now more than 20 in the UK. The colleges move away from traditional therapeutic approaches to an *education* framework, with individuals attending as students and learning about their recovery via a range of courses (Perkins et al., 2012). In contrast to the traditional teacher-led classroom of educational settings, however, all courses are co-produced and co-facilitated by those with lived experience of mental health challenges (Oh, 2013) and students can be service users, carers and professionals.

The distress experienced from symptoms of mental health challenges is reported to impact significantly on quality of life, leading to a sense of being defined by illness (Connell, Brazier, O'Cathain, Lloyd-Jones & Paisley, 2012). Recovery colleges aim to enable the individual to see beyond their symptoms and to develop a sense of hope for the future by building on their strengths, with or without the presence of symptoms (Perkins et al., 2012). They are co-run by peer workers, communicating the message that lived experience of mental health challenges is something of value which can be utilised and shared (Slade, 2013). Peer workers aim to instil hope in others by sharing their story, as relatable people who are finding meaning in life and reconstructing a positive self-identity despite the challenges of a mental health difficulty (Repper, 2013).

### **The *Telling My Story* Course**

The Telling My Story (TMS) course is one of many courses offered at Recovery College East (RCE; part of Cambridgeshire and Peterborough NHS Foundation Trust, CPFT). Its purpose is to equip the individual to tell their recovery story. A similar course is offered at other recovery colleges within the UK, but the following description outlines what the TMS course at RCE entails:

Our students come to the Telling My Story course with different motivations. Some people are sharing elements of their story for the very first time and are wanting to understand it better for themselves, others may want to build confidence in order to share more of their story with family members or friends. Often things are written or told about those of us with mental health challenges by other people and this course can be the first time that we get to be the authors of our own narrative. (Quote from a Peer Educator, Recovery College East)

TMS has grown somewhat organically at RCE, born out of peer support worker training on how to share elements of one's own story appropriately, which proved highly successful and suggested potential benefit for wider delivery to those with a mental health difficulty. TMS is underpinned by the idea that people understand the ideas of recovery best by

hearing from those who have been there and can talk about the reality of what it has been like, along with what has helped and what has got in the way during their recovery journey. It is hoped that this sharing of experience supports individuals to embark on their own road to recovery, and this can begin with telling their story.

The course now runs for four half-day sessions, over four consecutive weeks. The first three weeks support and prepare the individual for forming their story, and in the final session students share their stories with the group. Students are able to share as much or as little about themselves as they wish to. Tutors note that strong bonds tend to develop during the course, given that so much personal information is shared. It can be an emotionally demanding course, and for this reason, recovery college staff suggest to new students at the college that they sample one or two alternative courses first, to get to know the college and how it works before signing up for TMS.

### **Outline of Portfolio**

Chapter two provides a systematic review of the literature. The introduction to this paper distinguishes what is meant by the terms “narrative” and “storytelling”, and goes on to explore how storytelling is currently being used within mental health interventions and the available evidence on its efficacy. This provides the context for the empirical paper that follows, which is a qualitative exploration of a specific storytelling intervention being used within a mental health recovery setting: the Telling My Story course based in a UK recovery college. An extended methodology chapter is offered, to give a greater depth of detail to the rationale underpinning the researcher’s chosen methodology. The portfolio closes with a discussion chapter, which draws together themes from the review and the empirical paper, using them to suggest future directions for research and service development. The discussion chapter draws on theory and approaches from the wider literature, including narrative approaches and broader theories of psychological distress. A separate, complete reference list and appendices are also provided.

## **Chapter Two – Systematic Review**

This chapter consists of the systematic review, written for the Mental Health Review Journal and formatted in accordance with their guidelines for submission (Appendix A). The systematic review is 10,079 words in length (the journal has no word limit for literature reviews). The abstract for the systematic review is 243 words in length (journal word limit for the abstract is 250 words, including keywords and article classification).

# How is storytelling used in interventions targeting mental health recovery? A review and comparison.

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## **Abstract**

**Purpose:** Increasingly, interventions for mental health recovery are incorporating personal storytelling. There is a lack of clarity, however, around the format and content of such interventions and whether they are helpful to the individuals who use them. This review addressed two questions: a) how is storytelling being used to target mental health recovery? and b) what evidence do we have to suggest that it might be effective?

**Design:** A systematic review of the literature was conducted and a total of 12 papers were included in the final review. Study quality was rated using the QATQS tool for quantitative studies, and the CASP tool for qualitative studies. Data were extracted and synthesised narratively.

**Findings:** A total of six different mental health storytelling interventions were described by the 12 included studies: Narrative Enhancement and Cognitive Therapy, Coming Out Proud, Anti-Stigma Photovoice, Recovery Narrative Photovoice, Tree Theme Method and Playback Theatre. The interventions are reviewed and compared in terms of conceptual framework, format, the nature of the storytelling component, and current state of evidence regarding efficacy. The review concludes with a discussion of key similarities and differences across the different interventions.

**Originality/value:** Although in its infancy, the current research offers preliminary evidence for the usefulness of storytelling in mental health recovery. There is a need for inductive exploration of the experience of storytelling, to guide the future development of storytelling interventions within a UK context.

**Keywords:** Storytelling; narrative; recovery; mental health.

**Paper type:** Literature review.

## Introduction

There has been convergent interest in the power of personal narratives to effect psychological change from linguistic (Pennebaker and Seagal, 1999) and clinical (White and Epston, 1990; Yanos *et al.*, 2011) psychology. Within the mental health recovery movement, we are also seeing a resurgence in the value placed on personal stories of mental health difficulties, with the goal of raising awareness and reducing stigma and self-stigma (Corrigan, 2014) and of instilling hope and finding meaning in life beyond the limitations of a mental health difficulty (Slade, 2013). The process of forming one's story is thought to help the individual make sense of what's happened to them, whilst sharing their story with others offers opportunity to feel heard and validated by others (Scottish Recovery Network, 2012).

The terms "story" and "narrative" are often used interchangeably and can cause confusion. For the purposes of this paper, we will offer a distinction between the two; story refers to an informal activity, whereas narrative is more formal, meditative and theoretical (Wiltshire, 1995). A story is the individual's personal account of their experiences, whereas a narrative is a more structured and formal account (East *et al.*, 2010). Clinical therapies exist to support people in understanding and reconstructing their overall narratives (for example, White and Epston, 1990). However, people tell stories, not narratives (Frank, 2000); so although the narrative may offer a structure that underpins one's story, it is the story that is told to others. The purpose of this paper is to explore the storytelling process, which is understood to include both the *forming* and *sharing* of one's story.

Storytelling is not a new concept; and organising our lives in story format and seeking meaning from experiences has long been acknowledged as an innate human tendency (Pennebaker and Seagal, 1999; Plummer, 1995). Early writings by Bruner (1987) suggest that we continuously interpret and re-interpret our experiences to construct a way of telling about ourselves that not only organises our historical life narrative, but also guides our interpretations for future experiences. Succinctly put by Drumm (2013), "It can be argued that the art of telling, and listening to, stories is at the heart of what it means to be human, how human beings articulate their experience of the world and make sense of it" (p. 3). The stories we tell about ourselves are inextricably bound with our personal and social identity (Bruner, 1987; Plummer, 1995); thus, we can understand how the presence of a mental health problem has the potential to not only disrupt our life story, but to impact negatively on our whole identity. To rebuild this identity, we must construct new stories and a new way of telling about ourselves.

Storytelling is thought to enhance psychological wellbeing in a number of ways. One theory proposed by Pennebaker and Seagal is that disclosure aids an individual's

cognitive processing by helping to integrate an event within their wider narrative, through telling it in an organised story format, such that they experience less distress. In their 1999 study, Pennebaker and Seagal used computerised text analysis of participants' trauma narratives and found that those who experienced the greatest benefit from disclosure were those who used more causation words (such as *because* or *effect*, indicating attempt to "piece together" what had happened) and more insight words (such as *consider*, or *know*, indicating a level of reflective thought). They discuss how this greater level of integration allowed for the processing of difficult emotions, such that a more cohesive story is formed and the individual can then move on from the event more easily. Benefits to both mental and physical wellbeing are documented. Some trauma-focused interventions recommended by the National Institute for Health and Care Excellence (2005) now incorporate narrative reconstruction components to integrate difficult experiences and alleviate post-traumatic symptoms (Peri and Gofman, 2014; Schauer *et al.*, 2011). Perhaps the same psychological processes apply when constructing and sharing mental health recovery stories, such that psychological wellbeing improves.

Storytelling that involves the sharing of distressing information is also thought to aid psychological wellbeing by providing a sense of catharsis (Frattaroli, 2006); building on the notion that suppressing difficult emotions can lead to psychological distress (Sloan, 2010). A meta-analysis by Aldao *et al.* (2010), for example, found emotional suppression and avoidance to be associated with psychological difficulties such as depression, anxiety, substance-related disorders and eating disorders. Disclosure of previously inhibited emotions can help an individual to process upsetting events, such that they achieve a more integrated sense of self (McLean *et al.*, 2007) and are able to regulate emotions (Pennebaker and Seagal, 1999). Decreasing emotional avoidance is a target in many third wave cognitive therapies that have emerged in recent years, such as Acceptance and Commitment Therapy (ACT; Harris, 2009) and Dialectical Behaviour Therapy (DBT; Linehan, 1993).

More recently, storytelling has been identified as one of four common components within interventions that target mental health self-stigma (Yanos *et al.*, 2014). Self-stigma can be defined as the internalising of negative attitudes held by others, such that the individual comes to hold these stigmatising beliefs about themselves (Corrigan and Rao, 2012). Self-stigma has been found to impact on self-esteem and hope, and subsequently on quality of life (Mashiach-Eizenberg *et al.*, 2013). It can also reduce social functioning and delay help-seeking from mental health services (Corrigan and Rao, 2012). Self-stigma is therefore becoming a target for intervention in mental health recovery, and narrative enhancement is suggested as one way to address it (Yanos *et al.*, 2012). In their review of self-stigma interventions, Yanos *et al.* (2014) speculate that what is helpful about narration

is “its potential to help persons make sense and create meaning out of experiences and to help them experience themselves as active agents within their own lives” (p. 7).

Storytelling is now a central feature of the UK mental health recovery movement and interventions that support individuals to tell their story are beginning to emerge within the recovery college context specifically. Alongside this, storytelling is also being used within the wider context of mental health services. We are seeing the emergence of formalised interventions that incorporate features of storytelling to support the overarching goal of alleviating the distress associated with mental health difficulties. However, there is a lack of clarity around how storytelling is being used across these different interventions, and no review to date of any evidence to suggest whether storytelling components are supporting individuals in their recovery from a mental health challenge. It is useful to look at the various ways that storytelling approaches are being utilised and to look at outcomes, in order to progress with future development of storytelling interventions for mental health recovery. This systematic review seeks to answer: a) how is storytelling being used to target mental health recovery? and b) what evidence do we have to suggest that it might be effective?

## Method

### Inclusion/Exclusion Criteria

A systematic review of the literature was conducted. The eligibility criteria for inclusion in this study were based on the PICO framework (Aslam and Emmanuel, 2010), also recommended by Thomas *et al.* (2004). Articles were included for full review if they adhered to the following criteria:

- **Population:** Adults (aged 18 upwards, no upper limit) who had a recognised mental health difficulty. Storytelling interventions that were disorder-specific (for example, for dementia or trauma) were not included, given that storytelling in mental health recovery is not disorder-specific.
- **Intervention:** Research papers that examined storytelling interventions for mental health recovery and had been published in peer-reviewed journals. Studies that were quantitative, qualitative and mixed-methods were included.
- **Comparison:** There was no comparator restriction.
- **Outcome:** Studies that provided outcomes suggesting how storytelling interventions may be useful in addressing mental health recovery.

Studies were excluded if:

- They were not written in English.
- The focus was on analysing the *content* of recovery stories, rather than whether the *process* of storytelling is helpful in mental health recovery.

- No specific intervention was outlined (a general discussion of storytelling, or another domain such as self-stigma, was provided).
- An intervention approach was outlined, but neither quantitative or qualitative outcomes were reported.
- An intervention approach was outlined, but storytelling was not a key component.
- A storytelling intervention was outlined, but the focus was on something other than mental health recovery (for example, older adults' processes of ageing).

### **Search Strategy**

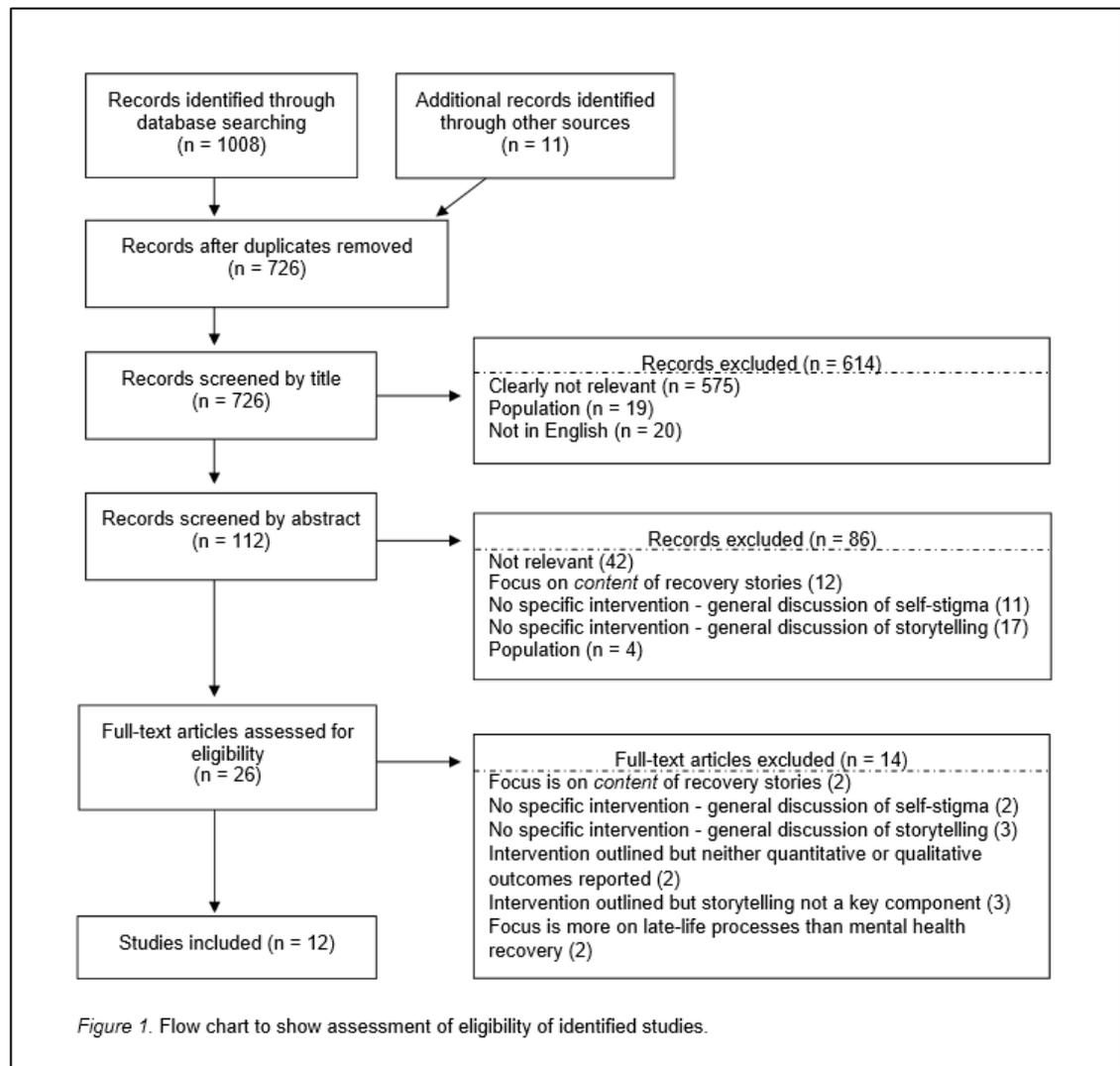
Studies were identified by searching seven electronic databases: Medline, PsycINFO, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Social Science Citation Index (SSCI), Embase, Applied Social Science Index and Abstracts (ASSIA), Applied and Complimentary Medicine Database (AMED) and the Cochrane Library. Searches were run in November 2016. The search terms used in each of the databases were as follows: (“story\*” OR “narrative”) AND (“intervention” OR “therapy”) AND (“mental health” OR “mental illness” OR “mental disorder”) AND (“recovery” OR “rehabilitation”). Reference lists of relevant studies were then scanned for additional studies of relevance. Finally, websites of organisations supporting the development of the recovery model within mental health services (Implementing Recovery through Organisational Change, Recovery Research Network, Scottish Recovery Network) were checked for any further studies of relevance. Initially titles were screened, followed by abstracts. For relevant studies, full texts were sourced.

The authors of all papers were contacted to retrieve any additional information linked to the interventions. There were three purposes to this step: a) to enquire about any other research being done in relation to the interventions (e.g. RCTs that are in progress), b) to obtain further information about the nature of each intervention and the conceptual framework underpinning it, and c) to obtain any qualitative papers associated with the intervention that may have been missed from the systematic searching of the literature. Cochrane guidance (Higgins and Green, 2011) warns that qualitative research is not always picked up by systematic literature searches.

A total of 12 papers were included in the review, outlining a total of six intervention approaches (three of the intervention approaches had more than one paper providing outcomes for that intervention). All full papers retrieved had been published since 2009, which is reflective of storytelling being a relatively new focus of mental health interventions. Figure 1 shows a flow chart of the search process.

## Assessment of Quality and Risk of Bias of Included Studies

All quantitative studies were assessed for quality and risk of bias using the Quality Assessment Tool for Quantitative Studies (QATQS; Effective Public Health Practice Project; EPHPP, 1998b). The tool is accompanied by a “dictionary” to assist the assessor in the process of rating (EPHPP, 1998a). This tool was selected because it can be used to assess all types of quantitative study design, on the domains of: selection bias, study design, confounders, blinding, data collection methods, and withdrawals and dropouts. Studies are rated as *strong* overall if there are no weak ratings on any of the above domains, *moderate* if there is one weak rating, and *weak* if there are two or more weak ratings. The two included qualitative papers were assessed for quality using the Critical Appraisal Skills Programme (CASP, 2014) qualitative checklist. This checklist provides a framework for systematically appraising the quality of qualitative research. No studies were excluded based upon quality grounds, but quality ratings are reported and issues of quality are discussed in relation to the interpretation of efficacy data.



## Data Analysis

Due to the inclusion of non-RCT studies, with varied methodological designs and approaches, data analysis followed the procedures of narrative synthesis outlined by Popay *et al.* (2006) and Thomas *et al.* (2004), alongside the guidelines within the Cochrane Handbook for systematic reviews (Higgins and Green, 2011). Such guidance supports the researcher in maintaining a systematic structure to the review, whilst acknowledging that what is offered is a generic framework rather than a prescriptive tool (Popay *et al.*, 2006).

The first stage was tabulation, whereby relevant data were extracted and presented in visual format to provide initial descriptions of the included studies (Popay *et al.*, 2006). Column headings followed the format of a recent review of self-stigma interventions that took a similar approach to amalgamating evidence from varied methodological designs and approaches (Yanos *et al.*, 2014). Qualitative case descriptions (Popay *et al.*, 2006) were then constructed for each of the six identified interventions, in turn. This is where descriptive data from the included studies was used to support the interpretation of reported outcomes, alongside consideration of study quality as identified by the EPHPP or CASP ratings. The final stage involved exploration of similarities and differences across the interventions (Higgins and Green, 2011) and discussion of overall robustness of the synthesis (Popay *et al.*, 2006), which then allowed for consideration of directions for future research.

## Results

Review of the literature identified six intervention approaches for mental health recovery that include storytelling as a central component: a) Narrative Enhancement and Cognitive Therapy (NECT; Hansson and Yanos, 2016; Roe *et al.*, 2010; Roe *et al.*, 2014; Yanos *et al.*, 2012), b) Coming Out Proud<sup>1</sup> (COP; Corrigan *et al.*, 2015; Rüsck *et al.*, 2014), c) Antistigma Photovoice (Ruscinova *et al.*, 2014), d) Recovery Narrative Photovoice (Mizock *et al.*, 2015), e) Tree Theme Method® (TTM; Gunnarsson and Björklund, 2013; Gunnarsson and Eklund, 2009; Gunnarsson *et al.*, 2010), and f) Playback Theatre (Moran and Alon, 2011). Table 1 presents the characteristics of each intervention by format, type of leadership, number of sessions, key features and identification of storytelling element, and state of available efficacy data.

Most interventions are in group format, with the exception of TTM which is delivered individually. Two of the interventions are led by professionals (NECT, TTM), two are peer-led (COP, Anti-stigma Photovoice), and two are jointly run by a professional/peer (Recovery Narrative Photovoice, Playback Theatre). The interventions vary in number of sessions, with COP being the shortest (three sessions) and NECT being the longest (20 sessions). However, session length varies across interventions so others may have a

Table 1

## Comparison of Storytelling Interventions for Mental Health Recovery

Intervention approach	Intervention format	Peer or professional led?	No. of sessions (duration)	Key features of approach <i>How is storytelling used?</i>	State of available data on efficacy
Narrative Enhancement and Cognitive Therapy (NECT)	Group	Professional	20 (1 hour)	Psychoeducation, cognitive restructuring, narrative enhancement.	Small RCT (Yanos <i>et al.</i> , 2012) Context: 39 participants with SMI recruited from three assertive community treatment teams in New York City, and one partial hospital program affiliated with a Veterans Affairs centre in Indianapolis, Indiana. Findings: No significant impact of NECT, but indication of feasibility. QATQS rating: strong
					Quasi-experimental study (Roe <i>et al.</i> , 2014) Context: 119 participants with SMI recruited from two psychiatric rehabilitation agencies and one university community clinic in Israel. Findings: Significant reductions in self-stigma. Significant increases in self-esteem, quality of life and hope-agency. QATQS rating: strong
					Open trial (Hansson and Yanos, 2016) Context: 48 participants with SMI recruited from a psychosis outpatient mental health setting in Sweden. Findings: Significant reduction in self-stigma. Significant increase in self-esteem and quality of life. Significant association between number of sessions attended and reduction in self-stigma. QATQS rating: strong
Coming Out Proud (COP)	Group	Peer	3 (2 hours)	Pros and cons of disclosure, learning different ways to disclose, telling your story.	Qualitative study (Roe <i>et al.</i> , 2010) Context: Interviews conducted with 18 people who had completed NECT in Israel, with the aim of exploring the experience of NECT and identifying helpful/unhelpful aspects. Findings: Grounded theory analysis revealed six themes about the experience of NECT: <i>experiential learning, positive change in experience of self, acquiring cognitive skills, enhanced hope, coping, and emotional change</i> . Participants valued the group environment and narration encouraged the adoption of an active role. Concluded that the narrative component was a novel and helpful addition to traditional cognitive techniques, in terms of supporting recovery/overcoming self-stigma.
					RCT (Rusch <i>et al.</i> , 2014) Context: 100 participants with SMI recruited from a variety of mental health services in Zurich, Switzerland. Participants self-selected to take part. Findings: No intervention effect on self-stigma or empowerment, but significant reduction in stigma stress and secrecy, as well as a reduction in disclosure-related distress. QATQS rating: moderate
Anti-Stigma Photovoice	Group	Peer	10 (1 ½ hours)	Stigma psychoeducation, photography and	Controlled Clinical Trial (Corrigan <i>et al.</i> , 2015) Context: 205 participants with self-identified mental illness self-selected to take part from a variety of mental health services in California, USA. 126 went on to complete the study. Findings: Significant improvements at post-test and follow-up for the more harmful aspects of self-stigma. Significant reduction in stigma stress. QATQS rating: weak
					RCT (Rusinova <i>et al.</i> , 2014) Context: 82 participants with SMI recruited from a psychosocial rehabilitation program in the USA.

					narrative, reducing self-stigma.							Findings: Significantly reduced self-stigma, significantly greater use of proactive coping with societal stigma, significant increases in community activism, significant improvements in perceived recovery and growth. QATQS rating: strong
Recovery Narrative Photovoice	Group	Joint – professional and peer co-facilitator	10 (2 hours)		Psychoeducation, photography and narrative, identity, sharing stories (with group and wider community).		Cohort study (Mizock <i>et al.</i> , 2015)					Context: 16 participants with SMI recruited from a psychosocial rehabilitation centre in the UK. Findings: High attendance and engagement suggests feasibility for use in psychiatric rehabilitation settings, but no formal outcome data as of yet. QATQS rating: weak
Tree Theme Method® (TTM)	Individual	Professional (OT)	5 (1 ½ hours)		Creative task (painting a picture of a tree) combined with storytelling and planning for the future.		Quasi-experimental cohort study (Gunnarsson and Eklund, 2009)					Context: 35 participants with SMI recruited from outpatient mental healthcare units in Sweden. Aim was to measure process aspects of intervention, but some outcomes reported relating to impact on individual. Findings: In terms of wellbeing: significant improvements in sense of coherence, self-mastery, and some psychological symptoms. In terms of everyday occupations: significant improvement in performance and satisfaction. QATQS rating: moderate
							Follow-up cohort study (Gunnarsson and Björklund, 2013)					Context: 31 of the original participants from the 2009 study were recruited for follow-up. Findings: In terms of wellbeing: significant improvement in sense of coherence, improvements in self-mastery and psychological symptoms were maintained. In terms of everyday occupations: significant increase in performance and satisfaction. QATQS rating: moderate
							Qualitative study (Gunnarsson <i>et al.</i> , 2010)					Context: Interviews conducted with 20 of the 35 participants who took part in the 2009 study in Sweden, with the aim of exploring client perceptions of TTM. Findings: Qualitative content analysis revealed one overarching category ( <i>the client made a journey, engaged in a difficult process, offering new life perspectives</i> ) and six themes ( <i>from feeling a pressure to perform to becoming focused and expressive; expressing oneself and one's life situation led to awakening of memories and feelings; new perspectives of self-image, everyday life and relations to others; story-making led to sharing and reconstructing one's story; interaction was of importance and feelings for the development of the therapeutic relationship</i> ). RCT to measure effectiveness outcomes (rather than the above that focuses more on process aspects).
Playback Theatre (PT)	Group	Professional facilitator ("instructor"), but group co-facilitated with peers ("actors")	10 (1 ½ hours)		Uses theatre to combine storytelling with social connection.		Mixed-methods cohort study (Moran and Alon, 2011)					Context: 19 participants with SMI recruited from the Boston area. Individuals self-selected to attend this course, offered as part of the recovery education program at the Centre for Psychiatric Rehabilitation, Boston University. Findings: Significant improvements on intervention-specific measure, non-significant improvements in self-esteem and recovery. QATQS rating: weak Qualitative findings: reports benefits of PT at both the personal and interpersonal level.

similar overall time commitment to NECT (for example, Recovery Narrative Photovoice is only 10 weeks in duration, but each session is two hours long as opposed to one hour in NECT). All interventions are available in English, but some have been translated into other languages for use internationally (NECT into Hebrew, Russian and Swedish; COP into German).

Below, each intervention approach is discussed in relation to its conceptual framework, its format, the nature of the storytelling component, and the current state of evidence regarding its efficacy. The review concludes with a discussion of key similarities and differences across the different interventions.

### **Narrative Enhancement and Cognitive Therapy (NECT)**

NECT was developed in response to emerging evidence that a failure to address self-stigma can create a “roadblock” to recovery from severe mental illness (SMI; Yanos *et al.*, 2011). The authors recognised a need to not only educate individuals about mental illness and self-stigma, but to move beyond this and include components that focus on self-concept. They therefore turned to two major theoretical areas: cognitive restructuring, and narrative models of positive identity development.

NECT offers a 20-session manualised intervention aimed at combatting self-stigma for people diagnosed with SMI. The group is led by a professional and the ideal group size is four to eight members. Each session follows a set structure: 5-10 minutes “check-in” and homework return, 40 minutes didactic content with worksheets/exercises, 10-15 minutes “processing time” with an opportunity for mutual support and setting homework. The intervention is comprised of four distinct stages, one of which has a storytelling component: *narrative enhancement*. Each stage will be discussed briefly, before outlining the storytelling component in greater detail.

During an *introduction* session, group members engage in exercises that elicit descriptions of their self-conceptualisations and relationship to their mental illness (including their degree of self-stigma). The first treatment phase (three sessions) focuses on *psychoeducation*; where the aim is to educate group members with empirical findings about mental illness and recovery that can be used to challenge myths and replace stigmatizing beliefs. The focus then turns to *cognitive restructuring* (eight sessions), whereby group members learn to identify unhelpful beliefs and thinking errors. There is a focus on working as a group to challenge these beliefs and develop more adaptive and accurate alternatives.

The final component, *narrative enhancement* (eight sessions), is placed at the end of the intervention once the group has developed in its cohesiveness and members are likely to feel more comfortable in sharing their personal stories. The inclusion of a narrative

component is built upon the argument that the individual's self-beliefs are inextricably linked with the stories they tell about themselves (Bruner, 1987). In order to fully integrate new beliefs and reject a stigmatized view of oneself, a new personal story must be constructed (Roe *et al.*, 2014). The group format offers opportunity for feedback from group members and collaboration in challenging stigmatizing beliefs. The narrative enhancement component serves to integrate the information obtained through psychoeducation, with the cognitive restructuring skills learnt, together with one's overall sense of self as expressed in the personal story. Roe *et al.* (2014) summarise: "disempowered narratives in which themes dominated by internalized stigma prevail can be gradually reframed and revised so that the narrator becomes the protagonist and themes of agency and personal strength prevail" (p. 304).

In a small RCT (Yanos *et al.*, 2012) 39 people diagnosed with SMI were randomised to either NECT or treatment as usual (TAU). Assessments were conducted at baseline, posttreatment and at a three-month follow-up. Out of the 21 individuals assigned to NECT, 15 attended enough sessions to be classified as "exposed" to treatment. Results indicated no significant difference between the NECT and TAU groups. Although the QATQS quality rating was *strong* (contributed to by the randomised design, use of validated measures, and adequate reporting regarding confounders/dropouts), a small sample size and 29% dropout rate could have resulted in failure to detect an effect. A call for a larger sample size led to a larger quasi-experimental study being conducted with 119 participants diagnosed with SMI (Roe *et al.*, 2014). Again, the QATQS quality rating for this study was *strong* (contributed to by the use of validated measures, adequate reporting regarding confounders/dropouts) and findings showed significant reductions in self-stigma across pre-post assessments, alongside significant increases in self-esteem, quality of life and hope-agency. However, random assignment was not used and 46% dropped out. Dropout is an acknowledged difficulty within mental health populations, with data from the World Health Organization indicating an average dropout rate of 31.7% for mental health treatment worldwide (Wells *et al.*, 2013). However, the dropout rate of this study is comparably high. We must bear in mind that the sample is potentially biased in only providing data for those who a) chose to take part in NECT, and b) completed the full intervention. We do not know why the intervention was not helpful for those who chose not to take part, or dropped out.

The above studies were conducted within New York/Indianapolis, and Israel, respectively. Although this demonstrates some cross-cultural applicability, we cannot assume that the results would generalise to other clinical contexts, for example within the UK. More recently, the feasibility of NECT has been tested within an open trial in a Swedish mental health context (Hansson and Yanos, 2016). A total of 48 participants diagnosed with SMI were recruited from a psychosis outpatient department, of whom 31 completed the NECT

programme. Pre-post analysis of ratings on validated measures revealed significant improvements in self-stigma (large effect size), self-esteem (moderate effect size) and subjective quality of life (small effect size). Due to the lack of control group within this open trial, causal conclusions about the relationship between exposure to NECT and the improvements seen cannot be drawn. However, the purpose of this open trial was to test the feasibility of further application of NECT within a Swedish context (with the possibility of a future RCT). A further finding of a significant dose-response effect in terms of a positive correlation between number of sessions attended and reductions in self-stigma suggests that NECT may, at least in part, contribute to the improvements seen. The overall QATQS quality rating for this study was *strong* (contributed to by use of validated measures, adequate reporting regarding confounders/dropouts). However, post-intervention ratings were only taken from those who completed the intervention (35% dropped out) and may therefore represent a biased sample of individuals who felt able to engage for the duration.

These studies provide some indication that NECT may be a helpful intervention for targeting self-stigma, although we cannot be sure to what extent these findings would generalise to broader mental health contexts and other populations. In addition, it is not possible to ascertain how much of the improvement seen can be attributed to the storytelling component, given that outcomes are presented for NECT as a whole and the narrative enhancement component is only one aspect of the intervention. One final paper associated with NECT and identified through the literature search takes a qualitative approach, whereby interviews were conducted with 18 participants who had taken part in the first trial of NECT in Israel (Roe *et al.*, 2010). The aim was to explore participants' experiences of receiving the intervention, to offer insight into which aspects may be helpful or unhelpful.

Grounded theory methodology identified six themes: *experiential learning* (including learning about SMI and dispelling myths, as well as emotional processes of normalisation and feeling connected to others), *positive change in experience of self* (gaining confidence), *acquiring cognitive skills* (an ability to challenge negative thoughts relating to self-stigma and thus socially integrate more), *enhanced hope* (gained from seeing what others diagnosed with SMI have achieved), *coping*, and *emotional change* (feeling open and liberated from opening up to others) (Roe *et al.*, 2010). The authors conclude that these qualitative findings support models of recovery, which move away from a sole-focus on symptom reduction and promote a reformation of sense of self through narrative change (Slade, 2013).

NECT appears novel in that it not only teaches skills to challenge negative beliefs about self (as is common to a number of cognitive therapies), but also provides an opportunity to

reshape a sense of who one is in the world through a specific focus on telling a different story about oneself. Participants reported valuing the accepting environment, which provided a safe space for disclosure and an audience to assist in the construction of one's story and the integration of the "before illness self" with the "illness self". The therapeutic alliance was also valued. The process of narrating was reported to be beneficial, in terms of fostering the adoption of an active role through telling one's story. CASP framework quality ratings did, however, raise questions about potential bias. The sample was heavily weighted towards men, there was a lack of reporting on why some may have chosen not to take part, a lack of consideration of potential researcher bias, a lack of transparency around interpretations of findings, and apparent under-reporting of negative experiences of NECT.

### **Coming Out Proud (COP)**

COP is a 3-session manualised intervention that focuses specifically on disclosure of one's personal story as a means of combatting distress and self-stigma in mental illness. COP is peer-led and the aim is to empower individuals to make a personal choice about whether or not to disclose their mental health difficulty to others. "It is not the aim to make them disclose their condition, but to assist them in finding the solution that is right for them" (Rüsch *et al.*, 2014, p. 392). The intervention is born out of research with sexual minorities and within a mental health context, which indicates that secrecy can be harmful and disclosure can be beneficial. The course is designed to provide a space for individuals to reflect on their personal stories of mental illness, and to empower them with the skills to share it should they wish to do so.

The typical group size is six to 10 members and the course runs across three consecutive weeks, each session lasting two hours. Session one involves analysis of the risks and benefits of secrecy and of disclosure in a variety of settings, such that the individual can make an informed decision about which settings they are comfortable disclosing in. The group considers how to frame their experiences of mental illness and personal identities in relation to this. Session two focuses on how to assess the appropriate level of disclosure (from social withdrawal/complete non-disclosure through to broadcasting one's experiences) and how to manage the reaction of the listener. The final session looks at helpful ways to tell one's story in different settings, with a focus on preparation for future disclosures.

Some evidence regarding outcomes of COP are beginning to emerge. An RCT described by Rüsch *et al.* (2014) involved 100 people diagnosed with SMI from various mental health services in Zurich (Switzerland). Participants self-selected to take part in the study (which was advertised locally via leaflets and posters), and eligibility criteria included having at least moderate "disclosure-related distress". Participants who met the eligibility

criteria were then randomly assigned to either the COP (n=50) or TAU (n=50) group. Pre, post and three-week follow-up measures of self-stigma, empowerment, stigma stress, secrecy and perceived benefits of disclosure were obtained. The paper reports no intervention effect on self-stigma or empowerment, but does report a significant decrease in stigma stress (medium effect size, although only partly sustained during three-week follow-up) and secrecy following attendance of the group. In particular, distress relating to disclosure was found to decrease significantly, both during the intervention and during the follow-up period. Finally, COP was found to increase the perceived benefits of “coming out”, and this effect remained stable throughout the three-week follow-up. The QATQS quality rating for this study was *moderate*, considering the potential selection bias given that all participants self-referred to the programme.

A second RCT (Corrigan *et al.*, 2015) has investigated whether COP has greater impact on the more harmful aspects of self-stigma. The self-stigma measure selected (Self-Stigma of Mental Illness Scale; Corrigan *et al.*, 2012) is able to capture these progressive stages of self-stigma: 1) being *aware* of stereotypes about mental illness, 2) *agreeing* with stereotypes, 3) *applying* these stereotypes to oneself, and 4) whether this application leads to *harm*. The efficacy of COP was then explored in relation to these different stages of self-stigma a person is experiencing. Initially, 205 individuals from the California area who perceived themselves to have a mental illness (information on diagnosis was not formally obtained) and reported associated shame, self-selected to take part and were randomly assigned to COP (n=107) or waitlist control (n=98). However, dropout rates were high with only 51 completing COP (52% dropout) and 75 completing the waitlist control (23% dropout). Due to a lack of reporting of the randomisation process, this study is classified as a *controlled clinical trial* according to the QATQS dictionary (EPHPP, 1998), and achieved an overall quality rating of *weak*, given the high selection-bias and high dropout rate. The findings should therefore be interpreted with caution, but for those who completed the study significant improvements were found at post-test and follow-up for the more harmful aspects of self-stigma (stigma harm and applying stereotypes to oneself), compared to the control group. The authors also measured stigma stress and found this to significantly improve after completion of COP. The authors note increased resilience following the COP programme, with participants reporting significant improvements in general coping resources (and specifically, ability to cope with stigma) as compared to the control group.

Overall, these studies provide some evidence to suggest that COP may be helpful in alleviating mental illness self-stigma, but this evidence is lacking in methodological rigour and further exploration is needed to identify which processes of the intervention (for example, constructing one’s story, versus telling it to others) are most helpful to the individuals who participate. A significant limitation of both COP trials is that they included

a self-selecting sample and data was only analysed for those who completed the intervention, increasing the likelihood of outcome bias. A suggested future direction for measuring COP's efficacy is to map how it fits with processes of narrative enhancement that are outlined in NECT, given its central focus on telling one's story. To date, however, the focus of COP has been on whether it reduces self-stigma, and links to processes of narrative construction have not been explicitly explored.

There are currently no qualitative studies associated with COP, although the authors comment on informal qualitative data-gathering. In particular, Rüsç *et al.* (2014) note that participants valued the peer-led approach, appreciated the group setting and mutual feelings of struggling with disclosure, enjoyed the pros and cons approach of discovering what level of disclosure was right for them, and valued having time for reflection. It is also reported, however, that the short duration (three sessions) was perceived as demanding by some; both in terms of an unmanageable workload and in terms of pressure to disclose to group members within the first session. In addition, some wanted more time for cognitive challenging of negative self-statements, which is an aspect that does not formally feature within this intervention (although it does within NECT). Perhaps the short length of this intervention contributes to the lack of intervention effect and change that was only partly sustained at follow-up, described by Rüsç *et al.* (2014).

### **Anti-Stigma Photovoice**

Photovoice is a long-established community-based participatory research method, where participants take photographs and construct narratives around them to open up dialogue that addresses important health and social issues (Catalani and Minkler, 2010). Its aim is to empower the individuals and communities who use it, and it has been applied to various problems, including physical and psychiatric illness, unemployment and poverty (Mizock *et al.*, 2015). It is thought that the use of photography makes the intervention accessible to all, regardless of cognitive and communicative abilities (Mizock *et al.*, 2014). Individuals are encouraged to photograph objects or experiences in their everyday life, and construct narratives around them to tell their story in relation to the topic area. The photo component therefore provides a structure for the forming of a narrative around it.

This intervention is peer-led and runs for 10 weekly 90-minute sessions. Early sessions focus on psychoeducation about stigma, alongside experiential exercises aiming to reduce participants' endorsements of mental illness stereotypes. Group members are taught to use the Photovoice methodology, and are then encouraged to photograph objects or events in their everyday lives that relate to their mental illness and stigma experiences. The peer facilitator uses guided questions to support individuals to construct narratives around their photographs; combining confrontation of stereotypes with developing new perspectives and coping with stigma.

The RCT associated with this study (Ruscinova *et al.*, 2014) is rated as *strong* on the QATQS, with low dropout rates (5%) and evidence of methodological rigour (randomised design, use of validated measures, adequate reporting regarding confounders/dropouts). A total of 82 participants diagnosed with SMI, recruited from a psychosocial rehabilitation program in the USA, were randomly assigned to either the Anti-Stigma Photovoice condition (n=40) or waitlist control (n=42). Intervention group participants reported significantly greater decreases in internalized stigma; particularly on the subscales of stereotype endorsement and stigma resistance. They were also significantly more likely to report using proactive strategies to cope with societal stigma; particularly in terms of educating others and challenging others. Results also indicated significant improvements in perceived recovery and growth, and significantly greater increases in community activism and autonomy. This is the only study within this review to include a personal recovery measure, and there is a growing body of evidence to suggest that recovery is a domain in itself to be captured when measuring mental health outcomes (Shepherd *et al.*, 2014). No differences were found between groups in relation to depression or self-efficacy.

Within their discussion, the authors surmise:

It is possible that the construction of a personal narrative regarding the individual's experience with stigma through the photovoice methodology, combined with teaching behavioural strategies for addressing negative stereotypes about mental illness, led to more robust changes in participants' ability to handle social situations involving stigma than if the intervention had focused on self-stigma alone. (Ruscinova *et al.*, 2014, p. 245).

However, it is not possible to draw definitive conclusions about what proportion of the improvements seen might be attributed to the storytelling component specifically, as opposed to other aspects of the intervention (for example, peer support or time for reflection).

### **Recovery Narrative Photovoice**

Recovery Narrative Photovoice is a manualised programme “designed to facilitate recovery, empowerment, community integration, and positive identity among individuals with serious mental illnesses” (Mizock *et al.*, 2015, p. 279). This intervention uses the same Photovoice methodology outlined above, but is also informed by ideas from narrative therapy and from the mental health recovery movement. The narrative component of the intervention focuses on co-constructing stories that are non-stigmatizing and non-pathologizing, using recovery-focused language. There is an emphasis on working with the individual's values and goals in order to regain a sense of identity beyond

the symptoms of illness, and to re-integrate oneself into the community. These are key features of the recovery movement (Perkins *et al.*, 2012).

The group runs for 10 weekly 2-hour sessions. The intervention combines psychoeducation, writing exercises, co-construction of recovery stories, and managing identity in the context of mental health stigma. Each participant is assigned three 'photo missions' throughout the ten sessions, which involves a photo/narrative task relating to each of the following topics: "Who I am", "My Story" and "My Recovery". Participants are encouraged to reflect on how mental illness has affected their identity, and to develop empowering narratives around this. Within the final sessions, participants prepare presentations for a community exhibit; thus there is a focus on sharing their stories with the wider community.

Outcome data for this intervention are currently lacking. A small feasibility study (Mizock *et al.*, 2015), with 16 participants diagnosed with SMI recruited from a psychosocial rehabilitation and education centre in Northeast England, has provided some preliminary evidence for its potential use in such settings to aid processes of recovery, empowerment, regaining a positive identity, and re-integrating into the community. A high level of engagement (in terms of attendance and production of works) was reported amongst the 16 participants who received the intervention and dropout rates were low, indicating treatment palatability. Given its status as a feasibility study, however, the study's quality is rated as *weak* on the QATQS; with particular limitations being sample size and lack of established protocol for outcome measurement. No significant differences were found between pre and post measures of psychological wellbeing, empowerment or community integration. However, measures were not used consistently across the two waves of participants receiving the intervention as the selection of appropriate outcome measures had not been fully established. Although this study is limited to drawing conclusions about feasibility only, the paper offers early indications that this storytelling intervention may support individuals in their recovery, which warrants further research as the intervention progresses.

### **Tree Theme Method (TTM)**

TTM was developed within an Occupational Therapy context that aims to use creative activities to promote the individual's self-expression, sense of control, and ability to cope in light of mental illness (Gunnarsson and Eklund, 2009). The individual paints a 'tree' to symbolise the various aspects of their life up to the period of illness, and is encouraged to tell their story using the trees as a focus, and then develop plans for the future. "The life-story thus created is used to look forward and make bridges between the client's images of his/her old and new identity" (Gunnarsson *et al.*, 2010).

The intervention is led by an occupational therapist and delivered one-to-one (Gunnarsson *et al.*, 2006). It runs over five sessions, each introduced with a progressive muscular relaxation component. The client is asked to paint a different tree each session, to represent their: current life situation (session one), childhood (session two), adolescence (session three) and adulthood (session four). The tree image is used as a start-point to initiate reflection and discussion on the individual's skills and limitations at various life stages, using its different components (roots, trunk, crown) as metaphors for human developmental processes such as growth or maturity (Gunnarsson *et al.*, 2010). The final session (session 5) focuses on developing a tree that symbolises the future, based on the life story up until that point. Throughout the intervention the individual is encouraged to develop strategies for coping with daily life, by drawing on their strengths.

A quasi-experimental study (pre-post and correlational design) reports initial outcomes for the TTM method (Gunnarsson and Eklund, 2009). Thirty-five participants diagnosed with SMI were recruited from four outpatient mental health care units in Sweden. The focus of this study was to measure process aspects of the intervention (therapeutic alliance and client satisfaction). Nonetheless, there are some outcomes reported in relation to the intervention's impact on the individual; namely significant improvements in engagement with everyday occupation (in terms of both performance and satisfaction) and significant improvements in individual wellbeing (in terms of sense of coherence, sense of mastery, and some psychological symptoms). The overall QATQS rating for this study was *moderate*, with limitations in study design (lack of control group), selection bias (due to self-selection), questionable intervention fidelity (delivered by multiple professionals and no comment on fidelity checks) and possible confounding variables (for example, the sample was skewed towards females). It is not possible, therefore, to draw causal conclusions about the reported improvements being due to the TTM intervention rather than other influencing factors, or to assume generalisability of findings to other populations. It should be noted that no participants dropped out, indicating treatment palatability. The authors took this as indication of high client satisfaction within TTM.

Another paper included in this review is a 3-year follow-up of the above study (Gunnarsson and Björklund, 2013), which focuses specifically on the domains relating to wellbeing and everyday occupations. Thirty-one of the original 35 participants were recruited. The QATQS rating for this study is *moderate*, given that it retained the methodological limitations of the earlier study. Positive significant changes were found in terms of sense of coherence, occupational performance, and satisfaction with occupational performance, between the end of the initial intervention and the time of follow-up. Ratings for self-mastery, psychological symptoms and activity level were found to be stable. Again, however, causal conclusions cannot be drawn about the improvements seen being a result of TTM rather than other influencing factors (for

example, alternative interventions received, social/personal circumstances). The authors address the need for further quantitative designs that incorporate a control group, and informal communications with the main author (BG) have confirmed that an RCT is in progress.

Building on findings from the initial study (Gunnarsson and Eklund, 2009), Gunnarsson *et al.* (2010) investigated clients' experiences of participating in the TTM intervention, alongside their perceptions of the therapeutic relationship (focus of interest to the authors). The aim was to move beyond reported outcomes and explore what specific aspects of the intervention are important to participants. Interviews were conducted with 20 of the 35 participants from the 2009 study.

Qualitative content analysis revealed one overarching category (*The client made a journey, engaged in a difficult process, offering new life perspectives*) and six key themes within this. The first theme, *from feeling a pressure to perform to becoming focused and expressive*, refers to some participants finding the task pressurising at first but then relaxing and expressive, whilst others did not feel they engaged with it deeply throughout the intervention. *Expressing oneself and one's life situation led to awakening of memories and feelings* was a second theme, including participants' reports that the intervention provided an opportunity to let out earlier thoughts and feelings, and take the time to process them from a different perspective. *New perspectives of self-image, everyday life and relations to others* was about positive changes in everyday life that came from increased self-compassion and self-esteem, and from practice of relating to others more openly, rather than from the intervention itself. *Story-making led to shaping and reconstructing one's life story* describes how the forming of one's story was viewed as a process of gaining structure and connecting life events without getting caught up in the details. *Interaction was of importance when constructing one's life story* describes how participants valued the role of an accepting and validating other (the therapist) in shaping their own understanding of their experiences. Finally, *the attitude of the occupational therapist was of importance for the development of the therapeutic relationship* refers to many participants commenting on the therapist's role being a crucial part of the intervention; from valuing their warmth, empathy and reflections, through to mixed opinions about whether the therapist should hold more of a friendly or superior stance.

The authors discuss that TTM seems to enhance the individual's sense of coherence (SOC; reported in both the quantitative and the qualitative paper), which they define as the "individual's perception of the world and his/her environment as a whole" (Gunnarsson *et al.*, 2010, p. 206), involving its comprehensibility, manageability and meaningfulness. The authors speculate that TTM's process of systematically reflecting on specific time periods helps to develop SOC; that the opportunity for expression of both unpleasant and

pleasurable feelings acts as catharsis, and that the practical task of forming their story helps to develop a sense of agency.

The above qualitative findings offer some insight into the mechanisms that may be experienced as helpful to individuals using storytelling interventions, although we cannot assume the results generalise to the other intervention methods discussed in this review. The CASP tool was used to systematically assess the paper's quality and it is clear that the authors took steps to enhance trustworthiness (controlling for researcher bias by including interviewers who held a neutral stance towards research outcomes, offering transparency around inter-researcher ratings). Issues of sample bias exist, however, in that findings report the views of those who chose to participate (thus, we cannot assume that the same themes would be reported by those who did not wish to be interviewed) and the sample was skewed towards women which poses questions over generalisability to men. This qualitative paper highlights the centrality of the therapeutic relationship to TTM storytelling, which is perhaps to be expected given its individual rather than group format.

### **Playback Theatre (PT)**

The PT method combines creative expression with personal storytelling and empathic listening (Moran and Alon, 2011). It builds on the idea that the transformation from an "illness story" to a "recovery story" is central to recovery, and that a safe/accepting interpersonal context is an essential catalyst for this change. It therefore uses the arts (theatre) to combine storytelling with social connection. The course is offered within the recovery education program at the Centre for Psychiatric Rehabilitation at Boston University.

Within the playback group, there are various roles including teller, conductor, actors and audience. Moran and Alon (2011) describe that the teller tells their personal story, whilst the conductor interviews the teller about this experience. The actors (two-four group members) listen to the teller's story and try to put themselves in the teller's shoes, which requires a non-judgmental stance. The actors then "play back" the story through acting it out with empathy. For the teller, the process of observing their own story can provide a "stepping back" to gain perspective, alongside feeling heard/validated. The idea is that the course provides the context for re-authoring one's story. The method can be taught to individuals without previous acting experience.

Research on the method is reported to be scarce and this study is the first to attempt to capture how PT may impact on recovery for individuals diagnosed with SMI. It takes a mixed-methods approach, combining quantitative pre-post measures with qualitative participant feedback. Participants were individuals diagnosed with SMI from the Boston

area, who self-selected to attend the course. Initially 38 self-selected, but only 19 went on to complete the course. Of these, only 9 completed the quantitative measures and it is unclear how many contributed to the qualitative data. One validated measure of self-esteem was used (Rosenberg, 1965) but validity was not reported for the remaining two measures (recovery measure, intervention-specific measure). The reporting of quantitative findings is very basic; suggesting a significant positive change on the intervention-specific measure, and positive change in self-esteem and recovery but not at a significant level. The authors do not comment on the trustworthiness of these findings or likelihood of error, given the small sample size (n=9) and use of non-validated measures. The lack of control group also means there was no consideration given to improvements that may have been seen regardless of the specific treatment approach. The reported outcomes only represent individuals who fully engaged in the intervention and fails to consider the results of those who dropped out. Finally, no causal relationship can be drawn between PT and the improvements seen, because participants may have been attending other courses within the recovery setting they were recruited from.

The QATQS quality rating for this study is *weak*, given the lack of methodological rigour and insufficient reporting on quantitative data within these preliminary findings. The qualitative component is similarly lacking in methodological rigour, but so long as it is interpreted with caution regarding its transferability it may offer some helpful insight into possible benefits of storytelling in this context. Participants were invited to answer an open-question written survey at the end of the course. Data were analysed thematically and presented in terms of benefits at the personal and interpersonal level. At the personal level, participants reported a sense of fun and relaxation, greater creativity and self-expression, improvements in self-esteem, opening up more, increased self-knowledge, an ability to be present, and being able to cope with unresolved stories. At the interpersonal level, participants reported benefit from being connected with others, feeling part of a group, and an enhanced ability to empathise with others. The authors also noted their own observations, that individuals told more emotion-laden stories as the group went on, that individuals reported increased self-esteem carrying over to relationships outside of the class, and that friendships developed in the group. It should be noted that there is no reporting of negative aspects, which raises the question of bias in terms of what has been reported.

## **Discussion**

This review has considered interventions for adult mental health recovery that incorporate storytelling elements. The twelve papers retrieved through the systematic search identify a total of six interventions, each with a slightly different therapeutic orientation. NECT combines a storytelling component with traditional cognitive techniques from

psychological therapy, whilst COP focuses more on the social aspects of telling one's story as a route towards recovery. TTM, Anti-Stigma Photovoice, Recovery Narrative Photovoice and PT all offer a creative element for telling one's story (painting, photography, and theatre). TTM has its roots in occupational therapy and therefore focuses on the "doing" of storytelling via painting, to encourage an active therapy that can lead on to increased occupation. Anti-Stigma Photovoice, Recovery Narrative Photovoice and PT focus more on the artistic expression of and engagement with one's story. Three of the interventions (NECT, COP and Anti-Stigma Photovoice) are also specifically targeting a reduction in self-stigma, as this has been associated with improved recovery outcomes (Mashiach-Eizenberg *et al.*, 2013).

### **Core Components of Storytelling**

Despite the diverse range of interventions seen, there are some core components of storytelling that feature across them. Firstly, all six interventions appear to offer a space for *reflection* that is valued by participants. The process of forming one's story requires some form of "stepping back" from everyday life, which perhaps gives the opportunity for objectivity and new perspective. PT, for example, involves distancing in the form of the individual watching their own story be acted out by peers. Gunnarsson *et al.*'s (2010) qualitative findings indicated that systematic reflection and looking at the whole self leads on to a greater sense of coherence.

The second core component is *reframing* experiences, which may include updating previously held beliefs through psychoeducation (NECT, TTM, Recovery Narrative Photovoice), cognitive restructuring (NECT), or guided questioning from the facilitator (TTM, Anti-Stigma Photovoice, Recovery Narrative Photovoice). This may relate to ideas about telling a different story, in order to build a new identity beyond mental illness (Kondrat and Teater, 2009). Participants tend to be encouraged to draw on their strengths and tell their story in a new light.

The third common component is *agency*. The teller adopts an active role in forming and sharing their story, which can then act as a catalyst for a renewed sense of control over their life in general (Pennebaker and Seagal, 1999). Having a story, in whatever format, is a way of externalising what's happened and the practical task of constructing/telling one's story offers opportunity for a sense of mastery. In narrative therapy, the development of personal agency is reported to be the aspect of therapy that clients value most, over and above externalising conversation or the development of an alternative story (St. James-O'Connor *et al.*, 1997).

A final core component is *validation*. Most studies referenced that participants valued the opportunity to share their story in a safe environment, and to have their disclosure met with acceptance and empathy; which in turn can foster feelings of connection (not being

alone in facing such difficulties) and hope (seeing others in a similar position who have felt the same, but have overcome adversity).

The core components identified above indicate that storytelling – although a less formal activity (Wiltshire, 1995) – may achieve some of the aims of formal narrative therapy. The processes of reflection and reframing are comparable to *externalising conversations* that are used in narrative therapy to reposition the problem outside of the individual, such that they can gain distance from the problem and can then consider new ideas for how to manage it (Morgan, 2002). Reframing experiences is also comparable to narrative therapy's focus on looking for *unique outcomes* within a *problem-saturated narrative* (White and Epston, 1990) in order to build an alternative story that supports the individual to move forwards, linking to the agency component outlined above. The final component, validation, is perhaps more prominent within storytelling where there is focus on telling the story to others (Frank, 2000), meaning that the audience and their responses are an important part of the experience.

### **Distinguishing Factors**

Aside from these common core components, there are also some key distinguishing factors between the interventions discussed. Crucially, the interventions differ in whether they focus more on the *forming* or the *sharing* of one's story. COP, for example, focuses solely on disclosure, with little support offered to the individual in constructing their story (although narrative enhancement is acknowledged as a component to consider in future developments of the intervention). PT is similar in that it focuses on the sharing and performing of one's story, with little emphasis on its construction. It could be argued, however, that the story is co-constructed as it is then acted out and developed with peers. Although the other interventions include some form of telling of one's story, the main focus is weighted towards story construction. NECT's focal phase involves the reconstruction of a more helpful self-narrative using cognitive techniques; whilst the remaining interventions focus primarily on self-expression through creative narrative methods (photographs, painting, written narrative). The telling may come alongside forming one's story, or often at the end of the intervention within the final session. Most of the interventions involve a group of peers who act as an audience for the story, with the only exception being TTM (although there is still one listener, the therapist). Three of the interventions (COP, Anti-Stigma Photovoice, and Recovery Narrative Photovoice) also involve sharing the story with wider society, beyond the intervention setting. It would be interesting to know more about how this was experienced by individuals, as it may be closer to the experience of telling one's story in everyday life.

Programmes also vary in format. In terms of duration, COP is the shortest (three sessions). However, there is some discussion about the workload being too demanding

within this amount of time, and the intervention being too short to have a significant impact on self-concept and self-stigma (Rüsch *et al.*, 2014). Given that most of the other interventions run for ten sessions or more, perhaps storytelling is an approach that requires more time, particularly when greater focus is given to forming one's story and addressing issues relating to self-concept, as well as the telling of it. TTM is the other anomaly, at just five sessions, although this is also the only intervention to offer an individual format and therefore the whole hour is dedicated solely to one person's story. Variation is also seen in terms of whether interventions are led by professionals or peers. TTM and NECT are professional-led; the former showing some positive outcomes for storytelling in the context of individual therapy, and the latter for storytelling in a group therapy format. The remaining four interventions, however, are jointly-led or peer-led.

The literature on mental health recovery advocates the role of *experts by experience* in instilling hope in others. This operates via shared understanding and mutual empowerment between individuals in similar situations (Repper, 2013). All interventions involving a group format alluded to participants benefitting from peer support within these settings, although it was less clear how important it was that the facilitator was a peer versus a professional. Only the TTM papers discussed the therapeutic relationship at length, as this was a focus for outcome measurement. The role of an empathic therapist was highlighted as important (which is perhaps similar to the acceptance and empathy received from peers in the group format of the other five interventions) and mixed opinions were reported in the qualitative interviews about whether the therapist should remain in the professional role, or take on more of a "friend" role (Gunnarsson *et al.*, 2010).

Fidelity is considered to some degree across most interventions and training of facilitators is described at varying levels of detail. The ethos of the recovery movement, however, is about offering a "map" for supporting with recovery rather than step-by-step prescriptive programmes, because it is such an individual journey (Slade, 2013). Perhaps, therefore, the variation across the interventions offered, as well as the flexibility within them in terms of their actual delivery, is appropriate for mental health recovery. The difficulty that then arises is how to measure outcomes in a consistent way.

### **Summary of Current Evidence and Implications for Future Research**

The research evidence for the six interventions is in the early stage of being established. It is encouraging that positive outcomes are being reported for storytelling approaches across an array of domains, including self-stigma, hope, agency, recovery, occupation, stress relating to stigma and disclosure, sense of coherence, and psychological symptoms. This shows that storytelling can be applied in a variety of mental health settings, and from a range of therapeutic orientations. There are some RCTs that achieve a level of methodological rigour amongst the findings of this review, as indicated by their

QATQS ratings. However, further research is needed to test these interventions in a variety of settings, and to improve the quality of research design for those in the earlier stages of being assessed, so that stronger conclusions could be drawn about the efficacy of interventions. Some of the studies reported dropout rates that are higher than the 31.7% worldwide average reported within mental health treatment in general (Wells *et al.*, 2013). It is important to consider why storytelling interventions may not be meeting the needs of those who do not complete them, or indeed those who decline to participate. Follow-up studies are also required, to assess whether positive changes are maintained over time.

A persistent difficulty across the included papers is a lack of clarity around to what extent the reported outcomes can be attributed to the actual interventions, and how much may be due to other influencing factors (such as change in social circumstances, other therapeutic interventions received, or natural recovery). In addition, it is difficult to ascertain what proportion of the effects seen may be attributable to the storytelling components of these interventions, given that some combine storytelling with additional therapeutic techniques (for example, cognitive skills), and other factors regarding intervention format may also be having an impact (for example, relationships with peer or therapist facilitating change). This issue is noted within both qualitative papers included in this review (Gunnarsson *et al.*, 2010; Roe *et al.*, 2010).

Most of the studies included samples of participants diagnosed with SMI, as defined by published diagnostic manuals. The only exception is Corrigan *et al.*'s (2015) COP study, whereby participants self-identified as having a mental illness and no data was collected regarding diagnosis. SMI is a broad category and diagnoses reported within this included schizophrenia spectrum disorders, depressive disorders, anxiety disorders, and others. This lack of homogeneity meant that more specific data on severity and chronicity of participants' mental health difficulties was also lacking. Recovery approaches often are not diagnosis-specific, due to the focus on the personal meaning of a mental health difficulty regardless of symptomatology (Slade, 2013). However, the limited homogeneity of samples within the papers included in this review makes it difficult to draw conclusions about the palatability of these interventions for specific diagnoses.

It is positive that storytelling is being used in so many different ways, from a range of therapeutic angles, because it can then be accessible to a wide range of populations. In terms of generating a reliable evidence-base, however, it means studies lack consistency in how outcomes are being measured because each intervention has a slightly different focus. It may be useful in future to develop a measure that can capture storytelling's impact on the individual. However, this would not be possible until we understand the precise components of storytelling that are experienced as helpful by the individual. We

have included two qualitative papers in this review, which offer some insight into what individuals find helpful about NECT and TTM. Whilst this is a helpful starting point, further research of this kind is needed across other storytelling interventions.

Further research should focus on exploring the experience of storytelling from an inductive perspective, gaining an understanding of individual experiences and what the storytelling process means to them. An inductive approach might allow for exploration of other mechanisms or domains of storytelling, which have not previously been considered, along with some further elucidation of the helpful and unhelpful aspects of storytelling. Ideas about unhelpful aspects of storytelling are absent within the current evidence. Future findings from inductive research could, therefore, inform how the interventions are developed, and provide clarification over which domains are important to measure in order to capture the outcomes of storytelling interventions.

Finally, research on storytelling within a UK context is lacking, given that most papers included in this review have taken place internationally. There are now interventions such as *Telling My Story* offered at some UK recovery colleges and it would be helpful to utilise the findings from this review and assess whether they translate to storytelling within a UK context. Slade (2013) acknowledges that the knowledge base within the recovery approach is built on personal narrative and on research situated in a social context, rather than the traditional approach of placing the greatest value on RCTs and systematic reviews. Perhaps, therefore, research into storytelling within a UK mental health recovery context should begin with an inductive approach (which this review highlights as important). Exploration of the *process* and *meaning* of telling one's story may then inform the ongoing development of storytelling interventions in the UK and provide direction regarding outcome measurement.

### **Limitations**

There are some limitations of this systematic review of the literature that must be acknowledged. Firstly, no studies were excluded on the basis of quality ratings which has meant that findings must be interpreted with caution regarding their trustworthiness. It should be emphasised that the evidence-base for storytelling interventions is in its early stages of becoming established. The available evidence provides preliminary indications that storytelling can be helpful within a range of settings and formats, but further research is needed to obtain trustworthy evidence regarding the efficacy of storytelling interventions in mental health.

A further limitation of the review is that it was conducted by only one researcher. Ideally, included studies would be reviewed by at least two reviewers (Thomas *et al.*, 2004), but due to the constraints of the context within which this review has been conducted, review by multiple authors was not possible. The review therefore offers a synthesis of findings

from the perspective of one researcher who is interested in the use of storytelling in mental health recovery, but it is acknowledged that the robustness of this synthesis would be enhanced had the review included the perspective of other researchers.

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### **Endnotes**

<sup>1</sup>Please note that the 'Coming Out Proud' (COP) intervention is now referred to as 'Honest, Open, Proud', with no changes to the content. For the purpose of this study, however, we will continue to call the intervention 'Coming Out Proud', given that this is how it is referenced in the included studies.

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## **Chapter Three – Empirical Paper**

This chapter consists of the empirical paper, written for the Mental Health Review Journal and formatted in accordance with their guidelines for submission (Appendix A). The empirical paper is 6997 words in length (journal word limit is 7000 words, including references). The abstract for the empirical paper is 192 words in length (journal word limit for the abstract is 250 words, including keywords and article classification).

# A qualitative exploration of Telling My Story in mental health recovery.

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## Abstract

**Purpose:** Creating more positive individual narratives around illness and identity is at the heart of the mental health care recovery movement. Some recovery services explicitly use personal storytelling as an intervention. This paper looks at individual experiences of a personal storytelling intervention, a recovery college *Telling My Story* course.

**Design/methodology/approach:** Eight participants who had attended the Telling My Story course offered at a UK recovery college were interviewed. Data were analysed using Interpretative Phenomenological Analysis.

**Findings:** Five key themes emerged: *a highly emotional experience, feeling safe to disclose, renewed sense of self, two-way process and a novel opportunity.*

**Originality/value:** The findings suggest that storytelling can be a highly meaningful experience and an important part of the individual's recovery journey. They also begin to identify elements of the storytelling process which might aid recovery, and point to pragmatic setting conditions for storytelling interventions to be helpful. More time could be dedicated to individuals telling their story within UK mental health services, and we can use this insight into the experience of personal storytelling to guide any future developments.

**Keywords:** Storytelling; mental health recovery; interpretative phenomenological analysis; narrative therapy.

**Paper type:** Research paper.

## Introduction

Personal recovery in mental health involves a deeply individual journey of finding meaning in life, beyond the limitations of a mental health problem (Anthony, 1993). The recovery approach moves away from professional-led care and instead empowers individuals to become experts in their own self-care; building on their strengths to re-discover an identity that is separate from illness or disability (Perkins *et al.*, 2012). The key concepts found to be important in personal recovery are conceptualised by the CHIME framework (Leamy *et al.*, 2011): Connectedness, Hope and optimism, Identity, Meaning and purpose, and Empowerment.

An innovation in the UK recovery movement has been the development of recovery colleges, which take an educational approach to addressing mental health difficulties. Individual service users, professionals and carers can attend as students on courses that are co-produced and co-facilitated by those with lived experience of mental health problems (Perkins *et al.*, 2012). Recovery colleges are underpinned by an ethos of experience-sharing and normalising of mental health difficulties, and personal storytelling is at the heart of this. Peer workers aim to instil hope in others by sharing their story; as relatable people who are reconstructing a positive self-identity despite the challenges of a mental health problem (Repper, 2013). In addition, individuals are encouraged to form their own recovery story and to share this with others (Shepherd *et al.*, 2014).

It is thought that having a self-authored record of what has happened supports the individual to move forwards in their recovery, through making sense of their experiences and feeling heard by others (Scottish Recovery Network, 2012). Some recovery colleges offer specific courses that equip people to tell their own recovery story. Recovery College East (RCE; part of Cambridgeshire and Peterborough NHS Foundation Trust) is one example, offering the *Telling My Story* (TMS) course that runs for four weekly half-day sessions. The TMS course is novel in that it brings together the *forming* (sessions 1-3) and the *sharing* (session 4) of one's recovery story, supporting individuals to make sense of what has happened to them and celebrate who they are, with others. Peer support tutors facilitate the course and it can be attended by service users, carers and Trust staff members. Typically, four to eight people attend per cohort.

Given that TMS has grown somewhat organically, formal research and evaluation data are lacking, as it is elsewhere in other recovery settings (Shepherd *et al.*, 2014). The course is highly valued by students and staff, but reports of how storytelling impacts on students is limited to informal feedback. Given the centrality of personal stories to the culture of mental health recovery, it seems vital to know more about the experience of storytelling.

We can look to the wider literature for some insight. Telling personal stories is recognised as a fundamental aspect of human experience (Plummer, 1995). We unremittingly interpret and re-interpret our experiences; constructing a way of telling about ourselves that is inextricably bound with our personal and social identity (Bruner, 1987). The presence of a mental health problem has the potential to put one's life story – and indeed, one's identity – into disarray. It is suggested that storytelling allows us to regain a sense of order by making links between our sense of self, temporality, social standing and morality (Crossley, 2000).

Constructing a narrative has shown to impact positively on both physical and mental wellbeing (Pennebaker and Seagal, 1999) and the disclosure of distressing information can have cathartic benefits (Frattaroli, 2006). We see narrative interventions used widely in mental health; from narrative exposure for trauma (Schauer *et al.*, 2011), through to narrative therapy (White and Epston, 1990). Typically, however, these approaches focus on forming the story at a private level, whereas storytelling involves sharing the story on a public platform and therefore exposes the self to social shaping by the responses of others (McLean *et al.*, 2007).

There is some preliminary evidence to suggest that interventions incorporating storytelling are helpful in reducing symptoms and increasing functioning (Gunnarsson and Eklund, 2009; Roe *et al.*, 2014; Russinova *et al.*, 2014). However, the lack of qualitative literature exploring the individual's experience of these interventions means that attempts to capture outcomes are being made without clarity around which domains to measure. Preliminary findings about service user experiences of two specific storytelling interventions are available. Roe *et al.* (2010) found that group storytelling led participants to experience a reformation of self through narrative change; facilitated by an accepting environment and taking an active role through narration. Amongst the themes were ideas of connection to others, emotional change from opening up, and increased hope from seeing others' achievements. Gunnarsson *et al.* (2010) reported that one-to-one storytelling with a professional helped participants to develop a sense of coherence and facilitated emotional catharsis, whilst the practical task of forming a story helped to develop agency.

The qualitative findings outlined above offer some insight into the experience of storytelling, but are limited in transferability since the studies took place in Israel and Sweden with specific interventions. What is needed is inductive exploration of the experience of storytelling in a UK mental health recovery context; the TMS course offered at RCE provides such an opportunity. It is hoped that this paper will increase our understanding of how the storytelling process is experienced by and impacts on those who use it, in order to inform service development and future research and evaluation.

## **Method**

### **Study Design**

The study used in-depth interviews with participants who had completed the TMS course at RCE. Ethical approval was obtained through the North West – Liverpool Central Ethics Committee (REC 16/NW/0148). The initial proposal underwent review by the local NHS service user panel.

The study draws on the Interpretative Phenomenological Analysis (IPA) framework; chosen because it is particularly suited to health and social research that aims to explore how individuals make sense of their world, to gather valuable insight that can inform clinical practice (Smith and Eatough, 2007).

### **Participant Recruitment**

A total of eight participants were recruited (demographic details are outlined in Table 1). Two others were approached within the recruitment process: one did not respond and the other chose not to take part. All eight met the inclusion criteria. Written consent was obtained for each participant on the day of interview, following discussion with the first author to confirm eligibility/capacity to consent, and prior to any discussions taking place.

The inclusion criteria were:

- people aged 18 or over, with a recognised mental health difficulty for which they had received support from secondary mental health services
- people who had completed the TMS course within the last year.

The following exclusion criteria were applied:

- people who were not fluent in speaking and understanding English
- people who lacked the capacity to consent, lacked the cognitive ability to take part, or were functionally impaired to the extent of being unable to take part
- carers and staff members who attended the course.

### **Data Collection**

Semi-structured interviews were conducted by the first author (KN). The interview guide was developed collaboratively via focus group discussion with recovery college students who were not recruited to the study. This is fitting with the recovery model's emphasis on co-production within the design of research and evaluation projects (Corrigan, 2014).

All interviews were audio-recorded and later transcribed verbatim by KN. Ethical considerations were prioritised throughout the interview, including checking for ongoing verbal consent and debriefing as appropriate.

Table 1

*Participant demographic details*

Participant <sup>1</sup>	Age	Gender	Ethnicity	Length of time involved with RCE
Sarah	35	F	White British	1 year
Paul	71	M	White British	2 years
Mark	58	M	White British	6 months
Brad	46	M	White British	1 year 7 months
Janey	50	F	White British	3 years
Lisa	29	F	White British	2 years
George	58	M	Mixed British & Asian	1 year 4 months
Judy	63	F	White British	6 months

**Analysis**

Interview data were analysed following guidance on the conduct of IPA (Smith *et al.*, 2009). By an iterative and immersive process, a list of codes was produced for each transcript, then clustered into superordinate themes for that particular participant. After this idiographic stage of analysis (Smith and Eatough, 2007) superordinate themes were developed for the group as a whole, which captured similarities and differences in participants' individual experiences.

**Validity and Rigour**

Analysis was primarily undertaken by KN and aligns to IPA's hermeneutic underpinning, offering this particular researcher's interpretation of how the participant was making sense of their experiences, at that particular time (Smith *et al.*, 2009). A number of steps were used to increase transparency, rigour and trustworthiness of the data including keeping a reflective journal (which also documented all a priori and post hoc analysis decisions), a second focus group with another group of recovery college students (for participant-group feedback on the initial analysis), and joint coding sessions with supervisors (to retain fidelity to IPA's epistemological stance and methods).

**Results**

Five superordinate themes were identified. Throughout the analytic process, however, the *individuality* of the storytelling experience was highly evident: each person's story was unique to them, and a reflection of where they were in their recovery at that particular time. The analysis describes each theme in turn. However, the individuality shown across participants is explored within each theme.

## **Theme One: A Highly Emotional Experience**

Storytelling was experienced as emotionally charged in both helpful and challenging ways. A number of participants described a sense of catharsis achieved from “getting it all out”, contrasted to keeping things inside whereby “it just festers and becomes toxic” (George). There was a strong sense of liberation from being able to express previously hidden parts of self.

Brad: “Well I’d had a certain level of weight lifted from my shoulders. It’s- I got the full story I wanted to tell off- off my chest, so it- it had- it’s actually helped lighten me- lighten my mood a great deal.”

Lisa described expressing her difficult early experiences that she had previously kept hidden. This was a significant step along her recovery journey:

Lisa: “It was the first time I really got it all out [...] I-I still need to go back and have some therapy on some stuff from when I was a kid, to learn to deal with it, but I’m much more stable now to do that, and [pause] telling my story was a big part of that because it let me tell people what had gone on with my childhood.”

Storytelling enabled participants to externalise difficult internal experiences, such that their emotional impact became more manageable. Lisa did this through song, and another participant used a yoyo to give physical presence to the emotional ups and downs that she was experiencing on the inside, with a hopeful message that she would always “bounce back up”. Most participants stressed, however, that the benefits of storytelling were coupled with it being a highly demanding emotional experience. Sarah described an initial catharsis, coupled with high anxiety when telling her story and exposing herself, followed by positive feelings upon reflection once the intense emotion had reduced.

Exploring the more difficult parts of self (those often repressed, or avoided) stirred up a lot of difficult feelings, and some participants feared that this would exacerbate dwelling on negatives. For some, it was important to include humour in their story to counterbalance the difficult aspects and “release the tension” (Brad); both for themselves, and the listener. Some participants spoke about using positivity to cope with the emotional demands of storytelling.

Janey: "I felt a lot more positive about my story because it- it made me frame it in a positive light. This course made me like- like it was a requirement to frame it positively, which I- is something I find very difficult."

As noted by Janey's description ("This course made me"), positive reframing is somewhat imposed by the course structure. However, participants valued this and reported that including positive elements to their story became essential to their recovery.

### **Theme Two: Feeling Safe to Disclose**

All participants made reference to the idea of safety and how this impacted on their level of disclosure. Within the course environment, participants gained comfort in knowing that other students would be understanding of their difficulties.

Mark: "It allows you to share things totally, without fear, without thinking that anyone's going to think badly of you, and that they're all on your side."

Words such as "warm" (Sarah, Brad, Lisa), "supportive" (George) and "nurturing" (Janey) were amongst descriptions of the TMS environment. For many, this was their first experience of feeling safe enough to tell their story. This was frequently compared to other environments, whereby it felt unsafe to disclose and fear of negative judgment prevailed. Some referred to experiences of stigmatisation in social and personal arenas (Mark, Janey), and the majority of participants spoke about keeping their story from those closest to them. For some, this was due to fear of upsetting those who may be closely tied to the story (Paul, Brad, Lisa). Others described family context that did not support open sharing and emotional connection (Mark, Brad) and for George this was linked to his cultural background where mental health issues were not discussed openly.

In contrast, the TMS course was experienced as a place where others were "willing to listen" (George) and individuals were "given time" (Sarah). Participants referred to a deeper level of connection achieved through mutual sharing, at times in contrast to relationships outside of the course:

Janey: "You don't really go into deep meaningful conversation with somebody [laughs] as you would- as you would do on the course. So, you know, you kind of really felt you had a connection with some- you know, with people on the course."

For one participant, however, the course environment was not such a safe space. Paul described his storytelling experience as "overwhelming" because he felt that he was

shocking others, and he experienced others as disbelieving. Paul described a history of not being believed in relation to his psychotic experiences, which may have contributed to a feeling of not being believed by other students, and left him feeling emotionally uncontained (linking to theme one). As a result, he regretted his disclosure and did not anticipate sharing his story beyond the course.

### **Theme 3: Renewed Sense of Self**

For all participants, telling their story seemed to lead to some kind of discovery (or re-discovery) about themselves, which acted as a catalyst for starting to overcome their suffering. The story format prompted participants to acknowledge past difficulties, and give them some kind of order. Sarah told her story chronologically, in a storybook format with photo images.

Sarah: "I just feel like it's, like, organised my brain a bit more."

This allowed for sense-making and for new understandings to develop (for example, linking early experiences to later life challenges). A number of participants felt their story provided some kind of grounding or waymark; a reference point for future sense-making and development of self.

Brad: "Hopefully it's going to be something I can look at, and identify where I've moved forward, as I- as I carry on through it's something I'll look back on and say okay yeah, I've- I recognise I was feeling like that but now I can see that I'm feeling much more relaxed with different things."

Brad's ability to "recognise I was feeling like that" was significant within the wider context of his interview. Telling his whole story allowed him to acknowledge the difficult times he'd had, which facilitated understanding of what was keeping him stuck, such that he could make positive changes and re-engage with his values. One such value was writing; after writing his story on the course he set up an online blog, through which he continued to tell his story and re-integrate himself with others.

Re-integration and increased engagement was reported by many. For George, whose feelings of not being worthy had led him to social isolation and depression, the experience of being heard and validated had begun to open up opportunities for re-engaging in the social world:

George: "I've always been a loner. Yeah I'd sit at home and eat takeaways and watch YouTube videos. Very sad, you know. I don't have much of a life at all really, because I don't feel like- I have no right to say anything. Well I haven't had a right to say anything, and I- I'm starting to see how a social life works, you know. Taking an interest in- in [short pause] the theatre, or you know, music."

Having attended the course for the second time, George described how he was gradually learning more about himself, and expressed a desire to attend the course again in future to continue this process. Across all participants' experiences, there was a sense that stories aren't static. Rather, they evolve over time according to the individual's stage of recovery. Lisa had subsequently shared her story on a different recovery college course, and reflected on how her relationship to her story changed over time.

Lisa: "I was stronger. I was more connected to myself [...] I'm more able to connect and feel- excuse me- and feel [short pause] almost sad for myself, and empathise, and connect with that [...] So I can now think [short pause] some of that was- well my stuff as a kid wasn't my fault, but some of my decisions I made as an adult were my fault, but I can forgive myself for that, and I can move forwards."

Becoming more emotionally connected has allowed Lisa to be more compassionate towards herself, empathising with the things that have happened out of her control, and taking responsibility for the things that she can influence moving forwards. Acknowledging and accepting the more problematic parts of self was reported by many as instrumental in allowing them to progress in their recovery.

Two participants benefited from organising their story, but had difficulty reflecting on how storytelling had impacted on their sense of self. For Judy, it was particularly important to have developed a new perspective regarding her psychotic symptoms, but there was a feeling of emptiness within the interview when prompted for further reflection on what this meant to her. A reflective journal entry, made following the interview, reads:

"She was speaking in quite a detached way. My interpretation was that forming her story had helped her to organise experiences, but there wasn't much emotion or meaning there; it was reporting of facts. I feel quite sad for her, but I'm wondering how much of this is me needing to adjust my expectations of how storytelling "should" impact on somebody, to be most beneficial. For me, just noting the key events wouldn't have helped much; I'd need to go further than this. Perhaps for Judy and her stage of recovery, however, this organising of experiences was enough to have a positive impact and help her regain a sense of control over what's happened."  
(Reflective Journal, 30.09.16)

It was important for KN to bracket her own preconceptions (Smith *et al.*, 2009) and enter Judy's world to understand the personal context of her storytelling experience. This led KN to a new understanding of how storytelling can impact people on different levels, according to their stage of recovery and what they need or are ready for at that time.

## Theme Four: A Two-Way Process

Participants valued the opportunity to experience both the *teller* and the *listener* role. As tellers, participants received feedback from the listeners, which often shaped how they felt about themselves and their story. This was hugely significant for Lisa, whose past attempts to disclose childhood abuse had been met with disbelief and rejection.

Lisa: “The first time I saw the reaction on people’s faces at what I was saying, was the first time I’d really felt [short pause] any empathy.”

Receiving empathy from others allowed Lisa to begin to accept the hidden parts of herself, which in turn allowed her to become more emotionally connected (theme three). A number of participants said they regularly revisited their feedback cards (completed by group peers after an individual had told their story) and felt warmed by the positive comments received.

Telling your story also provides an opportunity to impact upon the listener. Many participants hoped that their story could provide support to others. Janey had previously told her story in a counselling context, which she found emotionally draining and quite unhelpful. Her storytelling on the course had a different focus:

Janey: “Instead of like me just telling it for me, it was more looking at it in the point- from the point of view of how it could help other people that are listening to me tell my story [...] In telling it in a way that will inspire others, you’re also telling it in a way that will inspire yourself.”

For Janey, telling her story in a way that would inspire others, had the added benefit of enabling her to feel inspired herself. Other participants felt that they would be more likely to share their story in future if they perceived it would benefit the listener.

When in the listener position, participants described feeling inspired by other people’s progress in spite of adversity, particularly if they could relate to the teller in terms of similarities in experiences. There was a sense of “if they can do it, I can”, felt by many and described here by George:

George: “Other people here sort of gave me the confidence to- knowing that they have had difficulties, you know, that they have started to [short pause] through the recovery process have started to try see their lives in different ways. It gave me the confidence to think well I can do the same, you know.”

George identified as a “loner” and described “stuckness” when he first told his story as he struggled for hope and motivation. It wasn’t until hearing stories from others whom he

could relate to about successfully making changes that he felt compelled and confident to do the same for himself.

Another important aspect of the listener role was offering feedback to other tellers.

Lisa: "It meant a lot. It meant that I could show them that I had listened, and that I did care."

Although giving positive comments was encouraged by the course format, there was a genuine sense across all participants of wanting to reciprocate meaningful feedback to others. Many people commented that feeling that they were helping others fostered feeling good about themselves.

The process of *self to other comparison* was described in some way by all eight participants. For most, this seemed a positive experience; resulting in either favourable self-other comparison ("it made me think I was doing quite well" – Judy, others were "worse off" – Mark), or at least a reaffirmation that they aren't alone in the challenges they face. For Paul, however, the self-other comparison was unfavourable. When asked whether anything would have made the storytelling process more useful to him, he replied:

Paul: "If other people had been in the same situation, had been abused, along those lines, then I could have said yes I've been, and I wouldn't have felt so out of place, but it seems a lot of them were just, what I'd say, got little niggles. [laughs] They're [pause] on the scale of one to ten they are probably about a two or a three, while I'm up at eight or nine."

The storytelling process seemed to reinforce feelings of isolation that Paul experienced in his wider life. He perceived himself to be "worse-off" than others, which perhaps left him in a cut-off position. Subsequently, he held back from full disclosure of his psychotic experiences and past abuse within his story. Linking to theme two, Paul did not experience connection to others or feel safe enough to disclose fully, so he did not have the same positive experience of being a teller or a listener that other participants described.

### **Theme Five: A Novel Opportunity**

This theme outlines participants' descriptions of storytelling as something novel, rather than an everyday act. This was seen in the language used to describe the experience, for example: "performance"/ "on the stage" (Janey) and "audience" (Brad). Participants reported a degree of planning, as sharing their story was not something they would just go and do. This is perhaps partly due to the TMS course format of three preparation

sessions, leading up to the sharing session. For some, sharing their story on the course led them to feel that future sharing was possible, but many felt unsure about whether, or in what context, they might feel compelled to share their story beyond the course. This seemed to link to feelings of safety within the course environment, which participants felt they could not guarantee in other environments (theme two).

The novelty of storytelling on TMS appears to offer both benefits and drawbacks. Participants valued the opportunity for reflection, described by Mark as “standing outside of myself”. This seemed to allow individuals to engage in sense-making and gaining new perspectives, as seen in theme three. Others were particularly appreciative of being given the time and freedom to tell their story how they wanted to.

Sarah: “I just think it gives some- you a chance to have your own voice. It gives an opportunity to maybe say once and for all what your whole story is, rather than tell bits here and there to different people. It’s like you’re kind of coming together as one and saying “right, *this* is it.”

For Sarah, the protected time to have her “own voice” and tell her “whole story” was hugely significant to her recovery. She suffers with high anxiety and often struggled to articulate herself within the interview. In the excerpt above, however, she demonstrated greater assertion (fluent speech, emphasis on “*this*”), indicating that she had indeed “found her voice”. Sarah told her story through photography, which provided physical embodiment of a more difficult time that is no longer obvious, but that she does not want to simply forget.

The sense of “wholeness” referred to by Sarah was mentioned by a number of participants, and often contrasted with time-pressured clinical environments where individuals might have told some of their story, but with partial details or where the telling was constrained by a professional agenda.

Brad: “I think with a counselling session, there’s a lot- I have a lot less focus for myself because it’s more led by the questions of the counsellors, and I- so I [short pause] I- I feel less able to tell it in the way that I want to- want to tell it and so I- I can’t always exp- tell the- the entire story that I might want to tell.”

Brad had not felt able to express his complete story until attending the TMS course, which had meant he felt he had never quite understood himself or felt understood by professionals. This is in the context of experiencing high social anxiety, and the excerpt above shows some difficulty articulating himself within the interview (indicated with stuttering, hesitation, pauses; and body language observed at interview). It seemed highly important for participants to have choice and freedom in how they told their story, so that it could be a true reflection of who they are.

The drawbacks to storytelling being a novel activity centred on it being anxiety-provoking and challenging, particularly for those who suffered with elevated anxiety as part of their mental health difficulty. We saw within theme one that storytelling can be a highly emotional experience, and some described how the act of sharing made them feel “scared” (George), gave them “stage-fright” (Janey), or created pressure to tell a good story.

## Discussion

The findings provide some empirical evidence to support the popular notion that storytelling may have an important role to play in personal recovery (Scottish Research Network, 2012; Shepherd *et al.*, 2014). This is evident in how the themes link to the CHIME framework (Leamy *et al.*, 2012): mutual sharing through storytelling allowed for *connectedness* to others (themes two and four); feeling inspired by others’ stories led to increased *hope* (theme four); individuals gained a renewed sense of *identity* from connecting with their emotions and experiences through telling their story (themes one and three); reflection and making sense of experiences allowed for new *meaning* and reconnecting to values (themes three and five); and taking an active role through telling one’s story provided *empowerment* and greater confidence to re-engage in life (themes three and five). TMS was in general highly valued by participants, but it has to be considered that perhaps those students with more negative experiences would not have come forward to participate.

The findings expand upon Bruner’s (1987) notion that storytelling is inextricably linked to both personal and social identity. At the individual level, storytelling can have a profound impact in terms of emotional catharsis (theme one) and identity reformation (theme three), and the story itself can be a form of self-expression (theme five). However, the *telling* in storytelling makes it a social act; and themes two and four show that the role of other people is central to the storytelling experience.

These findings support ideas that storytelling helps to develop a sense of coherence (Gunnarsson *et al.*, 2010) and facilitates some kind of reformation of self (Roe *et al.*, 2010). Engaging with TMS required individuals to adopt a new way of telling about themselves, following the story format and drawing out positives. Plummer (1995) identifies common structural components that tend to feature within the stories we tell (a sense of journey, some form of suffering, and then triumphing over adversity), and particularly in *survivor narratives* seen across many minority groups. Plummer highlights how “stories breed stories” because one person speaking out against the dominant narrative (in this case, stigmatising discourse around mental health) enables others to also “come out”, such that negative experiences are transformed into stories of survival

and overcoming adversity. The findings suggest that the stories participants told about themselves may have been shaped by the narrative demands of the course, which facilitated: the expression and documentation of suffering that may have previously remained hidden (themes one and five), organising of experiences in a logical format that allowed for new perspectives to emerge (theme three), and the inclusion of hopeful or triumphant elements in order to inspire others (theme four). For most, this new way of telling about oneself (theme three) facilitated a more positive self-identity (Bruner, 1987).

Theme five highlights the importance of having protected time, allowing the individual to tell their *whole* story exactly how they want. The practical task of forming and sharing one's story led to increased agency, as reported elsewhere (Gunnarsson *et al.*, 2010; Roe *et al.*, 2010), and seems to facilitate engagement in wider life; particularly when coupled with reconnection with personal values and increased hope about being able to live by these (themes three and four). Agency is considered an important factor for recovery (Davidson, 2003) and emphasises empowering individuals to become experts in their own self-care (Perkins *et al.*, 2012). Storytelling appears to act as a catalyst for this change in dynamic because it is reliant on the individual taking the lead. Perhaps this is an argument for other therapeutic approaches to begin with structured personal storytelling, to foster empowerment for the individual from the start.

This research highlights how feeling safe facilitates richer disclosure, whereas feeling unsafe acts as barrier (theme two). The (often novel) opportunity for acceptance and validation from others was highly valued, with many participants internalising the positive feedback of others, such that they came to hold these more positive beliefs about themselves. This could counteract any self-stigma about mental health problems, if the individual has internalised any negative and stigmatising views of others (Roe *et al.*, 2010).

The mutuality of storytelling within this group context fostered feelings of connection and belonging (Maslow, 1943), but also provided an opportunity for individuals to reciprocate their positive experience of storytelling through being both a validating listener and an inspiring teller. This perhaps contributes to increased agency by bringing the individual out of the patient role and into thinking about others, and it is well documented that altruistic acts can foster feeling good about oneself (Post, 2005). Shepherd *et al.* (2008) state that "finding you have something to give, as well as needing help is central to building a positive sense of self-esteem and this is at the heart of recovery" (p. 5). Perhaps storytelling can help facilitate this.

The group processes involved in storytelling and seen in this study support the well-documented notion within recovery that hearing other people's stories can inspire hope (Repper, 2013). Seeing a peer progress with their recovery despite adversity may challenge the individual's perception of what it means to have a mental health problem, inspiring an attitude of "if they can do it, I can" so that having a mental health problem is no longer as limiting.

Across the themes, we can see how the process of storytelling can impact upon the individual's wider sense of self and how they position themselves in the social world. Having a mental health problem can lead to a sense of "spoiled identity" due to feeling socially "abnormal" (Goffman, 1963). The self-stigma that this can create is thought to lead to low self-esteem, low self-efficacy and reduced self-worth (Corrigan and Rao, 2012), with the emotional core of shame (Luoma and Platt, 2015). The findings of this study show that storytelling can offer a platform for experiencing meaningful connection, acceptance and validation from others, which can normalise experiences that might have previously been considered shameful. According to shame resilience theory (Brown, 2006) it is this empathic relational response that allows an individual to overcome shame; because feelings of unworthiness or inadequacy are replaced with a sense of acceptance and belonging, which provides the basis for re-engagement through regaining power and freedom over one's life.

Shame is now a recognised core component that is common to a broad range of mental health difficulties (Gilbert, 2009), and a construct that perhaps needs greater consideration within the organisation and delivery of mental health services (Leeming and Boyle, 2013). Perhaps storytelling has an important role to play in this, given that the social experience of telling one's story has shown to provide some of the conditions that are understood to be necessary for the alleviation of shame (Brown, 2006).

We are reminded in the case of Paul, however, that non-identification with the group can leave the individual feeling more isolated; rather than accepted, validated or inspired. Thus, feelings of shame may be maintained or even exaggerated. This raises the question of whether the group format of storytelling is appropriate for all, or whether the individual needs to have reached a certain point in their recovery journey prior to telling their story. This is perhaps an area for further investigation.

### **Limitations**

We have only heard from those who wanted to speak about their storytelling experience; it could be that those who declined to participate or give consent to being contacted had a more negative experience. In addition, the participants had varying degrees of prior

storytelling experience, and were at varying stages of recovery. The IPA methodology allowed for reflection on each individual's context, but we are mindful that this variation makes it difficult to assume transferability of results. Similarly, the lack of cultural diversity within the sample limits the transferability of findings to those from other ethnic backgrounds.

Fitting with IPA, the results presented offer an interpretation from the perspective of one researcher, without making claim to any absolute truth about the experience of storytelling for all. Although steps were taken to maximise quality and rigour, and increase trustworthiness, the bulk of the analysis was carried out by one researcher (KN) and other studies have benefited from taking a team approach to analysis, to include multiple perspectives.

### **Implications for Practice**

It is argued that personal stories should have a central place in mental health support, given that their *content* can preserve individuality within our evidence-based world (Roberts, 2000). The findings of this study complement this notion, by suggesting how meaningful the *process* of constructing and sharing a recovery story can also be for individuals. More time could be dedicated to personal storytelling within clinical interventions in the UK, in order to empower agency in the client, dedicate time to free expression of the whole story, and aid therapeutic engagement, within a safe and containing setting for disclosure.

Future research could explore the factors that impact on an individual's readiness to tell their story, and factors that might influence how storytelling is experienced, to guide the future development of storytelling interventions across other contexts. Further research is needed to explore other potential formats of storytelling (one-to-one, for example), given that the group environment was shown to have unhelpful elements for one person.

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### **Endnotes**

<sup>1</sup>Pseudonyms have been used throughout when referring to participants, to protect their confidentiality.

## Chapter Four – Extended Methodology

The purpose of this additional chapter is to supplement the methodology section of the empirical paper, with a greater level of detail regarding the specific qualitative analysis method chosen and the rationale for this. The chapter begins by outlining the lead researcher's approach to using a qualitative research design. It then moves on to a discussion of the chosen methodology, Interpretative Phenomenological Analysis (IPA), before working through each aspect of the study procedure in chronological order.

### Qualitative Methodologies

The aim of qualitative research is to understand how people make sense of their world and how they experience events (Willig, 2001). In contrast to quantitative methodologies that aim to test hypotheses and prove theory in order to predict outcomes, qualitative researchers aim to develop an understanding of the research phenomena in terms of the meaning attached to it by the participants themselves (Elliott, Fischer & Rennie, 1999). It therefore moves away from seeking objective truths about the phenomena, and instead focuses on “understanding by people” (Stiles, 1993), where the researcher has a key role in the development of these new understandings (Finlay, 2011).

### Lead Researcher Context

Owning one's perspective and reflecting on personal investment in the research is advocated as a crucial part of being a qualitative researcher (Elliott et al., 1999; Ortlipp, 2008). The lead researcher (KN) has undertaken this project as part of doctoral training in Clinical Psychology and was first introduced to the recovery model of mental health during university presentations regarding possible research topics for the doctoral thesis. KN felt drawn towards the area because it struck a chord with her personal background. A reflection on this from an early research journal entry reads:

I am passionate about making mental health problems something that we can talk about, in society as a whole, and reducing the stigma around mental health. Some of this interest stems from living alongside close family members who have had their own mental health challenges; who have battled with having the “label” of a mental health problem and managing this within their social and professional arenas. I can relate to their experiences to some degree, from times when I have battled with my own mental health; and although I do not claim to have experienced the same degree of suffering that others around me have faced, I feel it has given me some insight into the experience of having a mental health challenge. I strongly advocate that we all have mental health, and our own best and worst version of how we like to be; therefore, we can all relate to what having a mental health challenge might be like,

and no one of us is immune to experiencing a difficulty of this kind at some stage in life. (Reflective journal entry, 02.11.15).

It is this stance that has created KN's passion to challenge mental health stigma and make mental health something that can be spoken about openly. This has led to KN's interest in discovering how the Telling My Story (TMS) course, designed to do just that, is experienced by individuals who take part. There is potential bias here, in that KN's hope for the course to be a positive experience could lead her to selectively attend to the benefits of the course experience, and be less attuned to participant reports of more negative aspects. This has been considered within KN's ongoing reflections on how her own interpretative framework is influencing the research process.

### **Reflexivity**

Reflexivity refers to the process by which the researcher demonstrates awareness of the concepts, values and preconceptions that they bring to the research process (Yardley, 2000). Qualitative literature frequently refers to the need for the researcher to "bracket" their habitual ways of perceiving the world in order to approach the phenomenon with as fresh a perspective as possible. Succinctly put, "taken-for-granted assumptions, judgments and theories are temporarily suspended (or at least reigned in) in order to see the world anew" (Finlay, 2011, p. 23). KN focused on "bringing the unconscious into consciousness" (Ortlipp, 2008, p. 703) and tried to be mindfully curious about her own interpretative framework throughout the research process.

### **Reflective Journal**

KN has kept a research journal throughout the research process, to facilitate reflexivity (Ortlipp, 2008). Documenting preconceptions and reflections is a helpful way to increase the researcher's self-awareness of their own thoughts and feelings, and how these may be impacting on the research process. Lamb (2013) discusses how the process of reflective writing allows the researcher to reach new and rich understandings of the data, but also warns of over-indulging the self if these reflections are relied upon too heavily. It seems, therefore, that there is a balance to be struck in incorporating the reflective journal into the analytic process. The keeping of a reflective journal is a helpful way to adhere to standards of rigour in qualitative research, whereby the researcher aims to be transparent about the process of interpretation and offer critical self-reflection throughout the research process (Yardley, 2000).

## Interpretative Phenomenological Analysis (IPA)

### What is IPA?

Interpretative Phenomenological Analysis (Smith & Osborn, 2008) is a specific form of qualitative analysis, which offers a systematic approach to the interpretation of first-person accounts. It draws on symbolic interactionism; concerning how individuals construct meaning within both their social and personal world (Shinebourne, 2011). The aim is to for the researcher to immerse themselves in the participant's world in order to understand the first-person perspective from the third-person position, so far as is possible. This is thought to be particularly suited to health and social research that aims to explore how individuals make sense of their world, such that clinical practice is better informed (Smith & Eatough, 2007).

### Theoretical Underpinnings and Epistemological Framework

IPA was first introduced in the mid-1990s with the argument that psychology could and should be both experimental and experiential (Shinebourne, 2011). IPA draws on theoretical ideas from hermeneutics, phenomenology and idiography.

#### Phenomenology

Phenomenology is the study of human experience and phenomenological research is concerned with detailed examination of the participant's lifeworld (Smith & Osborn, 2008). Early ideas from the philosopher Husserl underpin the phenomenological aspect of IPA. Husserl coined the term *phenomenological attitude*, which involves stepping back from the *natural attitude* (whereby one is unreflectively experiencing a taken for granted world) and entering into a more reflexive stance that allows for examination of everyday experience (Shinebourne, 2011). Smith, Flowers and Larkin (2009) describe that in adopting the phenomenological attitude, "we turn our gaze from, for example, objects in the world, and direct it inward, towards our perception of those objects" (p. 12). Husserl believed that by bracketing our own assumptions (thus, suspending the natural attitude) it is possible to access the core features of phenomena, which transcend the context in which it is experienced. This can then illuminate a given experience for others.

As a philosopher, Husserl focused on applying the phenomenological attitude to his own life experiences. IPA research develops this idea by adopting this same phenomenological attitude in systematically reflecting on the everyday experience of research participants (Smith et al., 2009). The authors note how the experience that the research participant is reflecting on can be first-order activity (their interpretation of direct experience with an entity), or second-order mental and affective responses to the first order activity (cognitive processes such as remembering, regretting, desiring). What is key is that this is always experience *of something* – for example *remembering of something*,

or *regretting something*. IPA is interested in exploring the relationship between an entity, and the individual's consciousness of it; thus, what it *means* to them.

This phenomenological attitude also lends itself towards humanistic principles and values; understanding what the participants say to be their "truth" in terms of how they come to perceive the world (Finlay, 2011). This encourages a stance of non-judgment, acceptance and empathy from the researcher.

### **Hermeneutics**

IPA takes an interpretivist approach, which posits that in order to understand the experience, context and meaning that has shaped the individual's truth, we must talk to them and explore their world. This is where IPA draws from theory of interpretation, known as hermeneutics.

Philosophers such as Heidegger and Merleau-Ponty argued that it is not possible to make Husserl's reduction to the phenomenological attitude, because our observations are always made through our own lens of experience, context and meaning (Shinebourne, 2011). This is seen to be a fundamental aspect of what it is to be human; we seek to understand experience by assigning meaning, and we can only do this by drawing on our preconceptions from personal experience and context. These philosophers therefore argued that what can be offered is an *interpretation* of experience.

This idea underlies the concept of the double hermeneutic in IPA, drawing attention to two key processes: a) the way in which the individual makes sense of their experiences, and b) the way in which the researcher makes sense of how the individual is making sense of their experiences (Smith & Eatough, 2007). The IPA researcher engages with the participant's personal account to understand their experience of the phenomena; but in order to do this, they need to be able to identify and reflect upon their own experiences, preconceptions and assumptions. A suggestion is to "bridle" preconceptions as opposed to attempting to bracket them off completely (Finlay, 2011); preconceptions are reigned in so that they do not influence the research in an unconscious way.

### **Idiography**

Given that the IPA researcher aims to understand a particular person's relationship to a given phenomenon, in a particular context, at a particular time, it can be considered an idiographic approach. It is concerned with detailed case-by-case analysis, rather than a nomothetic mode of inquiry which seeks to make generalizations at group level (Smith & Osborn, 2008). The analytic process can move from the examination of one single case at a time, to more general claims, but these will be located in the particular and therefore developed cautiously (Smith et al., 2009). The lead researcher of this study is concerned

with each particular participant's experience of forming and sharing their recovery story, rather than general or universal concepts about storytelling in mental health.

### **The Lead Researcher's Theoretical Framework**

KN reflected on her understanding of the IPA methodology in the reflective journal:

As I see it, the interpretative phenomenological approach is not so concerned with whether one can discover an absolute truth about a phenomenon; rather, it is concerned with understanding what that experience means to the individual, through the eyes of the researcher. Therefore, what I am seeking to "know" is what the experience of constructing and sharing recovery narratives is like for each individual. I am not concerned with making generalised statements about the pros/cons of the TMS course. Rather, I am interested in understanding how each individual I interview has experienced the course. It may be that there is some consensus amongst participants, but it may be that the experience is very individual. Looking for any patterns across the data set will be secondary to understanding each individual's experience. (Reflective journal entry, 02.11.15).

KN has approached this research from an interpretivist-phenomenological stance; concerned with learning what the experience of forming and sharing a recovery story means to individuals, rather than whether it is possible to discover an absolute truth about this experience. KN's ontological stance steers towards relativism; believing that knowledge cannot be purely objective, but is always shaped by the context and perspective of those who create it.

## **Method**

### **Ethical Approval**

The initial research proposal was reviewed by the Inspire service user panel within Norfolk and Suffolk NHS Foundation Trust and advice incorporated, before full ethical approval being granted by North West – Liverpool Central Research and Ethics Committee (REC 16/NW/0148, Appendix B).

### **Study Design**

Interviews were chosen as the data collection method. This approach is advocated by Patton (2002) as a way to gather the individual's story and discover their perspective; thus fitting with this project's aim of understanding what the experience of forming and sharing a recovery story means to the individual. It was felt that this is best done on a one-to-one basis as opposed to focus groups, to enable each individual to focus totally on their own experience and to share both the positive and negative aspects of this.

Literature on the use of interviews as a data collection method advises that the richness of data elicited at interview is largely dependent on the skill of the interviewer (Newton, 2010). KN has limited experience in conducting research interviews, but greater experience of conducting interviews in a clinical context. This level of expertise was considered when deciding on how structured the interviews should be. Semi-structured interviews were chosen after considering the strengths and weaknesses of each approach, as outlined in Table 4.1 (adapted from Patton, 2002).

Table 4.1

*Strengths and weaknesses of unstructured, semi-structured and structured interviews*

<b>Interview type</b>	<b>Features/uses</b>	<b>Strengths</b>	<b>Weaknesses</b>
Informal conversational interview (unstructured)	Questions and topics are not pre-determined. Questions emerge from natural conversation with the participant.  (Particularly useful when there is opportunity for multiple interviews per participant.)	The interview can be tailored to the individual and their circumstances.	Less systematic. Topics and questions may vary greatly from one participant to the next. Salient topics may be missed.
Interview guide approach (semi-structured)	The interviewer follows a guide that outlines topics to be covered. Wording/ordering of questions is not pre-determined.	Interviews are more systematic by covering the desired topics; whilst the interviewer can still hold a conversational style and follow the interviewee's lead.	Salient topics could still be missed and flexibility in sequencing/wording of questions can make it difficult to compare responses across participants.
Standardized open-ended interview (structured)	The exact wording and sequencing of questions is pre-determined.	All interviewees are asked the same questions in the same order, such that comparability across responses is increased. Reduces interviewer effects and ensures all pre-determined topics are covered.	Lack of flexibility in terms of responding to individuals and their circumstances. Factors that are important to the individual may be missed due to the pre-conceived ideas of the researcher.

Given that IPA is more concerned with exploring the participant's individual lifeworld than producing generalizable findings, a degree of flexibility in the interview schedule seemed important. Equally, however, the time constraints of the project and the relatively novice skill of the lead researcher required some level of structure to the interview. Taking these factors into consideration, this study adopted the *interview guide approach*. This ensured that the interviews remained focused in order to make the best use of time. However, the interviewer was able to use the guide spontaneously within the interviews, such that a conversational style was maintained and a greater richness of data was achieved through the participant being the experiential expert (Smith & Eatough, 2007). Flexibility in the sequencing and wording of questions, alongside the option of pursuing the natural direction of conversation with additional questions, is acknowledged to be conducive to hearing parts of the participants' voice that might not have otherwise been expressed (Newton, 2010).

### **Lead Researcher's Attendance on the TMS Course**

Prior to any data collection, the lead researcher attended the TMS course herself. This was felt to be fitting with the aim of understanding the participants' world in IPA, and the collection of additional contextual data enabled greater sensitivity to the participant's context (Yardley, 2000). Lamb (2013) highlights that this does not mean the researcher claims to be uncovering "real truths" about the phenomenon; but rather it facilitates shared experience of it, which can create connection between interviewer and interviewee and lead to richer discussion. No participants were recruited from the course that KN attended because it was felt that this could have an unhelpful impact on the interview dynamic. Smith et al. (2009) caution that too heavy a focus on experience that is shared between interviewer and interviewee can shift the focus of the interview away from entering the participant's lifeworld, and instead make it more comparative.

### **Development of the Interview Guide**

An interview guide was designed with key topics to be covered. This was informed by KN's personal experience of attending the course and subsequent reflective journal entries, in addition to discussion with research supervisors about potential avenues of interest. This initial draft was developed further in a focus group with recovery college students, which aimed to ensure that the research is relevant to those who are at the centre of the service, and to identify any difficulties or sensitive areas that might be encountered (Smith & Osborn, 2008). Co-production is highly valued within the recovery model, and within the design of research and evaluation projects specifically (Corrigan, 2014; Doughty & Tse, 2011).

## **Focus group 1**

Of the three participants who attended the focus group, two were tutors of the TMS course, who had attended the course themselves prior to becoming tutors. One participant was a previous student of the course. Three other previous course students were invited to attend but were either unavailable or did not respond.

Participants were provided with the Focus Group 1 Participant Information Sheet (Appendix C) at least 48 hours prior to the focus group and were given the opportunity to ask KN questions beforehand. Written consent to participate (Appendix D) was obtained on the day of the focus group, prior to any discussions taking place. Participants were reminded that participation was voluntary and that they could withdraw at any point. It was reiterated that the purpose of the focus group was for patient-participant involvement in the design of the interview guide and would not be providing any actual data to be included in the analysis.

The focus group lasted for 45 minutes in total. KN facilitated a discussion that ran through the interview guide and explored participants' responses to the proposed questions. KN made notes on the discussions held. Participants reflected on the language used, issues of sensitivity relating to their own emotional responses to the questions, and issues of relevance. Overall, participants of the focus group felt the interview guide was interesting and would encourage a meaningful process of reflection for interview participants. There were, however, some suggested amendments. One key suggestion was for KN to disclose her own experience of attending the TMS course at the start of the interview. It was felt that this would increase mutuality and reduce power imbalance; thus facilitating richer disclosure. The sharing of lived experience is encouraged within the recovery college environment, and focus group participants advised that they would feel more at ease knowing this. KN therefore included a statement of her experience of the course, within the introduction to the interview. Other suggestions and subsequent amendments are detailed in Appendix E.

The final interview guide can be seen in Appendix F. The guide begins with a standardised introduction to the interview because it is advocated that providing clarity regarding the interview's purpose and topic will help the interviewee to feel at ease, and may subsequently reduce demand characteristics that would otherwise lead the participant to respond in particular ways due to an unhelpful perception of what the situation requires from them (Newton, 2010).

## **Participants**

A sample size of between six and eight participants is advocated as a suitable number for IPA studies (Smith & Eatough, 2007), ensuring there is enough data for in-depth analysis

of personal accounts and noting similarities and differences across the data set, but not so much that details are neglected.

### **Recruitment**

Participants were recruited from Recovery College East (RCE), which sits within Cambridgeshire and Peterborough NHS Foundation Trust and has been offering courses since 2013. RCE has bases in both Cambridgeshire and Peterborough, and courses are open to anyone over the age of 18 who has received or is receiving support from secondary services, as well as their carers and Trust staff members. The TMS course has grown somewhat organically within the college and aims to equip people to tell their own recovery story. The TMS course is novel in that it brings together both the *forming* (sessions 1-3) and the *sharing* (session 4) of one's recovery story, supporting individuals to make sense of what has happened to them and celebrate who they are, with others. All participants were individuals who had completed the TMS course within the past year.

The lead researcher had originally planned to attend the penultimate session of each TMS course to promote the study, and return in the final session to obtain consent. At the time of being granted ethical approval, however, the TMS courses for the academic year had finished. The back-up plan outlined in the protocol was therefore utilised, whereby RCE had obtained students' consent to be contacted regarding research opportunities, and the lead researcher made initial contact by phone or email, depending on the individual's indicated preference. Individuals who had attended as carers or Trust staff members would have been excluded from the study, due to this project's focus on storytelling for individuals who have a mental health problem. However, none of the students who attended the TMS courses that were recruited from were carers or Trust staff members, so this factor was not an issue.

A total of eight participants were recruited to the study. Two others were approached within the recruitment process, but one did not respond and the other chose not to take part. All participants were provided with the Interview Participant Information Sheet (Appendix G); and upon indication that they would like to take part, an interview was arranged. No participants dropped out after agreeing to take part.

### **Demographic information**

Participants of the initial focus group advised not to ask interview participants to disclose their diagnosis, given that they are not required to disclose this when attending courses unless they choose to. As such, demographic information collected was kept to: age, gender, ethnic background and amount of time involved with the recovery college.

Of the eight participants, four were male and four were female. The youngest person was aged 29 and the oldest was aged 71. Average age was 51 years. Seven participants

described their ethnic background as “White British”, and one as “Mixed British and Asian”. Their duration of involvement with the recovery college ranged from six months to three years. All participants were fluent in English and displayed the capacity to consent to and take part in the interview process.

## **Data Collection**

### **Interview process**

It is recommended that interviews take place in an environment that is familiar to the interviewee, as well as safe and free from interruptions (Smith et al., 2009). The interviews therefore took place at the RCE base that was most convenient for the participant to get to. The lead researcher liaised with recovery college staff in advance to secure a private room (conforming to principles of confidentiality) and met with each interview participant individually. Each participant was briefed on the interview process and reminded of all details in the participant information sheet, on arrival. They were given the opportunity to ask any questions, and written consent (Appendix H) to take part in the interview was obtained at this point. Interviews ranged from 50 minutes, to 74 minutes in duration. The average length of interview was 62.5 minutes. Interviews were audio recorded and transferred to an encrypted memory stick at the earliest opportunity following the interview.

### **Interview technique**

The lead researcher gave careful consideration to drawing upon her clinical interviewing skills, whilst being mindful of adapting interview technique to the research environment. Finlay (2011) comments on the centrality of using the body in understanding lived experience, just as a therapist would within the therapy session. This might include bodily responses that the individual reports to experience during the interview, as well as the interviewer’s own bodily experiences in terms of picking up on emotional transference. Appendix I provides an example of this within Sarah’s interview transcript and a subsequent reflective journal entry. In this interview, KN felt transference of Sarah’s anxiety and Sarah reported her “mind going blank”. In the excerpt in Appendix I, KN shares some of her own experience of the TMS course in an attempt to help Sarah to feel at ease and to feel able to re-engage with the interview. Throughout the data collection process, KN used the reflective journal to document transference processes observed within the interviews; such that later interpretations were informed not only by the content of what the participant was saying, but also the process by which this content was communicated. Where appropriate, KN commented on emotional shifts in-vivo, within the interview interaction, as these moments can provide further opportunity to explore the participants’ world by understanding their emotional responses to the questions being asked by the interviewer.

## **Ethical Issues**

### **Informed consent**

All participants were advised that participation was on an opt-in basis and that they had the right to withdraw from the study at any point, up until two weeks after their interview had taken place (after which point the data would start to be transcribed and analysed). Participants were provided with full details of the study via the participant information sheet (Appendix G) and were given opportunity to ask the lead researcher questions.

### **Risks, burdens and benefits**

Although it was hoped that the interview would provide a safe and enjoyable space for reflection, participants were warned of its potential to be emotionally demanding. The lead researcher monitored each participant's wellbeing throughout the interview and checked in with each participant immediately after; giving the opportunity to reflect on the interview experience. No participants reported a level of distress that required additional support.

The lead researcher consulted with each participant about their ability to get to the interview location. No participants had difficulty with this because they were used to attending RCE for courses. Participants were thanked for the time that they gave to the research. The lead researcher collected each participant's preferred method of feedback (email, letter or phone) and will disseminate findings to them at the appropriate time.

### **Researcher wellbeing**

The lead researcher followed lone working policy in terms of meeting participants at the NHS RCE bases within working hours, signing in/out accordingly, and ensuring that another member of staff was in the building at the time of interviews. Participants were able to contact the lead researcher's research mobile and university email address, but did not have access to any personal contact information.

### **Confidentiality**

Participants were advised of the NHS Code of Confidentiality; that all information disclosed at interview would remain confidential unless there was indication of risk of harm to self or others. No risk or potential harms were disclosed by any participant during the study.

The Data Protection Act (1998) was adhered to at all times. All data was anonymised by assigning each participant a pseudonym, to be used instead of their name. All data reviewed by research supervisors or peers was in full anonymised format. All required transfer of electronic data was by encrypted media. All electronic data was stored on encrypted media. Hard copies of participant consent forms were stored in a locked filing

cabinet at the University of East Anglia and only accessed by the lead researcher or research supervisors. After ten years, all data will be destroyed.

## **Transcribing**

All interviews were transcribed verbatim by the lead researcher. The level of detail included all features of talk that are important at the semantic level, including features such as significant pauses, stress and emphasis, and false starts (Smith & Osborn, 2008), with the aim of providing an accurate semantic record of all words spoken by everyone who was there (Smith et al., 2009). An example excerpt of transcript from Lisa's interview (annotated with initial noting and emergent themes) is provided in Appendix J.

## **Analysis**

The lead researcher followed the analytic framework offered by Smith et al. (2009). The authors acknowledge that although IPA provides a stance rather than a prescriptive method for the interpretation of data, it can be helpful for novice IPA researchers to follow an established process in order to give a systematic structure that will increase rigour. The stages to analysis are:

1. Reading and re-reading the transcript – immersing oneself in the original data. KN combined this with listening back to interview recordings to ensure a felt sense of the interview dynamics.
2. Initial noting – including descriptive (focus on *content* of what is said), linguistic (focus on *how* it is said through language) and conceptual (engaging at a more curious/interrogative level) comments.
3. Developing emergent themes for that particular case.
4. Searching for connections across emergent themes for that particular case. (Appendix K provides an example superordinate themes table for Lisa).
5. Moving to the next case and repeating the process.
6. Looking for patterns across cases (leading on to the development of superordinate themes for the group).

The analytic process draws attention to *how* the researcher interprets the participant's account. The notion of the hermeneutic circle is central here, whereby "to understand any given part, you look to the whole; to understand the whole, you look to the parts" (Smith et al., 2009, p. 28). Immersing herself in the participant's data allowed the lead researcher to move between different levels of interpretation; for example, from a participant's single word or sentence, to how this sits within interpretation of the whole transcript, and then back to single extracts. This provides an iterative process to the interpretations.

The lead researcher followed guidance in the IPA literature (Smith & Eatough, 2007) to approach the analysis from two interpretative angles: empathic hermeneutics (aiming to

see the experience from the participant's viewpoint) and critical hermeneutics (standing back and asking critical questions in order to reach a new understanding of what is going on).

Pen portraits for each participant are provided in Appendix L, to offer the reader a summary of each participant's account and an overall sense of their individual experience of storytelling.

The lead researcher has made use of support systems within the academic environment, to inform and reflect upon decision-making throughout the research process. Regular attendance at a qualitative research forum has provided peer discussion, support and advice. The supervisory team has offered perspectives from psychology and sociology. Supervisors and peers have engaged in joint coding sessions. There was no attempt to accomplish inter-rater reliability, given that this would assume an objective truth about the experience of forming and sharing a recovery narrative, which does not fit with the lead researcher's ontological and epistemological stance. However, joint coding has benefited the rigour of the study because identified variations in coding amongst raters has supported the lead researcher to become more aware of how her own interpretative framework is influencing her interpretations of data; thus, allowing her to become more reflexive and transparent (Yardley, 2000).

### **Focus group 2**

A second focus group was held with students of RCE to feed back on superordinate themes that were emerging from the analysis, and reflect on how this fits with their lived experience. Three people participated, two of whom were tutors of the TMS course and had attended focus group 1. One participant was a previous student of the course. Three other previous course students were invited to attend but one did not respond, one was unavailable last minute, and one did not turn up. The same process regarding participant information (Appendix M) and informed consent (Appendix D) was followed, as for focus group one. The focus group lasted for 60 minutes in total.

Interview participants were not asked to validate superordinate themes. It is felt that this can be counter-productive to IPA methodology (Chambers et al., 2015); interview participants may expect to see more of their personal story in the data, whereas the IPA researcher is presenting an amalgamation of responses from a particular point in time. The focus group participants were invited to compare and contrast their own experience with the lead researcher's interpretations that were emerging from the analysis. Overall, they reported that the themes made sense to them and fit well with their own experiences. This was a helpful opportunity for reflection and key points of the discussion are outlined in Appendix N.

The lead researcher brought focus group discussions into the shaping of themes where appropriate. One example is with the naming of theme five. KN had initially called this “a novel performance” given that interview participants themselves described their storytelling experience as a “performance” and likened it to being “on stage”. However, focus group participants reflected that this made the experience sound disingenuous and lacking in authenticity, when actually it was highly meaningful for them. KN reflected on her interpretation of this theme and felt that the core aspect of this theme was the “novelty” of storytelling, and appreciated that the connotations raised by the reader’s interpretation of the word “performance” may give a misleading impression of what this theme entails. The theme title was amended to “a novel opportunity”, in accordance with these reflections.

### **Write-up and Dissemination**

The results of the study have been written up in the form of an empirical paper, as part of the lead researcher’s thesis portfolio. Participant data and reflective journal entries are presented throughout to provide an audit trail whereby interpretations are grounded in examples from the research process (Lamb, 2013). This allows the reader to follow the lead researcher’s interpretations, and also consider their own (Elliott et al., 1999). This is fitting with the relativist ontological stance of this paper; whereby the researcher is offering a clear story of how they came to interpret the data, rather than claiming that there is any kind of absolute truth to be discovered in the data. It also helps in adhering to Yardley’s (2000) criteria of transparency in qualitative research, whereby the reader is able to follow the research journey with clarity.

Findings will be fed back to Recovery College East in the first instance, and all participants offered feedback via their preferred method of contact. Findings will then be disseminated more widely throughout the recovery college network and NHS recovery network, and submitted for publication to a peer-reviewed journal. It is hoped that there will be opportunities to share findings at recovery-based conferences and throughout the ImROC network.

## Chapter 5 – Discussion and Critical Evaluation

This chapter provides a discussion and critical evaluation for the whole portfolio. It begins with the lead researcher's reflections on the research process; before expanding on the discussion of findings of the empirical paper, and positioning these within the findings of the systematic review, the wider literature and relevant theory. Clinical implications are discussed, as well as strengths and weaknesses of the project, and suggestions for further research into storytelling in mental health.

### Reflections from the Lead Researcher

The research process has led to the identification of some common themes across participants' accounts, in terms of how storytelling impacts upon and is experienced by individuals who use it. What has struck KN throughout the process, however, is the strong sense of individuality within this commonality. The specifics of each person's journey were unique to them, and the story they chose to tell was a reflection of where they were in their personal recovery at that particular time. This meant that for some, the *forming* of their story was the most helpful aspect; making sense of experiences and developing their understanding of themselves. For others, the *telling* of their story held the greatest meaning; connecting to others through sharing and experiencing catharsis from "getting it all out". For some, the course was their first experience of telling their story, whereas others described various experiences of personal storytelling (in other therapeutic contexts, or on other courses). Those who drew on previous experiences acknowledged that the experience of storytelling changes over time.

The storytelling experience therefore seemed adaptable to being whatever the individual needed it to be, for them, at that particular point in their journey. Throughout data collection and analysis, KN reflected on how her own understanding of what a recovery story "should" look like in order to be meaningful and helpful to the individual, was being shaped through her interactions with participants. Some of this occurred through attending the Telling My Story (TMS) course herself. However, it wasn't until KN stepped back from her own experience of storytelling, and absorbed herself in each participants' world through the IPA approach, that she started to understand more precisely how the storytelling experience varies significantly between individuals. The excerpts below provide some examples of this from KN's reflective journal:

The medium that she chose to tell her story was quite different to mine, and this has altered my thinking on what a recovery story "should" be. There are very few words in hers, and it's more about ordering things and feeling ok to acknowledge/talk about her difficulties with others. I need to be mindful of individual perceptions of what "story" means to each person. (Reflective journal entry, following interview with Sarah.)

This one struck me as different again, in that the key benefit of the course for him was the *making sense* of his own experiences, and having the time/space/structure to do this, and to then share it in an environment whereby he felt safe to do so, and felt validated. It's not something he wants to share in other contexts, but it has helped him a lot in terms of self-awareness, which is then starting to help him to manage things better in other contexts. (Reflective journal entry, following interview with Mark.)

His way of telling his story contrasts with my own ideas about what a recovery story "should" involve, in order to be effective. I think it requires the individual to *really* go there, to engage with the content, get in touch with their emotions, make good sense of it. But actually that's just what would work for me. For some people, just naming their difficulties is huge, and to delve too deeply too soon is painful – it might not be something they ever want to do. (Reflective journal entry, following interview with George.)

Following other people's interpretations of what a recovery story is, has shaped KN's own framework about what a recovery story can be. As a result, attempts have been made to retain a sense of the individuality of the storytelling experience throughout the results section of the empirical paper, in line with the above reflections and the idiographic stance of IPA (Smith, Flowers & Larkin, 2009).

### **Further Discussion of Findings**

Consistent with other qualitative research into storytelling experiences (Gunnarsson, Peterson, Leufstadius, Jansson & Eklund, 2010; Roe, Hasson-Ohayon, Derhi, Yanos & Lysaker, 2010), the empirical paper results suggested that storytelling is a highly emotional experience and involves some form of emotional catharsis for most. Participants reported benefit from being able to express things that they had previously kept hidden or had avoided. The wider psychological literature highlights that suppression and avoidance of emotions within oneself can lead to psychological distress (Sloan, 2010), and can be associated with many mental health difficulties such as anxiety, depression, eating disorders and substance-related disorders (Aldao, Nolen-Hoeksema & Schweizer, 2010). In telling their story, individuals may be exposing themselves to previously hidden or repressed parts of self, which seems to alleviate distress.

We can look to some of the literature on trauma work to understand this process further. Narrative Exposure Therapy (NET; Schauer, Neuner & Elbert, 2011), for example, is a treatment approach that requires the individual to tell their life story and to repeatedly talk about past traumatic events in detail, whilst re-experiencing all emotions, cognitions and

sensory elements associated with each event. Exposure to the traumatic event allows for habituation of the emotional response over time, such that anxiety symptoms reduce. The therapist then guides the individual to reconstruct their autobiographical memory and develop a more consistent narrative. This is thought to help the individual gain a sense of control and integration, and there is some evidence to suggest its effectiveness as a treatment intervention (Gwozdziwycz & Mehl-Madrona, 2013).

It is possible that a similar process occurs in storytelling. Although on the TMS course there is a less formal form of exposure than that seen in NET, telling one's story in this context still requires the individual to face hidden parts of the self. Participants may begin to process the associated emotions, which may involve habituation, and as such their distress begins to decrease. The process of narrative reconstruction is not addressed formally on the TMS course, as it is in NET. However, NET advocates integrating positive life experiences within the reconstructed narrative (Schauer et al., 2011), which is also encouraged on TMS and reported as beneficial by a number of participants in terms of aiding their management of the emotional experience (theme one).

We saw in theme three how all participants engaged in some kind of reflection and sense-making through constructing their story, which allowed them to gain a more integrated sense of self. This is consistent with other findings that storytelling facilitates gaining a sense of coherence (Gunnarsson et al., 2010), and strengthens the systematic review finding that *reflection* and *reframing* are common components across storytelling interventions of varying formats. The systematic review highlighted that some storytelling interventions formally address the reframing of previously held beliefs – for example, using cognitive restructuring in Narrative Enhancement and Cognitive Therapy (Yanos, Roe & Lysaker, 2011) – whereas others facilitate reframing through psychoeducation or guided questioning from the facilitator, which is perhaps closer to what happens on the TMS course. It seems, therefore, that reframing of past beliefs is a process that occurs through storytelling to some degree, regardless of whether the intervention formally addresses narrative reconstruction.

It is interesting to consider how the narrative demands of the course (putting experiences into a story format, positive reframing of past difficulties) shaped the stories that participants told about themselves. Through adopting the common structural components of a story (Plummer, 1995), participants were able to develop a new way of telling about themselves that led to a more positive self-identity (Bruner, 1987). Although imposed by the course format, all participants made reference to how this process of organising distressing experiences in story format provided some sense of structure that allowed for new perspectives to emerge and made the emotional impact more manageable (Pennebaker & Seagal, 1999). Stories were commonly referred to as some form of

ongoing journey, perhaps reinforced by this being a popular concept within the recovery environment. For some, talking about their experiences in story format was the first time they had fully acknowledged the suffering within their plot (this was perhaps previously avoided or repressed), and for others it was particularly important to work on including a sense of overcoming adversity (for example, to move on from feeling stuck and to foster hope for the future).

We can turn to literature on the process of externalising (White & Epston, 1990) to further understand the emotional and cathartic benefits achieved through storytelling. This is a concept developed within narrative therapy, viewing “problems as being things and not as part of people” (Morgan, 2002, p. 88). Narrative therapy acknowledges that individuals tend to locate problems within themselves, which leads to *problem-saturated* self-narratives (White & Epston, 1990). A narrative therapist will support the individual to externalise the problem, positioning it outside of themselves such that they can gain distance from it in order to be able to consider new ways of talking about the problem and of managing it (Morgan, 2002).

The empirical paper findings suggest that storytelling is a form of externalising distress, allowing the teller to gain distance from their problems, such that they were no longer defined by their mental health difficulty. Participants gave physical embodiment to internal experiences in a variety of ways (through written/spoken prose, song, photography, physical symbolic objects such as the yoyo), allowing them to bring something that was difficult to conceptualise or verbalise into the real world in tangible form. Some participants’ externalisation involved metaphor; a tool encouraged within psychological therapy to aid a client in expressing themselves. Loue (2008) writes “like the sugar that helps the medicine go down, the use of metaphor helps clients tolerate the unpleasantness that they may experience on their journeys to self-knowledge” (p. 8). She goes on to discuss that metaphor can create a safe space for the individual to bring their problematic internal experience into the relatable world. This links to theme two: perhaps metaphor supports the individual in feeling safe to disclose the more problematic parts of self.

The literature on narrative approaches discusses personal stories as socially constructed phenomena, their content being shaped by the social context in which they are told (McAdams, 2008). As such, we can never be sure that the story an individual chooses to tell within a certain context is directly representative of their internal experiences. Indeed, we saw in the empirical paper findings that what the individual chooses to disclose is mediated by how safe they feel and what they are ready for in terms of their recovery. The story that a person tells can therefore be fluid across time and context (Drumm, 2013). A helpful outcome of this research, however, is that we now know what can be done to

facilitate an environment that allows the individual to share their story in a way that feels right for them, at that particular time, such that the *process* of telling their story can be meaningful, regardless of the *content* that they choose to share. Firstly, it is vital that the individual feels safe to disclose (in terms of being accepted rather than rejected); and secondly, the individual needs to be given the time and freedom to express their story in the way that they want to, with the idea of being able to tell their *whole* story emerging as particularly important.

The empirical paper findings suggest that telling one's story in a way that feels meaningful can lead to an increased sense of agency. This supports the systematic review finding that gaining agency is a common component across storytelling interventions, given that the forming and sharing of a story requires the teller to take an active role. In the systematic review, however, this finding linked to a sense of mastery obtained from forming and sharing the story, whereas the empirical paper participants spoke less of this. Rather, the idea of increased agency within the empirical paper findings seemed to relate more closely to the individual reconnecting with their personal values through telling their story, and crucially gaining the confidence to live by these after being both inspired and validated by others. This indicates that agency doesn't just develop from within; others in the group impacted on the individual's level of agency also. Perhaps acceptance and validation from others gives the individual "permission" to resume an active role and re-engage with life.

We saw in the systematic review that most – although not all – mental health interventions that incorporate storytelling components tend to be offered in group format, creating an environment of shared experience and an audience to hear the stories. Roe et al.'s (2010) paper refers to some reported benefits of the group format of NECT, in terms of: normalising mental health difficulties through connection to others; enhancing hope from seeing what others with a mental health problem have achieved; providing a safe space to test out disclosure; and the presence of an audience to assist in the integration of "before illness self" and "illness self". The findings of the empirical paper suggest that the group format of TMS also contributes a lot to the individual's experience of storytelling, and we can look to the wider psychological literature to understand why this might be.

As acknowledged within the literature on narrative approaches, stories are told within social relationships, rendering the self and indeed the story (as a representation of self) open to shaping according to context and response from others (McAdams, 2008; McLean, Pasupathi & Pals, 2007). Across the themes of the empirical paper (and particularly within themes two and four) we saw the importance of relational processes (acceptance, validation, connection) in shaping the individual's sense of their own identity and understanding of themselves. We can draw upon the literature on attachment theory

to understand this further. Links to theories on attachment were noted by KN at the analytic coding stage, and considered within the reflective journal:

I'm finding myself really tuning in to language and concepts around attachment. There are a lot of themes emerging around the course offering a more positive experience of safety, warmth, validation and acceptance – and reciprocation within this. I'm finding myself making assumptions that this is probably quite a different experience to the participants' earlier experiences, or experiences of attachment in their personal lives, given that there are known links between disordered attachment and mental health problems. As a psychologist, I value understanding an individual's early attachment experiences and making sense of how these may be influencing patterns of relating and being in later life – so I'm aware that I'm interpreting these interviews from that lens. Equally, however, I feel that this is coming directly from the data itself. Now that I've brought my "attachment lens" into awareness, I'll need to be mindful to ensure that further interpretations around this are coming directly from the participants' data, as I don't want to be bringing in potentially relevant theories until a later stage – based on IPA advice (Smith, Flowers & Larkin, 2009). (Reflective journal entry, 17.01.17).

KN took care to bracket these ideas (Finlay, 2011) and stick close to the data and to the language used by the participants themselves throughout the analytic process and naming of themes. However, it is now appropriate to discuss how the findings might relate to attachment theory, given that the purpose of the discussion chapter in IPA is to situate findings within the context of the wider literature (Smith, Flowers & Larkin, 2009).

The language used by participants throughout their interviews frequently referred to ideas of "warmth", "safety", "connectedness" or "nurture" provided by the TMS course environment. This links closely to the conditions required for establishing a *secure base* (Bowlby, 1988); a safe place from which the individual can explore the world with confidence. Bowlby's attachment theory is rooted in child development, but he acknowledges that the need for a secure base continues into adulthood, providing the adult with the comfort and reassurance that they need to be able to operate confidently in the world. We see in theme two that safety was deemed a necessary prerequisite to disclosure of one's story, and the TMS course appeared to provide this for most participants.

Roe et al. (2010) suggest that it is the environment of mutual storytelling that makes it safe to take risks in testing out disclosure. The shared experience of mental health challenges means that the response of others is likely to be one of acceptance, rather than rejection, because others have been through similar experiences. Again, we can draw parallels to Bowlby's (1969) ideas of attachment involving "psychological

connectedness between human beings” (p. 194), something that is perhaps facilitated by shared experience of having a mental health problem. Environments of mutual storytelling therefore provide opportunity for receiving a response to disclosure that is different to what individuals might have experienced elsewhere. This was certainly described by students of the TMS course within this study; and the systematic review findings indicated that validation from others was a common component that was valued across storytelling interventions in general. Safety and belonging are two innate psychological needs commonly highlighted within humanistic psychology (Maslow, 1943), so it is perhaps understandable that they are emerging as important.

We can look to Bion’s (1959; cited in Finlay, 2015) theory of containment to further enlighten the experience of feeling accepted and validated by others. Bion’s theory explains how a mother’s role is to receive the child’s distress, hold it, and return it to them in a more palatable form with warmth and acceptance. This allows the child to express themselves, within a safe environment, so that in time they can internalise this process and learn to contain their feelings themselves. In therapeutic environments, the therapist can take on this “container” role for the client, which allows the client to safely think through and understand their emotional experience, and over time develop an ability to contain their own feelings (Finlay, 2015). Bion upheld that social groups can also provide this sense of containment, which is perhaps what we are seeing within the TMS course and other environments of mutual storytelling as indicated in the systematic review.

The findings of the empirical paper highlight an array of relational processes that occur through storytelling, and it may be helpful to draw on object relations theory to understand these further. Object relations theory (Gomez, 1997) is underpinned by the idea that the child internalises their experience of early interactions with their primary caregiver (*other-to-self* patterns of relating); which not only forms a template for how they expect others to treat them in future, but also impacts on how they come to understand and relate to themselves (*self-to-self* patterns of relating), and affects how they relate to others in later relationships (*self-to-other* patterns of relating). Cognitive Analytic Therapy (CAT; Ryle & Kerr, 2002) is a psychological approach that is particularly concerned with attachment and object relations theory. There is a focus on forming a trusting relationship with the therapist that provides a secure base for developing an understanding of relational patterns that are playing out, and to then explore new ways of relating. The therapist relates to the client with empathy and containment (*other-to-self*), which the client can then internalise (*self-to-self*). The client can also test out new ways of relating to another person, through their interactions with the therapist (*self-to-other*), which they can then take to other relationships in their wider life.

It is possible that the group environment of storytelling facilitates similar relational processes. We see in theme four of the empirical paper that storytelling is experienced as a two-way process. In the direction of other-to-self, participants described the feelings of acceptance and validation already discussed. This often contrasted with the more stigmatising or rejecting experiences that many participants described from others in their relationships or interactions outside of the course environment. This new other-to-self experience on the course can therefore offer a new template for how other people might respond. We then saw in theme three how individuals were developing new ways of relating to themselves, which perhaps reflects an internalisation of others' warmth and acceptance, thus allowing the individual to have a kinder and more accepting self-to-self relationship. For some, this translated to greater openness in other relationships, if they felt safe enough. For all participants, there was a desire to reciprocate the warmth and validation that they had received from others. Therefore, we can also see some changes in the self-to-other pattern of relating.

At this point it may be helpful to consider what the findings say about how storytelling might impact upon the individual's overall identity and broader sense of who they are in the world. We can turn to the wider psychological literature regarding self-stigma and shame to consider this further.

Having a mental health problem can significantly impact on an individual's identity, perhaps leading to a sense of a "spoiled identity" due to feeling socially "abnormal" (Goffman, 1963). This may be further emphasised by use of the term "mental illness", as discussed in the introduction to this portfolio, and contributes to the argument to move towards person-first language that avoids presenting a mental health difficulty as an illness or abnormality. Many participants in this research reported to have experienced stigma from others, regarding their mental health difficulty. The literature on stigma in mental health describes how the negative views of society/others can become internalised, such that the individual comes to hold these views about themselves; termed *self-stigma* (Roe et al., 2010). Self-stigma is thought to lead to low self-esteem and low self-efficacy, which in turn contributes to reduced self-worth and a "why try" effect (Corrigan & Rao, 2012).

The emotional core of self-stigma is thought to be shame (Luoma & Platt, 2015), defined as "an intensely painful feeling or experience of believing we are flawed and therefore unworthy of acceptance and belonging" (Brown, 2006, p. 45). There is a growing body of literature that identifies shame as a common experience accompanying a broad range of mental health difficulties (Gilbert, 2009; Gilbert & Choden, 2013; Luoma & Platt, 2015). Interestingly, the themes of the empirical paper suggest that storytelling may provide some of the conditions understood to be necessary for the alleviation of shame.

Shame resilience theory (Brown, 2006) places the experience of shame (which involves feeling trapped, powerless and psychologically isolated) directly opposite to the experience of empathy. It is thought that receiving an empathic response from others regarding a shame experience strengthens feelings of connection, power and freedom.

We can see across the findings that the environment of mutual storytelling fostered feelings of connection with others and normalised experiences that were once considered shameful. This perhaps facilitates a change in how the mental health difficulty is framed; moving away from ideas “illness” or “abnormality” and instead making sense of mental health difficulties as having arisen from particular contexts and in fact being “normal”. This aligns to the focus of third-wave therapies that endeavour to acknowledge suffering as a normal and shared aspect of human experience, and thus something that we can all relate to (Gilbert, 2009; Harris, 2009; Neff, 2003).

In turn, the accepting environment reduced participants’ fear about being devalued and therefore allowed participants to feel safe to acknowledge and disclose their experiences (theme two); actions that are identified as important for the repair of shame (Corrigan & Rao, 2013; Leeming & Boyle, 2013). For some, the experience of receiving empathy and acceptance became internalised, leading to the development of a more accepting and compassionate relationship to oneself (theme three) and the ability to reciprocate with compassion (theme four). This is perhaps comparable to the aim of compassion-focused therapy, an approach that specifically targets the alleviation of shame and self-criticism through the development of compassion towards self and other (Gilbert, 2009; Neff, 2003).

Shame resilience theory argues that it is through this sense of reconnection that individuals are able to overcome shame and regain a sense of power and freedom over their lives (Brown, 2006), which is perhaps what can be seen in the empirical paper findings that relate to re-engagement and the development of a sense of agency through storytelling (theme three). Theme four highlights how hearing another person’s story of recovery can transform the individual’s perception of what it means to have a mental health problem. The individual sees others achieving something that they did not think was possible for someone who has a mental health difficulty, thus inspiring an “if they can do it, I can” attitude. East, Jackson, O’Brien and Peters (2010) describe how we can learn by reflecting on the personal stories of others and that “through this reflection, we can gain understanding and insight into how others have overcome and worked through their adversity and hardship, and how we can incorporate these insights into our lives and experiences” (p. 21). This draws parallels to the concept of *survivor narratives* that are seen across various minority groups (lesbian, gay, victims of rape or abuse), whereby a few key voices “coming out” and speaking against the dominant narrative can initiate a

pattern of “stories breeding stories” because others then feel able to do the same (Plummer, 1995).

On the TMS course, students also see peer tutors who have had their own struggles, progressing with recovery in spite of adversity. There is therefore modelling of finding meaning and purpose, by relatable others, which parallels the concept of peer support in mental health recovery (Repper, 2013). As a result, having a mental health difficulty no longer seems as limiting.

It seems, therefore, that what is provided through the process of storytelling is not a “treatment” for a mental health difficulty (which tends to be sought within the “illness” model of mental health), but rather an experience that begins to address one’s wider sense of who they are in the world, and thus influences how they relate to themselves and others. This is done through providing a platform for meaningful connection to others, where one can regain a more hopeful sense of self that centres on being worthy rather than ashamed. Shame is now acknowledged as a construct that we should be giving greater consideration to within the organisation and delivery of mental health services (Leeming & Boyle, 2013). Perhaps storytelling has a key role to play within this.

The discussion thus far has largely drawn out the ways in which storytelling can be beneficial, which is reflective of how it was predominantly spoken about by participants. However, the findings also showed some evidence of how storytelling can be experienced more negatively – within both the teller and the listener role. We have heard how, when in the teller role, non-identification with the group can inhibit a sense of connection, resulting in holding back from telling the full story (perhaps feeling less safe to disclose) and subsequently missing out on the opportunity for validation from others. McLean et al. (2007) explain how a lack of disclosure of a story that the individual perceives to be socially negative, can have a detrimental impact (in terms of emotions and behaviour) because it fails to be fully integrated into the self. Conversely, being able to voice these stories allows for validation on both a social and personal level, which can then lead to fuller self-integration. Feeling unable to disclose can therefore be detrimental to the individual’s sense of self, keeping them stuck with a sense of shame and needing to hide (Brown, 2006).

The empirical paper findings support what has been acknowledged elsewhere regarding the listener role, which is that hearing a good outcome in another person’s recovery story can sometimes leave an individual feeling discouraged or isolated, should they compare themselves unfavourably (Drumm, 2013; Scottish Recovery Network, 2012). Comparison to others within the group seemed to be a process that all participants were engaging in, and the process of reflection that this can provoke is often described as a helpful opportunity for incorporating others’ insights into one’s own life (East et al., 2010).

However, the findings of the empirical paper alert us to be aware that alongside its potential to be inspiring, storytelling can also be somewhat demoralising for the listener, depending on their individual situation. Investigation of the factors that make this more likely is an important area for further research.

### **Clinical Implications**

Within the empirical paper we saw how storytelling on the TMS course can be a highly meaningful experience for individuals, and one that appears to support the key aspects of recovery as identified by Leamy, Bird, Le Boutillier, Williams and Slade (2011). With this in mind, the TMS course should continue to run in RCE and other recovery colleges may benefit from using the findings of this study to develop similar courses. It will be important to consider how individuals are deemed to be ready for the course, given that the empirical paper highlighted shared storytelling as a potentially isolating experience if the individual is at a stage in their recovery where comparison to others is likely to be unfavourable. Perhaps there is a need for a more formal screening process prior to taking part, and a plan around identifying and supporting individuals in the group who may not be experiencing storytelling in a helpful way, should this happen. It may also be helpful to make it known to students from the start, that storytelling has been found to be a highly individual experience and that some students may wish to come on the course a number of times, given that stories and the experience of telling can change over time.

The findings of the systematic review highlighted some preliminary evidence that storytelling can support recovery in mental health. Internationally, it is approached from a variety of therapeutic orientations, with interventions offered in a range of formats (mostly group but some evidence for one-to-one, peer versus professional led, differing durations of intervention). The empirical paper findings offer further insight into how and why storytelling can be so meaningful to individuals in their recovery. It seems, therefore, that we should be making more use of personal storytelling as a recovery tool within UK mental health services. TMS is one way of utilising storytelling, within a recovery college environment. We heard how individuals benefited from the novelty of TMS in that it provided protected time to focus on both the forming and sharing of one's story, in a way that is meaningful to them. Perhaps storytelling could be introduced as a structured part of mental health interventions, in a way that protects its novelty (in terms of dedicating time to full/free expression of one's story), whilst making it accessible to more people. There could be scope for the wider development of storytelling groups within mental health services, given that this study highlighted the group environment (of shared experience, mutual telling, acceptance and validation) to be an important aspect of the experience, and a factor that facilitated recovery for many participants.

It is also interesting to consider whether storytelling could be developed further within a one-to-one therapeutic context in UK mental health services. This would offer another format for individuals to participate in storytelling, addressing the notion that the group experience of storytelling may not be right for everyone. It is interesting to consider to what extent a one-to-one intervention could retain the helpful aspects of group storytelling that were revealed within the empirical paper (for example, the experience of containment and validation that seemed to be enhanced by mutual telling/shared experience, or the sense of hope/agency that resulted from the two-way process with peers).

One intervention considered within the systematic review, Tree Theme Method (Gunnarsson & Eklund, 2009), shows some promising outcomes for storytelling in a one-to-one therapeutic context as opposed to the group format, and is also one of the two approaches to have explored the impact of the intervention qualitatively (Gunnarsson et al., 2010). Some similar findings were reported in terms of the individual's experience of storytelling: it was an emotionally difficult task, but a cathartic one that allowed for the processing of earlier memories and feelings from a new perspective; story-making led to gaining structure and connecting life events; and individuals experienced a renewed self-image, which led to positive change and increased agency in everyday life. This provides some evidence that one-to-one storytelling with a professional can still have a profound impact on the individual, despite the absence of peers. Of course, the therapist can still offer an experience of validation and acceptance, but what is missing is the sense of connection gained from shared experience and the opportunity for learning from others who are in a similar position. The one-to-one experience appears to focus more on the individual developing their sense of coherence (Gunnarsson et al., 2010), which is understandable given that the entire therapeutic hour is dedicated to just one person's story. It is worth considering whether this one-to-one approach to storytelling is more suitable for some individuals; for example, for Paul in the empirical paper who had a lot of confusion surrounding his own story, and for whom listening to other people's stories was an unhelpful experience. We have seen how some individuals benefit more from the forming of their story, whereas for others the telling is particularly important. The one-to-one format would focus less on the telling, but perhaps this is suitable for some.

So far, we have considered how the findings implicate the future development of storytelling interventions as formal or structured interventions in their own right. On a more informal level, however, mental health professionals are asking service users to share parts of their story all of the time within clinical assessment, and we can use these findings to inform practice in terms of how this is done. We have heard how important it is for individuals to be given the time and freedom to tell their whole story and to express it how they would like to. We have also seen how storytelling empowers agency within the client. Given that recovery involves empowering individuals to become experts in their

own self-care (Perkins et al., 2012), perhaps we should be dedicating more time to personal storytelling when individuals first come to services (or at a point when they feel ready to tell their story) so that they feel empowered from the start. This is certainly the view within the recovery model (Shepherd, Boardman, Rinaldi & Roberts, 2014) and increasingly it is argued that the content of personal stories is an essential component of clinical assessment, in order to reach beyond globalised understanding of a diagnosis or disorder, and instead understand the experience in terms of what it means to that particular individual (Drumm, 2013; Roberts, 2000). The findings of this study also emphasise the impact that storytelling can have on the listener, and therefore support further use of personal stories in services to inspire hope in those who have mental health difficulties, but also to educate the public (and more specifically, supporting the training of healthcare staff) and to continue to challenge stigma (for example, within the growing number of media campaigns that are now being seen).

Moving specifically to the context of psychological therapy, the findings of this study offer a helpful insight into what therapists are asking their clients to do when they come to sessions. As much as storytelling can support recovery, it is also a highly emotional experience and one that can be quite challenging. It is important that we are sensitive to this. Perhaps there is an argument here for therapists to have their own experience of personal therapy, in order to truly relate to the experience of being the client. Some participants highlighted that past efforts to tell their story within a counselling context felt less meaningful and more emotionally draining than on TMS, due to being subjugated by therapist-led questioning. Perhaps we should be giving more time for free expression of the story, rather than leading with formalised questions. The findings also alert us to considering how safe our clients feel to share their story with us in therapy. As therapists, we should be mindful of how storytelling is being experienced by clients within sessions, as a negative experience could impact on engagement and be detrimental to the individual's recovery.

A final implication of these findings is that we can now consider domains that might be important to measure when capturing outcomes of storytelling interventions in future. Suggested domains are self-stigma, self-agency and self-acceptance. Findings of both the empirical paper and the systematic review suggest that storytelling can help the individual to overcome self-stigma through reframing what has happened, internalising validation from others and replacing stigmatising self-beliefs with more positive or hopeful alternatives. Self-agency is consistently reported as a meaningful aspect of the storytelling process and one that can facilitate re-engagement in wider life. Self-acceptance seems to come from acknowledging and processing hidden parts of self, internalising others' validation and having greater compassion towards oneself, through storytelling. Given that storytelling has shown to be a highly individual process, reduction of its impact to singular

domains should be done with caution. However, it is important that services are able to evidence the value of interventions and the findings of this research suggest that measurement of the above domains could go some way towards capturing the impact of storytelling for the individual.

### **Strengths, Limitations, and Considerations for Future Research**

A recognised limitation of interview studies is that the unnatural environment can lead to socially desirable responses from the interviewee. In conducting the interviews, KN was mindful of how her role as researcher could create a power dynamic that conflicts with the recovery college environment, which values a peer rather than profession-led approach. A strength of this study is seen in the efforts KN made to manage this dynamic, embracing opportunities to learn about mental health recovery and to approach the research with a recovery focus.

For example, KN attended training sessions within the Trust to develop her knowledge of the recovery model, and attended the TMS course in order to have personal experience of storytelling, which aided sensitivity to context (Yardley, 2000). KN was transparent with each interviewee by disclosing her personal experience of the course at the start of the interview. It was hoped that this would help to reduce power imbalance, by KN presenting herself as a peer-researcher rather than a professional-researcher, which can be less daunting for the individual and foster a sense of connection that can lead to richer discussion (Lamb, 2013). The interview guide was developed collaboratively with students and tutors of the recovery college, ensuring that it was accessible to participants in terms of the language used and topics raised. KN then drew on her clinical skills throughout the interviews, to make it as warm, empathic and genuine an interaction as possible. Some examples of how this was done include: setting up a comfortable environment where the individual felt in control; maintaining a stance of curiosity; using summarising to show reflective listening and apply each question to the individual's unique experience (Newton, 2010); and responding empathically to mood shifts within the room.

Use of the above steps seemed to facilitate a dataset that was rich in content and provided valuable insight into the storytelling experience. The fact that every superordinate theme had contributions from most (if not all) participants indicates a degree of validity, whilst the analysis retained a sense of individuality and adherence to the idiographic stance of IPA by exploring the individuality within each theme (Smith, Flowers & Larkin, 2009). Nonetheless, we have to bear in mind that interview data is limited to what the individual chooses to share within the context of the interview, and we cannot assume that what they have disclosed is fully representative of their internal experience.

The primary limitation of this study is that we have only heard from those who wanted to speak about their storytelling experience; it could be that those who declined to participate or to give consent to being contacted regarding research opportunities had a more negative experience, which therefore remains hidden. In addition, participants had varying degrees of prior storytelling experience – whether they had attended the TMS course previously, or had told their story in other therapeutic or clinical contexts. Participants were also at varying stages of recovery, which seemed to have some impact on what they were ready to share and how they experienced storytelling. This is difficult to control for without setting more stringent inclusion criteria. Controlling for these factors was perhaps unnecessary for this study; given that the IPA approach takes account of each individual's specific context when interpreting the meaning of an experience, and this has allowed for the identification of past experience and stage of recovery to emerge as potential influencing factors. Future research, however, could explore how the experience varies according to previous experience of storytelling and stage of recovery. This could guide the development of future interventions so that they are better able to meet the individual needs of those who engage.

Further limitations relate to the demographics of the sample. Firstly, the lack of cultural diversity means we cannot assume transferability of the findings to other ethnic backgrounds. George, whose ethnic background was classified as Mixed British and Asian, was the only participant who was not White British. It may be that this is representative of the proportion of students attending the course from other ethnic backgrounds, but we must be mindful of how cultural influences and varied openness in talking about mental health difficulties could impact upon the storytelling experience. There was some indication of this within George's account; he referred to holding back from disclosure with those closest to him due to his cultural background where mental health issues were not discussed openly. He also described his journey through storytelling, attending the TMS course previously and disclosing only a small amount, but gaining confidence to share more the second time around, and hoping to go on the course again in future as he continues to learn more about himself and become more comfortable with talking about his difficulties. We can see here how his experience was shaped by culture. Further comment on this is beyond the scope of this study, but future research could explore storytelling for mental health recovery across cultural contexts.

There were no observed differences in storytelling experience according to age or gender, although this is possibly a limitation of KN's interpretative lens and other researchers might have been more sensitive to this. One final area for thought in terms of demographics is diagnosis and symptom severity. Discussion within the first focus group and respect for the ethos of the recovery college environment led to the decision to not ask participants for information relating to their diagnosis. Indeed, the fact that the

recovery college model offers courses to individuals irrespective of diagnosis seems to foster the normalisation of mental health difficulties and the ethos of life beyond symptoms. However, in research such as this (and indeed, in the measurement of outcomes of courses such as TMS) it reduces the homogeneity of the sample and perhaps makes it hard to situate the sample. It is important to acknowledge that this research has not been able to consider how the experience of storytelling might vary according to the nature or severity of the mental health difficulty that the individual is experiencing. It might be that this was a factor influencing Paul's less positive experience of the TMS course, given that his psychotic experiences were somewhat unique from the experiences of others in the group. Future research should consider the nature and severity of the mental health difficulty in relation to its impact on the storytelling experience and outcome.

The sample size provided ample data for the emergence of superordinate themes that recur across cases. However, greater depth of each person's individual experience could have been explored if the sample size had been smaller. It is also important to acknowledge the limitations of IPA being a thematic approach, in that this inevitably involves some form of reduction and loss of depth of content of each individual's experiential account. An alternative approach could have been narrative analysis, which typically uses a smaller sample size and often multiple interviews per participant, therefore giving a fuller representation of each individual's account. Narrative approaches are concerned not only with the content of the individual's account, but also its structural form (plot structure, sequence of events, language used) and the social context in which the account is presented (Earthy & Cronin, 2008). It was felt that this would be fitting if the investigative focus had been on the content and structure of the individual's recovery story itself, or on how they had organised and presented their narrative about their storytelling experience. However, the investigative focus of this study was on the phenomena (storytelling in mental health) rather than how individuals constructed their narrative about their storytelling experience. This emphasis on the phenomena rather than the narrative form lends itself to IPA (Smith, Flowers & Larkin, 2009). Within IPA, the idiographic component works to retain a sense of each individual's account within the reduction of findings to themes. Thus, the analysis in this study attempted to show contributions from all participants and offer background to each of their individual situations within the overall themes. This is further supported by the pen portraits offered in Appendix L.

In keeping with IPA (Smith, Flowers & Larkin, 2009), the results presented within this study offer an interpretation from the perspective of one researcher, without claim of revealing any absolute truth about the experience of storytelling for all. It is important to remember that when using qualitative methods, the intention is not for results to be transferred (Gunnarsson et al., 2010). However, trustworthiness is lacking given that all

analysis was carried out by just one researcher, due to the context of it being conducted within a doctoral thesis. This is a potential weakness of the study, because although steps were taken to maximise quality and rigour, other IPA studies have enhanced their trustworthiness by reaching consensus on analysis from multiple perspectives.

### **Overall conclusion**

Storytelling can offer a highly meaningful experience to the individual and play a significant role in their recovery. The TMS course offers a novel opportunity for focusing on both the *forming* and the *sharing* of one's story. It has shown the potential for offering some of the therapeutic benefits that are aimed for within therapeutic interventions, whilst retaining the flexibility to be applied in a way that is meaningful to the individual and their stage of recovery. This indicates that storytelling is a tool that could be utilised more widely and more thoroughly within mental health services. At this stage, further research is needed to build upon the findings of this study and explore the factors that might influence how storytelling is experienced; in order to further our understanding of the conditions in which it may or may not benefit individuals, and to therefore guide the future development of storytelling interventions that can be adapted to meet individual needs.

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## Appendices

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Appendix	Description
A	Mental Health Review Journal Guidelines
B	Letters confirming ethical and research governance approval <sup>1</sup>
C	Focus Group 1 Participant Information Sheet
D	Focus Group Consent Form
E	Focus Group 1 Summary Table
F	Interview Guide
G	Interview Participant Information Sheet
H	Interview Consent Form
I	Interview Technique – Example Transcript and Reflections
J	Example Excerpt of Transcript – Lisa’s Interview
K	Example Participant Superordinate Themes Table – Lisa
L	Participant Pen Portraits
M	Focus Group 2 Participant Information Sheet
N	Focus Group 2 Summary Table

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<sup>1</sup>Please note that some documents within the appendices refer to the lead author as “Kate Pope”, which is her maiden name (she got married whilst undertaking this research).

# Appendix A

## Mental Health Review Journal Guidelines

### Author Guidelines

#### Manuscript requirements

Please prepare your manuscript before submission, using the following guidelines:

<b>Format</b>	Article files should be provided in Microsoft Word format. LaTeX files can be used if an accompanying PDF document is provided. PDF as a sole file type is not accepted, a PDF must be accompanied by the source file. Acceptable figure file types are listed further below.
<b>Article Length</b>	Articles should be between 4000 and 7000 words in length, except for literature reviews or review articles which have no word limit. This includes all text including references and appendices. Please allow 350 words for each figure or table.
<b>Article Title</b>	A title of not more than eight words should be provided.
<b>Author details</b>	<p>All contributing authors' names should be added to the ScholarOne submission, and their names arranged in the correct order for publication.</p> <ul style="list-style-type: none"><li>• Correct email addresses should be supplied for each author in their separate author accounts</li><li>• The full name of each author must be present in their author account in the exact format they should appear for publication, including or excluding any middle names or initials as required</li><li>• The affiliation of each contributing author should be correct in their individual author account. The affiliation listed should be where they were based at the time that the research for the paper was conducted</li></ul>
<b>Biographies and acknowledgements</b>	Authors who wish to include these items should save them together in an MS Word file to be uploaded with the submission. If they are to be included, a brief professional biography of not more than 100 words should be supplied for each named author.
<b>Research funding</b>	Authors must declare all sources of external research funding in their article and a statement to this effect should appear in the Acknowledgements section. Authors should describe the role of the funder or financial sponsor in the entire research process, from study design to submission.
<b>Structured Abstract</b>	<p>Authors must supply a structured abstract in their submission, set out under 4-7 sub-headings (see our "How to... write an abstract" guide for practical help and guidance):</p> <ul style="list-style-type: none"><li>• Purpose (mandatory)</li><li>• Design/methodology/approach (mandatory)</li><li>• Findings (mandatory)</li><li>• Research limitations/implications (if applicable)</li><li>• Practical implications (if applicable)</li><li>• Social implications (if applicable)</li><li>• Originality/value (mandatory)</li></ul> <p>Maximum is 250 words in total (including keywords and article classification, see below).</p> <p>Authors should avoid the use of personal pronouns within the structured abstract and body of the paper (e.g. "this paper investigates..." is correct, "I investigate..." is incorrect).</p>

**Keywords**

Authors should provide appropriate and short keywords in the ScholarOne submission that encapsulate the principal topics of the paper (see the How to... ensure your article is highly downloaded guide for practical help and guidance on choosing search-engine friendly keywords). The maximum number of keywords is 12.

Whilst Emerald will endeavour to use submitted keywords in the published version, all keywords are subject to approval by Emerald's in house editorial team and may be replaced by a matching term to ensure consistency.

**Article Classification**

Authors must categorize their paper as part of the ScholarOne submission process. The category which most closely describes their paper should be selected from the list below.

**Research paper.** This category covers papers which report on any type of research undertaken by the author(s). The research may involve the construction or testing of a model or framework, action research, testing of data, market research or surveys, empirical, scientific or clinical research.

**Viewpoint.** Any paper, where content is dependent on the author's opinion and interpretation, should be included in this category; this also includes journalistic pieces.

**Technical paper.** Describes and evaluates technical products, processes or services.

**Conceptual paper.** These papers will not be based on research but will develop hypotheses. The papers are likely to be discursive and will cover philosophical discussions and comparative studies of others' work and thinking.

**Case study.** Case studies describe actual interventions or experiences within organizations. They may well be subjective and will not generally report on research. A description of a legal case or a hypothetical case study used as a teaching exercise would also fit into this category.

**Literature review.** It is expected that all types of paper cite any relevant literature so this category should only be used if the main purpose of the paper is to annotate and/or critique the literature in a particular subject area. It may be a selective bibliography providing advice on information sources or it may be comprehensive in that the paper's aim is to cover the main contributors to the development of a topic and explore their different views.

**General review.** This category covers those papers which provide an overview or historical examination of some concept, technique or phenomenon. The papers are likely to be more descriptive or instructional ("how to" papers) than discursive.

**Headings**

Headings must be concise, with a clear indication of the distinction between the hierarchy of headings.

The preferred format is for first level headings to be presented in bold format and subsequent sub-headings to be presented in medium italics.

**Notes/Endnotes**

Notes or Endnotes should be used only if absolutely necessary and must be identified in the text by consecutive numbers, enclosed in square brackets and listed at the end of the article.

**Figures**

All Figures (charts, diagrams, line drawings, web pages/screenshots, and photographic images) should be submitted in electronic form.

All Figures should be of high quality, legible and numbered consecutively with arabic numerals. Graphics may be supplied in colour to facilitate their appearance on the online database.

- Figures created in MS Word, MS PowerPoint, MS Excel, Illustrator should be supplied in their native formats. Electronic figures created in other applications should be copied from the origination software and pasted into a blank MS Word document or saved and imported into an MS Word document or alternatively create a .pdf file from the origination software.
- Figures which cannot be supplied as above are acceptable in the standard image formats which are: .pdf, .ai, and .eps. If you are unable to supply graphics in these formats then please ensure they are .tif, .jpeg, or .bmp at a resolution of at least 300dpi and at least 10cm wide.
- To prepare web pages/screenshots simultaneously press the "Alt" and "Print screen" keys on the keyboard, open a blank Microsoft Word document and simultaneously press "Ctrl" and "V" to paste the image. (Capture all the contents/windows on the computer screen to paste into MS Word, by simultaneously pressing "Ctrl" and "Print screen".)
- Photographic images should be submitted electronically and of high quality. They should be saved as .tif or .jpeg files at a resolution of at least 300dpi and at least 10cm wide. Digital camera settings should be set at the highest resolution/quality possible.

#### Tables

Tables should be typed and included in a separate file to the main body of the article. The position of each table should be clearly labelled in the body text of article with corresponding labels being clearly shown in the separate file.

Ensure that any superscripts or asterisks are shown next to the relevant items and have corresponding explanations displayed as footnotes to the table, figure or plate.

#### References

References to other publications must be in **Harvard** style and carefully checked for completeness, accuracy and consistency. This is very important in an electronic environment because it enables your readers to exploit the Reference Linking facility on the database and link back to the works you have cited through CrossRef.

You should cite publications in the text: (Adams, 2006) using the first named author's name or (Adams and Brown, 2006) citing both names of two, or (Adams *et al.*, 2006), when there are three or more authors. At the end of the paper a reference list in alphabetical order should be supplied:

#### For books

Surname, Initials (year), *Title of Book*, Publisher, Place of publication.

e.g. Harrow, R. (2005), *No Place to Hide*, Simon & Schuster, New York, NY.

#### For book chapters

Surname, Initials (year), "Chapter title", Editor's Surname, Initials, *Title of Book*, Publisher, Place of publication, pages.

e.g. Calabrese, F.A. (2005), "The early pathways: theory to practice – a continuum", in Stankosky, M. (Ed.), *Creating the Discipline of Knowledge Management*, Elsevier, New York, NY, pp. 15-20.

#### For journals

Surname, Initials (year), "Title of article", *Journal Name*, volume issue, pages.

e.g. Capizzi, M.T. and Ferguson, R. (2005), "Loyalty trends for the twenty-first century", *Journal of Consumer Marketing*, Vol. 22 No. 2, pp. 72-80.

#### For published conference proceedings

Surname, Initials (year of publication), "Title of paper", in Surname, Initials (Ed.), *Title of published proceeding which may include place and date(s) held*, Publisher, Place of publication, Page numbers.

e.g. Jakkilinki, R., Georgievski, M. and Sharda, N. (2007), "Connecting destinations with an ontology-based e-tourism planner", in *Information and communication technologies in tourism 2007 proceedings of the international conference in Ljubljana, Slovenia, 2007*, Springer-Verlag, Vienna, pp. 12-32.

<i>For unpublished conference proceedings</i>	<p>Surname, Initials (year), "Title of paper", paper presented at Name of Conference, date of conference, place of conference, available at: URL if freely available on the internet (accessed date).</p> <p>e.g. Aumuefller, D. (2005), "Semantic authoring and retrieval within a wiki", paper presented at the European Semantic Web Conference (ESWC), 29 May-1 June, Heraklion, Crete, available at: <a href="http://dbs.uni-leipzig.de/file/aumuefller05wiksar.pdf">http://dbs.uni-leipzig.de/file/aumuefller05wiksar.pdf</a> (accessed 20 February 2007).</p>
<i>For working papers</i>	<p>Surname, Initials (year), "Title of article", working paper [number if available], Institution or organization, Place of organization, date.</p> <p>e.g. Moizer, P. (2003), "How published academic research can inform policy decisions: the case of mandatory rotation of audit appointments", working paper, Leeds University Business School, University of Leeds, Leeds, 28 March.</p>
<i>For encyclopedia entries (with no author or editor)</i>	<p><i>Title of Encyclopedia</i> (year) "Title of entry", volume, edition, Title of Encyclopedia, Publisher, Place of publication, pages.</p> <p>e.g. <i>Encyclopaedia Britannica</i> (1926) "Psychology of culture contact", Vol. 1, 13th ed., Encyclopaedia Britannica, London and New York, NY, pp. 765-71.</p> <p>(For authored entries please refer to book chapter guidelines above)</p>
<i>For newspaper articles (authored)</i>	<p>Surname, Initials (year), "Article title", <i>Newspaper</i>, date, pages.</p> <p>e.g. Smith, A. (2008), "Money for old rope", <i>Daily News</i>, 21 January, pp. 1, 3-4.</p>
<i>For newspaper articles (non-authored)</i>	<p><i>Newspaper</i> (year), "Article title", date, pages.</p> <p>e.g. <i>Daily News</i> (2008), "Small change", 2 February, p. 7.</p>
<i>For archival or other unpublished sources</i>	<p>Surname, Initials, (year), "Title of document", Unpublished Manuscript, collection name, inventory record, name of archive, location of archive.</p> <p>e.g. Litman, S. (1902), "Mechanism &amp; Technique of Commerce", Unpublished Manuscript, Simon Litman Papers, Record series 9/5/29 Box 3, University of Illinois Archives, Urbana-Champaign, IL.</p>
<i>For electronic sources</i>	<p>If available online, the full URL should be supplied at the end of the reference, as well as a date that the resource was accessed.</p> <p>e.g. Castle, B. (2005), "Introduction to web services for remote portlets", available at: <a href="http://www-128.ibm.com/developerworks/library/ws-wsrp/">http://www-128.ibm.com/developerworks/library/ws-wsrp/</a> (accessed 12 November 2007).</p> <p>Standalone URLs, i.e. without an author or date, should be included either within parentheses within the main text, or preferably set as a note (roman numeral within square brackets within text followed by the full URL address at the end of the paper).</p>

## Appendix B

### Letters Confirming Ethical and Research Governance Approval



#### Health Research Authority

##### North West - Liverpool Central Research Ethics Committee

3rd Floor  
Barlow House  
4 Minshull Street  
Manchester  
M1 3DZ

Telephone: 0207 104 8006  
Fax:

15 March 2016

Miss Kathryn (Kate) Pope  
Department of Clinical Psychology, Norwich Medical School  
University of East Anglia  
Norwich  
NR4 7TJ

Dear Miss Pope

**Study title:** A qualitative exploration of Telling My Story in mental health recovery.  
**REC reference:** 16/NW/0148  
**IRAS project ID:** 183263

Thank you for your resubmission of documents on 10 March 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mrs Carol Ebenezer, [nrescommittee.northwest-liverpoolcentral@nhs.net](mailto:nrescommittee.northwest-liverpoolcentral@nhs.net)

#### Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

*Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm*

A Research Ethics Committee established by the Health Research Authority

through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, [www.hra.nhs.uk](http://www.hra.nhs.uk) or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

#### Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Ethical review of research sites**

##### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [UEA Sponsor Insurance & Indemnity letter]	1	08 February 2016
Interview schedules or topic guides for participants [Interview Guide]	4	09 March 2016
Other [IH CV (Secondary supervisor's CV)]	1	07 February 2016
Participant consent form [Focus Group Consent form]	2	09 March 2016
Participant consent form [Interview Consent form]	3	09 March 2016

A Research Ethics Committee established by the Health Research Authority

Participant information sheet (PIS) [Focus Group 1 - Participant Information Sheet]	2	09 March 2016
Participant information sheet (PIS) [Interview Participant Information Sheet]	6	10 March 2016
Participant information sheet (PIS) [Focus Group 2 - Participant Information Sheet]	2	10 March 2016
REC Application Form [REC_Form_15022016]		15 February 2016
Research protocol or project proposal [Thesis Proposal]	2	01 December 2015
Summary CV for Chief Investigator (CI) [KP CV]	1	07 February 2016
Summary CV for supervisor (student research) [DW CV]	1	07 February 2016

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

##### Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

#### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

#### HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>16/NW/0148</b>	<b>Please quote this number on all correspondence</b>
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With the Committee's best wishes for the success of this project.

Yours sincerely



Signed on behalf of:  
**Mrs Julie Brake**  
Chair

Email: [nrescommittee.northwest-liverpoolcentral@nhs.net](mailto:nrescommittee.northwest-liverpoolcentral@nhs.net)

Enclosures: "After ethical review – guidance for researchers"

Copy to: Mrs Yvonne Kirkham

Ms Alexandra Leech-Faragher, CPFT R&D (Governance Officer)

16 May 2016

R&D Ref: M00763

Miss Kate Pope  
Department of Clinical Psychology  
Norwich Medical School  
University of East Anglia  
NR4 7TJ

Joint Research Office  
Box 277  
Addenbrooke's Hospital  
Hills Road  
Cambridge  
CB2 0QQ

Direct Dial: 01223 596472 ext 6472  
E-mail: [r&d@cpft.nhs.uk](mailto:r&d@cpft.nhs.uk)  
[www.cpft.nhs.uk](http://www.cpft.nhs.uk)

Dear Kate

**Re: 16/NW/0148 A qualitative exploration of Telling My Story in mental health recovery**

In accordance with the Department of Health's Research Governance Framework for Health and Social Care, all research projects taking place within the Trust must receive a favourable opinion from an ethics committee and approval from the Department of Research and Development (R&D) prior to commencement.

R&D have reviewed the documentation submitted for this project, and has undertaken a **site specific assessment** based on the information provided in the SSI form, and I am pleased to inform you that we have no objection to the research proceeding within CPFT.

**Sponsor: University of East Anglia**

**Funder: self-funded**

**End date: 06 March 2017**

**Protocol: Version 2, 01 December 2015**

**Conditions of Trust Approval:**

- The project must follow the agreed protocol and be conducted in accordance with all Trust Policies and Procedures especially those relating to research and data management. Any mobile devices used must also comply with Trust policies and procedures for encryption.
- You and your research team must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 1998 and are aware of your responsibilities in relation to the Human Tissue Act 2004, Good Clinical Practice, the NHS Research Governance Framework for Health and Social Care, Second Edition April 2005 and any further legislation released during the time of this study.
- Members of the research team must have appropriate substantive or honorary contracts with the Trust prior to the study commencing. Any additional researchers who join the study at a later stage must also hold a suitable contract.
- You and your research team must provide to R&D, as soon as available, the date of first patient first visit.

HQ Elizabeth House, Fulbourn Hospital, Cambridge CB21 5EF  
T 01223 726789 F 01480 398501 [www.cpft.nhs.uk](http://www.cpft.nhs.uk)

In partnership with the University of Cambridge



**If the project is a clinical trial under the European Union Clinical Trials Directive the following must also be complied with:**

- the EU Directive on Clinical Trials (Directive 2001/20/EC) and UK's implementation of the Directive: The Medicines for Human Use (Clinical Trials ) Regulations 2004;
- the EU Directive on Principles and Guidelines for Good Clinical Practice (EU Commission Directive 2005/28/EC); and UK's implementation of the Directive: The Medicines for Human Use (Clinical Trials) Amendment Regulations 2006;

**Amendments**

Please ensure that you submit a copy of any amendments made to this study to the R&D Department.

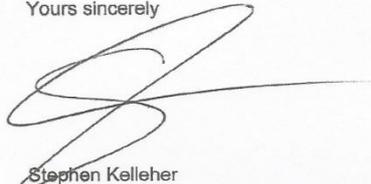
**Annual Report**

It is obligatory that an annual report is submitted by the Chief Investigator to the research ethics committee, and we ask that a copy is sent to the R&D Department. The yearly period commences from the date of receiving a favourable opinion from the ethics committee.

Please refer to our website [www.cpftr.nhs.uk](http://www.cpftr.nhs.uk) for all information relating to R&D including honorary contract forms, policies and procedures and data protection.

Should you require any further information please do not hesitate to contact us.

Yours sincerely



Stephen Kelleher  
Senior R&D Manager

Cc

Dr. Deirdre Williams, Department of Clinical Psychology ([Deirdre.williams@uea.ac.uk](mailto:Deirdre.williams@uea.ac.uk))

Dr. Imogen Hobbis, Department of Clinical Psychology ([i.hobbis@uea.ac.uk](mailto:i.hobbis@uea.ac.uk))

Tracey Bartlett, Recovery College East Manager ([tracey.bartlett@cpft.nhs.uk](mailto:tracey.bartlett@cpft.nhs.uk))

## Appendix C

### Focus Group 1 Participant Information Sheet

Date: 16.05.16  
Version: 3



#### **Focus Group 1 - Participant Information Sheet**

**Study title: A qualitative exploration of Telling My Story in mental health recovery.**

I would like to invite you to take part in a focus group. I am conducting a study that is exploring the role of forming and sharing stories in mental health recovery. The main study involves me interviewing students of the Telling My Story course to find out about their individual experience of forming and sharing recovery stories. This focus group has been set up to involve recovery college students in the design of the interview guide. Joining the focus group is entirely up to you. Before you decide whether to take part, I would like you to understand why the main study is being run, why this focus group is being held, and what taking part in the focus groups would involve for you. Please feel free to ask me any questions if anything is unclear, and/or to talk to others about the study if you wish.

#### **What is the research study investigating?**

This main study aims to look at the role of storytelling in mental health recovery. Specifically, it is interested in how the experience of constructing a recovery story, sharing this with others, and hearing others share their story impacts on the individual's recovery journey.

#### **What is the background?**

In recent years, mental health services have moved away from the traditional medical model that has focused on reducing symptoms, and are instead focusing on supporting people to find ways of living meaningful lives with or without ongoing symptoms of their conditions. Recovery colleges have been set up, with individuals attending as students, learning about recovery. Recovery-based interventions are led or co-produced by those with lived experience of mental health problems, and there's a suggestion within recovery research that what is needed in order to break down the stigma surrounding mental health is for those with lived experience to be able to share their stories. The 'Telling My Story' course at the recovery college is run by people with lived experience of mental health problems, and it aims to support individuals to construct a story of their recovery journey; making sense of what has happened and what it means to them.

#### **Why is the research study being done?**

Understanding what is helpful or unhelpful about forming and sharing recovery stories will help us to gain a better understanding of the role of storytelling in the individual's recovery journey. This can then guide the development of future interventions and contribute to our understanding of how recovery stories can be shared within our wider society to continue to reduce stigma around mental health. It may also guide the development of measures that can be used to evaluate courses like Telling My Story to see whether they are helping individuals.

#### **What service or intervention is being studied?**

The Telling My Story course at Recovery College East (Peterborough and Cambridge sites) provides an appropriate setting for exploring the role of story-telling within the recovery context.

#### **Why is this focus group being run?**

Date: 16.05.16  
Version: 3

The chief investigator (CI) is running this focus group in order to design the interview guide collaboratively with students of the recovery college. It is hoped that this will help to make the study relevant and useful to those who use the service.

**What will I have to do?**

You will be invited to take part in a focus group of between three and six people, which will be facilitated by the CI. The CI will introduce topics for discussion, which the group can then discuss freely. The focus group will not be recorded on audio or visual device and it will not generate any data to be included in the analysis. Rather, its aim is to generate helpful discussion around the topic area, so that the CI can obtain feedback that will inform the design of the interview guide. The CI will make written notes on the discussions held, which will not include any identifiable information.

**What will happen after the focus group?**

The CI will reflect on the discussions held and develop the interview guide based on feedback from focus group participants.

**Who is eligible to take part?**

Recovery college students who are not taking part in the interviews for the main study. You will also need to be fluent in speaking and understanding English, in order to participate in the focus group.

**Where will the focus groups be held?**

At Recovery College East, Peterborough or Cambridge base (to be decided with focus group participants – the CI will hold the focus group at the location that is most convenient for participants).

**How long will each interview last?**

The focus group is expected to last for approximately one hour.

**When will the study end?**

The research process is underway and will last until March 2017, when the project is submitted for assessment.

**How will the study findings be fed back to participants?**

The CI will arrange a time to feed back the overall results to the recovery college and you will be invited to attend, with the opportunity to discuss results and offer feedback. You will also be offered the opportunity for individual feedback via telephone discussion, email or in writing if you would prefer.

**Who else will the findings be shared with?**

The findings will be shared within the UK Recovery College Network and the National Health Service. The findings will be written up as the CI's doctoral thesis project. Findings may be published in journals and therefore be publicly available. No identifiable information will be included in the findings.

**How have patients and the public been involved in this study?**

Service-user involvement is highly valued within this project. A summary of the project, the participant information sheet and the consent form have been through an independent service-user

Date: 16.05.16  
Version: 3

panel for feedback. The interview guide will be developed collaboratively with students at the recovery college. The researcher will also meet with students of the recovery college during the analysis stage for service-user involvement. When the study has finished, there will be a feedback session at the recovery college, and the offer of individual feedback to each participant via telephone/email/letter.

**What are the possible benefits of taking part?**

There are no guaranteed benefits of taking part. However, it is hoped that contributing to research in this way will be a positive and enjoyable process for you. The CI values the involvement of recovery college students in the design of the interview guide, to make use of your expert experience and develop questions that are useful and relevant.

**What are the possible disadvantages of taking part?**

The focus group will require your time to travel and attend. The CI will endeavour to minimise this burden by running the focus group at the base that is most convenient for participants.

**What will happen if I no longer want to participate in the focus group?**

You have the right to withdraw from the focus group any point. A decision to withdraw will not affect your involvement with the recovery college in any way.

**What if I am unhappy with any aspect of the study?**

If you have a concern about any aspect of this study, you should ask to speak to the CI who will do their best to answer your questions (please see the contact details at the bottom of this sheet). If you remain unhappy and wish to complain formally, you can do this by contacting Ken Laidlaw (Programme Director, Doctoral Programme in Clinical Psychology, University of East Anglia, email: k.laidlaw@uea.ac.uk or tel: 01603 593600). You may also contact the Cambridgeshire and Peterborough Patient Advice and Liaison Service (PALS) on 01223 726789 or pals@cpft.nhs.uk.

**How will my information be kept confidential?**

Data will be stored in accordance with the Data Protection Act (1998) and University of East Anglia policy. Research data will be stored in either locked cabinets or on encrypted password protected media and will only be accessed by the CI and research supervisors. After ten years, all data will be destroyed. The focus group will not be recorded on an audio or visual device. The CI will make written notes but these will not include any identifiable information. Everything you say at the focus group will remain confidential. However, should you disclose any risk to yourself or others then the CI would need to pass this information on to the relevant professional.

**What should I expect during the consent process?**

The CI will provide you with this Participant Information Sheet and a Consent Form when you are approached about taking part. You can take this information away with you. The CI will then ask for your written consent at the start of the focus group, before any discussions are held. The CI will keep this written record. If you would like any further information at any point, please do not hesitate to contact the CI via the details at the bottom of this form.

**Who is organising and funding this study?**

The study is funded by the Doctoral Programme in Clinical Psychology at the University of East Anglia. The CI is a Trainee Clinical Psychologist on the Clinical Psychology Doctoral Programme.

Date: 16.05.16  
Version: 3

**Who has reviewed this study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by North West Liverpool Central Research Ethics Committee. It has also been approved by Cambridgeshire and Peterborough Foundation Trust Research and Development department.

**Further information and contact details:**

If you require any further information or would like to discuss participation further, please do not hesitate to contact the CI via the following details:

Chief Investigator's name: Kate Pope (Trainee Clinical Psychologist)  
Mobile: 07804 552684  
Email: [kate.pope@uea.ac.uk](mailto:kate.pope@uea.ac.uk)

## Appendix D

### Focus Group Consent Form

Version 3, 06.01.17

Participant Identification Number:



#### FOCUS GROUP CONSENT FORM

Title of Project: A qualitative exploration of Telling My Story in mental health recovery.

Name of Chief Investigator: Kate Nurser

Please initial box

1. I confirm that I have read the participant information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation in this focus group is voluntary and that I am free to withdraw at any point, without giving any reason and without my involvement with the recovery college, medical care or legal rights being affected.
3. I understand that the focus group will not be recorded on an audio or visual device, and that its purpose is to involve recovery college students in the design of the main interview study.
4. I understand that should any risk to myself or others be disclosed at interview, the chief investigator will need to pass this information on to the appropriate medical professional.
5. I understand that relevant sections of my research data collected during the study may be looked at by individuals from the University of East Anglia, regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.
6. I agree to take part in this focus group for the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name of Person  
taking consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in confidential study master file.

## Appendix E

### Focus Group 1 Summary Table

<b>Suggested amendment to interview guide</b>	<b>Summary of focus group discussions and further considerations by the research team</b>	<b>Details of any interview guide amendments made</b>
<p>“It would be helpful for KN to disclose at the start her personal experience of attending the course.”</p>	<p>It was felt that this would increase mutuality and reduce power imbalance; thus facilitating richer disclosure. The sharing of lived experience is encouraged within the recovery college environment, and focus group participants advised that they would feel more at ease knowing this.</p>	<p>KN informed participants of her personal experience of attending the TMS course within the introduction to the interview (noting any impact of this within reflective journal entries).</p>
<p>“When asking about what recovery means to the interviewee, do not ask participants what they are recovering from.”</p>	<p>This was felt to be quite intrusive because the recovery college environment does not require individuals to disclose their diagnosis. There are mixed opinions on whether or not diagnosis is a helpful concept.</p>	<p>Questions focused more on asking about <i>what recovery means</i> to the interviewee. KN did not ask any direct questions about diagnosis, unless the interviewee explicitly referred to a diagnosis.</p>
<p>“Ask specific questions about the feedback-giving exercise.”</p>	<p>In the final session of the TMS course, each student shares their story with the group and group members are then invited to offer positive feedback by writing comments on a card. It was felt that this can be particularly poignant – both positively and negatively. Participants advised that KN ask directly about what it was like to both give and receive this feedback.</p>	<p>Two questions added, regarding the giving and receiving of feedback.</p>
<p>“We would feel uncomfortable being asked directly about how we thought others on the course felt towards us.”</p>	<p>It was felt that interviewees would have the opportunity to talk about this when asked about feelings that came up for them, and through exploring their perceptions of other peoples’ responses, but that asking this question outright was too direct.</p>	<p>This question was removed from the interview guide.</p>
<p>“Asking interviewees directly about how they felt towards others in the group, as they shared their stories, is a potentially sensitive area.”</p>	<p>KN felt that this is an important area to explore because listening to other peoples’ stories and experiences is a key aspect of the course, particularly in the final session. However, it is understood that using the phrase <i>feelings towards others</i> could be experienced by interviewees as interrogative and intense.</p>	<p>The questions in this section were kept very open and exploratory, as with the question “was there anything in particular that struck you when listening to other peoples’ stories?”</p>

---

“Ask participants how their motivation to share their story after attending the course compares to their desire to share it prior to the course.”	It was pointed out that students’ expectations of what they will get from the course differ; i.e. some hope to feel more confident in sharing their story publicly, whereas others come with the aim of making sense of their experiences for themselves and the actual sharing of their story may be less of a priority.	Question added to the interview guide.
“A final question could be to ask the interviewee for their views on how useful it is to use storytelling approaches such as this one in mental health recovery.”	It was felt that this would provide opportunity for an overall reflection on the storytelling process.	Question added to the interview guide.

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# Appendix F

## Interview Guide

Version 6, 21.06.16

### Interview Guide

\*\* (co-produced with recovery college students/peer support tutors)

#### *Introduction to the interview:*

This interview is being conducted because I'm interested in hearing about your experience of attending the Telling My Story course and using stories in your recovery journey. I, myself, have previously attended the course; so I am aware of its structure and have my own experience of forming and sharing my story. I will ask some questions to guide us through the interview, and it is ok for you to share both positive and negative experiences. There are no right or wrong answers. The findings from this study may be used to help develop the course in the future, but this is by no means the sole purpose of the interview. My aim is to understand your personal experience, and what it's been like for you to work with stories within your recovery journey.

1. Before we start, I'd like to understand what the term 'recovery' means to you...
  - How would you define it? (key elements that are important)
  - Personal experience of 'recovery'/being in a 'recovery' setting.
  - To set the scene, I wonder if you could tell me a bit about your recovery journey so far?
2. How would you say the course has impacted on you?
  - Is there anything you have experienced differently as a result of attending the course?
  - Is there anything about the course that has made you think differently about your mental health? (either how it is currently, or how you frame things that have happened in the past?)
  - Feelings towards self\*\*
  - Feelings towards others\*\*
  - How you view your difficulties
  - Home life/Work life
  - Clinical experiences
  - Consideration of previous experiences (recovery college, recovery stories)
3. Can you describe what it was like to form your own recovery story on the course?
  - Did you find it helpful/unhelpful? Easy/difficult? (Explore specific aspects).
  - What aspects of your life did your story focus on? What was important for you to include? (e.g. diagnosis versus strengths/goals/recovery focused)
  - Has forming your story influenced how you feel about yourself or your difficulties?
  - Previous recovery story – did you have one? Similar/different? Has it changed at all by going on the course?
4. Can you tell me a bit about what it was like to share your story with others?
  - Medium of choice
  - Feelings that came up
  - What affected the decision about *how much* to share?
  - I won't ask you to disclose anything that you are not comfortable with sharing, but was there anything you felt you *couldn't* say?
  - Explore perceptions of others' responses

- Receiving feedback from others – what was this like? How did you experience the card-writing exercise?
  - Similarities/differences to telling your story in other environments or previous experiences (clinical setting, home setting, social setting).
5. Can you tell me a bit about what it was like to hear other people sharing their recovery stories on the course?
- Feelings that came up
  - Positives/negatives
  - Easy/difficult?
  - Was there anything in particular that struck you when listening to other peoples' stories?
  - What was it like for you to offer feedback (written or verbal) to others who had shared their story?
  - Has hearing other people's stories changed your own narrative or story about yourself and your recovery?
6. Were there any critical moments on the course which have stuck with you and which have had any lasting effects? Can you describe it/them to me and what impact they had on you?
7. Moving forward now, how do you feel about sharing your story with others?
- Motivated to share it? How does this compare to how you felt about sharing your story before attending the course?
  - Does sharing your story feel like *having to*, or *wanting to*?
  - Explore the experience of sharing with different audiences: with family, friends, wider society/publicly
  - Beyond the course setting, what role do you think your story will have in your life, moving forward?
  - Explore any barriers to sharing it
  - What would make you feel more/less able to share your story with others?
  - Is there anything that would have made the story-telling process more useful to you?
  - What are your views on the usefulness of using story-telling approaches like this one in mental health recovery?
8. Thank you and closing comments. Reflection and de-brief:
- What was the experience like for you?
  - Do you need any additional support to manage anything that came up?

## Appendix G

### Interview Participant Information Sheet

Date: 16.05.16  
Version: 7



#### Interview Participant Information Sheet

**Study title: A qualitative exploration of Telling My Story in mental health recovery.**

I would like to invite you to take part in my research study, which is exploring the role of forming and sharing stories in mental health recovery. It looks specifically at the Telling My Story course, interviewing course students to find out about their individual experience of forming and sharing recovery stories on the course. Joining the study is entirely up to you. Before you decide, I would like you to understand why the research is being done and what it would involve for you. This information sheet outlines the purpose of the study and what will happen if you take part, to help you decide whether or not you would like to take part. Please feel free to ask me any questions if anything is unclear, and/or to talk to others about the study if you wish.

#### **What is this research investigating?**

This project aims to look at the role of storytelling in mental health recovery. Specifically, it is interested in how the experience of constructing a recovery story, sharing this with others, and hearing others share their story impacts on the individual's recovery journey.

#### **What is the background?**

In recent years, mental health services have moved away from the traditional medical model that has focused on reducing symptoms, and are instead focusing on supporting people to find ways of living meaningful lives with or without ongoing symptoms of their conditions. Recovery colleges have been set up, with individuals attending as students, learning about recovery. Recovery-based interventions are led or co-produced by those with lived experience of mental health problems, and there's a suggestion within recovery research that what is needed in order to break down the stigma surrounding mental health is for those with lived experience to be able to share their stories. The 'Telling My Story' course at the recovery college is run by people with lived experience of mental health problems, and it aims to support individuals to construct a story about their recovery journey; making sense of what has happened and what it means to them.

#### **Why is the research being done?**

Understanding what is helpful or unhelpful about forming and sharing recovery stories will help us to gain a better understanding of the role of storytelling in the individual's recovery journey. This can then guide the development of future interventions and contribute to our understanding of how recovery stories can be shared within our wider society to continue to reduce stigma around mental health. It may also guide the development of measures that can be used to evaluate courses like Telling My Story to see whether they are helping individuals.

#### **What service or intervention is being studied?**

The Telling My Story course at Recovery College East (Peterborough and Cambridge sites) provides an appropriate setting for exploring the role of story-telling within the recovery context.

#### **What will I have to do?**

You will be invited to take part in a 1:1 semi-structured interview, which will be conducted by the chief investigator (CI) and be audio recorded. The CI will guide the interview by asking specific

Date: 16.05.16  
Version: 7

questions. However, the process will remain flexible in terms of you being able to freely express your views in relation to the topic area.

**What will happen after the interviews?**

The audio recordings will be transferred to a password-protected computer at the earliest opportunity and stored in accordance with the Data Protection Act (1998). The CI will transcribe each interview, ensuring that all identifiable information is anonymised. Audio recordings will be deleted once they have been transcribed. The research supervisors will review the anonymised data, but they will not see any identifiable data. The CI will analyse the data and the findings will be written up in report format.

**Who is eligible to take part?**

Anybody who is over the age of 18, has a recognised mental illness for which they have received support from secondary mental health services, and has attended (and completed) the Telling My Story course within the last year. Unfortunately, carers and staff members are not eligible to take part in this study, as it is focusing specifically on the experience of those who have a mental illness for which they have received help from secondary mental health services. You will also need to be fluent in speaking and understanding English, in order to participate in the interviews.

**Where will the interviews be held?**

Interviews will be held at the Recovery College East, which has bases in both Peterborough and Cambridgeshire. You will be interviewed at the Recovery College base that is most convenient for you and a room will be booked in advance.

**How long will each interview last?**

It is anticipated that each interview will last between approximately 45 and 75 minutes. However, this can be flexible to how long you feel comfortable talking about your experience.

**When will the study end?**

The research process is underway and will last until March 2017, when the project is submitted for assessment. It is hoped that interviews will be held between January 2016 and July 2016.

**How will the findings be fed back to participants?**

The CI will arrange a time to feed back the overall results to the recovery college and you will be invited to attend, with the opportunity to discuss results and offer feedback. You will also be offered the opportunity for individual feedback via telephone discussion, email or in writing if you would prefer.

**Who else will the findings be shared with?**

The findings will be shared within the UK Recovery College Network and the National Health Service. The findings will be written up as the CI's doctoral thesis project. Findings may be published in journals and therefore be publicly available. No identifiable information will be included in the findings.

**How have patients and the public been involved in this study?**

Service-user involvement is highly valued within this project. A summary of the project, the participant information sheet and the consent form have been through an independent service-user

panel for feedback. The interview schedule will be developed collaboratively with students at the recovery college. The researcher will also meet with students of the recovery college during the analysis stage for service-user involvement. When the study has finished, there will be a feedback session at the recovery college, and the offer of individual feedback to each participant via telephone/email/letter.

**What are the possible benefits of taking part?**

There are no guaranteed benefits of taking part. However, it is hoped that the opportunity for you to reflect on your experience of attending the Telling My Story course and constructing/sharing your story will be a positive and enjoyable process. The findings will be helpful in the on-going development of recovery-focused services; helping us to have a better understanding of what is/is not helpful to individuals in their recovery journey.

**What are the possible disadvantages of taking part?**

Talking about recovery and mental health can be an emotive topic. If you find that the interview is causing you distress, you will be given the opportunity to take a break or to end the interview, depending on your preference. You will have the opportunity to de-brief with the CI, should you wish to. Should you require further support, the CI will liaise with the appropriate member of staff at the recovery college and can provide details of appropriate charities/helplines if required.

**What will happen if I no longer want to participate in the study?**

You have the right to withdraw from the study at any point, up until two weeks after your interview has taken place. A decision to withdraw will not affect your involvement with the recovery college in any way. The deadline of two weeks post-interview for a decision to withdraw has been set because beyond this point your data will be anonymised and analysed within the whole data set; thus, it will not be possible to withdraw data from individual interviews beyond this point.

**What if I am unhappy with any aspect of the study?**

If you have a concern about any aspect of this study, you should ask to speak to the CI who will do their best to answer your questions (please see the contact details at the bottom of this sheet). If you remain unhappy and wish to complain formally, you can do this by contacting Ken Laidlaw (Programme Director, Doctoral Programme in Clinical Psychology, University of East Anglia, email: k.laidlaw@uea.ac.uk or tel: 01603 593600). You may also contact the Cambridgeshire and Peterborough Patient Advice and Liaison Service (PALS) on 01223 726789 or pals@cpft.nhs.uk.

**How will my information be kept confidential?**

Data will be stored in accordance with the Data Protection Act (1998) and University of East Anglia policy. Research data will be stored in either locked cabinets or on encrypted password protected media and will only be accessed by the CI and research supervisors. After ten years, all data will be destroyed. Everything you say at the interview will remain confidential. However, should you disclose any risk to yourself or others then the CI would need to pass this information on to the relevant professional.

**What should I expect during the consent process?**

The CI will provide you with this Participant Information Sheet and a Consent Form during the penultimate session of the course. You can take this information away with you. The CI will return the next week to obtain consent of anyone who wants to participate. If you would like any further

Date: 16.05.16  
Version: 7

information during this time, please do not hesitate to contact the CI via the details at the bottom of this form. It is your right to choose whether or not to participate in this study and your decision will not affect your involvement with the recovery college. If you choose to proceed, the CI will ask you to read and initial the boxes on the consent form to indicate your informed consent. The CI will keep this as a written record.

**Who is organising and funding this study?**

The study is funded by the Doctoral Programme in Clinical Psychology at the University of East Anglia. The CI is a Trainee Clinical Psychologist on the Clinical Psychology Doctoral Programme.

**Who has reviewed this study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by North West Liverpool Central Research Ethics Committee. It has also been approved by Cambridgeshire and Peterborough Foundation Trust Research and Development department.

**Further information and contact details:**

If you require any further information or would like to discuss participation further, please do not hesitate to contact the CI via the following details:

Chief Investigator's name: Kate Pope (Trainee Clinical Psychologist)  
Mobile: 07804 552684  
Email: kate.pope@uea.ac.uk

# Appendix H

## Interview Consent Form

Version 3, 09.03.16

Participant Identification Number:



### INTERVIEW CONSENT FORM

Title of Project: A qualitative exploration of Telling My Story in mental health recovery.

Name of Chief Investigator: Kate Nurser

Please initial box

1. I confirm that I have read the participant information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw up until two weeks after my interview has taken place, without giving any reason and without my involvement with the recovery college, medical care or legal rights being affected.
3. I understand that the information collected about me will be anonymised, and may be shared anonymously with other researchers in the future to support further research.
4. I consent to the interview being audio recorded and I understand that the data will be stored in accordance with the Data Protection Act (1998) and University of East Anglia policy. *Each participant will be given a number and their data stored anonymously with this number.*
5. I consent to my anonymised quotations being published.
6. I understand that should any risk to myself or others be disclosed at interview, the chief investigator will need to pass this information on to the appropriate medical professional.
7. I understand that relevant sections of my research data collected during the study may be looked at by individuals from the University of East Anglia, regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to this data.
8. I agree to take part in the above study.

_____	_____	_____
Name of Participant	Date	Signature
_____	_____	_____
Name of Person taking consent	Date	Signature

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in confidential study master file.

## Appendix I

### Interview Technique – Example Transcript and Reflections

Sarah presented as highly nervous within the interview. At various points she described her “mind going blank”, provided limited responses, or engaged in extended pauses. An excerpt from the lead researcher’s reflective journal outlines the anxiety that KN felt within the room when interviewing.

I noticed some transference of her anxiety. Although I’m aware that I was feeling a little anxious prior to the interview as well, this felt different once I was in the room with her. I noticed I mirrored her at times in the interview in my body language; for example, leaning forwards. I corrected myself when I noticed this to try and hold a more neutral/open stance, but this transference of anxiety gave me a bit of insight into how I think she was feeling. (Reflective journal entry, 12.08.16).

It was important for KN to be sensitive to Sarah’s anxiety and difficulty articulating herself, so that she felt supported, and in order to maintain the flow of the interview. The excerpt below is taken from Sarah’s transcript and presents an example of how KN responded to Sarah’s anxiety within the interview.

Interviewer: Sure, okay. So what affected your decision about how much of your story to share?

Sarah: [long pause]

Interviewer: [pause] You mentioned the, sort of, not wanting to bore everybody but wanting it to make sense. Is there anything else you thought about when deciding how much information to share?

Sarah: [long pause]

Interviewer: [pause] Is that a more difficult question to answer?

Sarah: Yeah I can’t really think of anything.

Interviewer: That’s ok, no problem. When you were putting it together- so it’s four weeks the course, isn’t it?

Sarah: Yeah.

Interviewer: I don’t know if your course was the same as mine, so tell me if it was different, but we were encouraged to start thinking about it at the start but then the actual writing was sort of session three or four

Sarah: Yeah

Interviewer: Getting it ready for four

Sarah: Mmm

Interviewer: Was it the same for you?

Sarah: Yeah

Interviewer: Yeah, so I think it wasn’t until towards the end that I started thinking “how am I actually going to put this together?”

Sarah: Mmm

Interviewer: Do you remember that time, when you were thinking about how to design it and how to-

Sarah: I think from- from the first session I kind of had this idea of photos, just because [laughs] photography, that's how my mind works, but then I was like oh no I'm not going to do that because I always do that so I'm not going to do that [laughs] and I thought of- I kind of wanted- thought of maybe doing like a powerpoint presentation or something like that, and then I thought oh am I a bit behind with the times I think in powerpoint, maybe there's like, you know, some kind of new, sort of IT thing that people use now over powerpoint and I'm a bit behind with that [laughs] So- so I kind of, you know, decided to shut my brain down thinking about anything like that, so it wasn't until- so I kind of, you know, thought I'll just cool down and, you know, let- let myself be taught and not think too much about it. So yeah- so it wasn't until like session three that- that I kind of started to think properly about what I wanted to do. And then I was just- yeah I think I was just wondering around Hobbycraft and sort of saw the- saw the books and then the idea just came to me.

Following the first pause, KN reflected some of what Sarah had previously said with the aim of encouraging her to build upon this. When she paused again, KN hoped that by asking "is that a more difficult question to answer?" Sarah would elaborate on why she was having difficulty articulating herself. This was a closed question, however, and Sarah did not respond as desired. KN then took a different approach, by offering some of her own experience of attending the course in an attempt to re-establish the shared experience between interviewer and interviewee. Whilst doing this, she "checked-in" with Sarah, to establish whether her own experience was similar to Sarah's. It was also hoped that this process would reduce the pressure on Sarah momentarily, so that she could feel more relaxed and then have the capacity to re-engage with the interview. Offering Sarah some shared experience seemed helpful, as Sarah then started to offer richer responses in return. Her laughs seemed to indicate that she was feeling more relaxed again. An important part of the storytelling experience on the TMS course for Sarah, was about establishing a deep connection with others and feeling safe to share. KN interpreted this to be important within the interview context also, becoming more attuned to Sarah's need to feel connected within the interview in order to feel safe to enter into a discussion with the interviewer. This seems to relate to Lamb's (2013) idea that shared experience between the interviewer and interviewee of the phenomena can foster connection that leads to richer discussion.

Sarah's interview was the first to be conducted and was followed by discussion with supervisors to reflect on technique. It was felt that as interviewer, KN was appropriately responsive to and validating of Sarah's emotional experience. However, these discussions highlighted potential for further exploration of the interviewee's experience of the interview "in-vivo", for example exploring thoughts and feelings that were coming up as questions were asked. KN endeavored to use this technique in later interviews. Reflective journal entries noted how some participants were more naturally reflective, which meant KN felt less need to follow questions up with further prompts and meant the interview was guided more strongly by the participant. This contrasted interviews where participants were either more anxious or less naturally reflective, which required KN to prompt more frequently. The interview guide seemed to offer a natural flow to the interview and did not require amendments across the interviews (perhaps due to it having been developed collaboratively with members of the participant group). Most interviews followed the order of questioning laid out on the guide, although some participants naturally covered later questions within earlier parts of the interview and so the ordering of questions was adapted where necessary.

# Appendix J

## Example Excerpt of Transcript – Lisa’s Interview

EMERGENT THEMES	INITIAL NOTING	KEY: plain text : descriptive underlined : conceptual green underlined: linguistic
<p><del>Safe</del></p> <p>Fear of exposure.</p>	<p>I: Can you remember at the time any feelings that came up for you as you were sharing it with other people?</p> <p>P: Anxiety. Fear. Relief.</p> <p>I: What was the anxiety and fear about?</p> <p>P: [short pause] Oh my god I'm speaking in front of all these people [laughs] and they're seeing my insides and they're going to think I'm dirty and disgusting. That was my main anxiety. Again, that was my fear, that people would think I'm dirty and disgusting.</p> <p>I: Yeah, yeah, that's quite a lot of personal information to share isn't it.</p> <p>P: Yeah.</p> <p>I: Yeah, yeah, okay, and I won't ask you to disclose anything that you're not comfortable with sharing, but was there anything that you felt you couldn't say when you were sharing your story on the course?</p> <p>P: No. I felt I could say what I wanted to, and if I didn't want to I didn't have to.</p> <p>I: Yeah, yeah okay. You mentioned a bit about other people's responses, when you noticed how they were responding. Can you tell me a bit about that? What did you notice about other people's responses?</p>	<p>Strong emotions.</p> <p>Highly exposing experience. "seeing my insides" "dirty" and "disgusting" – negative view of self, relating to internalised beliefs from HIV abuse.</p> <p>Fear of judgment.</p> <p>Felt safe to disclose or not disclose.</p>
<p>validation safe + environment</p>	<p>31mins01</p> <p>P: [short pause] Oh now you're asking [both laugh] I noticed the compassion afterwards when they asked questions and things. I just had a feeling of warmth, rather than oh my god get her away from me, if that makes sense.</p> <p>I: Yeah, okay. Yeah, so that acceptance that you mentioned before, and there's the feedback exercise isn't there with the card-writing task. Did you have that as well?</p> <p>P: Yeah.</p> <p>I: What was that like for you?</p> <p>P: Yeah that was really good. I mean, I put things like I loved your beard [laughs] and things like that on it 'cause I write silly things like that, to one of them, but we had</p>	<p>"compassion" and "warmth" – suggests a safe and containing response. validation. Asking questions – showing interest? wonder how it's perceived this. Hinting at past rejections/expectation of rejection.</p>

EMERGENT THEMES

Contained and validated and self

Mutual/ reciprocal

Inspired by peers

Inspired by tutor

INITIAL NOTING

that in the peer employment training too, and in the taking control.

I: So for you, receiving that feedback from others written on cards, what was that like?

P: Reassuring, and [pause] yeah just reassuring. I don't really know any other way to describe it.

I: Yeah. Did that feel like an important part of the course for you, or not so much?

P: [short pause] Yeah it felt like it was an important closure to the course. It wasn't the most important bit. The most important bit was getting it all out, for me, but [pause] it brought a nice closure to the course and it was good to have some feedback.

I: Yeah, sure, and was there anything more difficult about getting feedback from other people?

P: [short pause] No.

I: No, okay. So I wonder if you can tell me now a bit about what it was like to hear other people sharing their recovery stories whilst you were on the course.

P: Yeah, it was very emotional. I felt a lot of different emotions. I wouldn't be able to name them but I know I felt a lot of different ones. I know I felt happy for some when it ended, and inspired by others.

I: Sure. What sorts of things helped you to feel inspired?

P: Just where their story was at now. Where they were at now, where they'd got to. [pause] Yeah, that's what really inspired me.

I: Were there any particular themes that you can remember, that really made you feel that inspired?

P: Yeah when \*\*\*course tutor\*\*\* shared her story, which I can't obviously go in to telling because it's confidential [short pause] it made me think wow she's come so far, and she's still fighting, and it's worth fighting.

I: Yeah, yeah, sure, okay. Was there anything in particular that struck you when you were listening to other people's stories?

Repetition suggests this was meaningful, A wiser sense of self? Internalizing the reassurance of others, leading to greater self-assurance?

"Closure" suggests nearness, containment? Feedback secondary to catharsis.

No discourse of negatives.

Still struggling for emotional language, but greater awareness of emotional experience?

Reciprocity - other > self (inspired by others) - self > other (happy for others).

Seeing change in others makes it possible for self. Modelling, by people from same in-group.

Seeing that it's worth it. Hope?

## Appendix K

### Example Participant Superordinate Themes Table – Lisa

Superordinate theme	Page numbers & emergent themes supporting this
Freeing the hidden self <i>(largely through song)</i>	P3 – liberating emotions P7 – liberated from past P11 – expressing inner child P3 – expressing self through song P3 – song format P10 – song format important P10 – choosing a structure that’s right for her
Emotionally challenging for teller and listener	P5 – strength from exposure P10 – emotionally challenging for both teller and listener P16 – emotional impact of others’ stories P17 – emotionally draining
A safe environment makes it okay to disclose	P12 – safe environment P13 – safe and validating environment P13 – fear of exposure P14 – contained and validated self P18 – needing safety for disclosure P19/20 – importance of being believed P20 – importance of a safe environment General throughout – checking in, checking I’m understanding, managing self – due to not being believed in past?  <i>Versus:</i>
Holding back in unsafe environments	P5/19 – fear of upsetting others P12 – uncontainable experience with mental health services (‘freaked out’, ‘we need to stop this’, unhelpful cycle) P6 – holding back from those closest to her P5/19 – keeping full story from those closest to her P7 – negative experiences of mental health services P8 – needs not met by mental health services P18 – adjusting story to context
Two-way connection with others	P5 – sharing to help others P8/14/15/17 – inspired by others P14 – inspired by tutor P12 – empathy from others P14 – mutual/reciprocal process P16 – reciprocating meaningful feedback P19 – validated by others’ emotional responses P20 – reciprocity aids disclosure P21 – reciprocal relationships P16 – close relationships  <i>Versus:</i> P12 – guarded professionals P22 – closed off professionals
A more accepting/ connected self	P7 – open to facing past P9 – relationship to story changes over time P9 – becoming more emotionally connected

	<p>P9 – kinder relationship to self</p> <p>P12 – (internalised) empathy from others</p> <p>P21 – valuing herself</p>
Engagement through storytelling	<p>P2 – aspiring to help others</p> <p>P11 – engagement through storytelling</p> <p>P18 – sharing beyond course</p>
Making sense of my journey	<p>P3 – understanding self in stages</p> <p>P6 – structure</p> <p>P11 – organising experience with structure</p> <p>P21 – course structure</p> <p>P11 – building on therapy</p> <p>P3 – evolving story</p> <p>P10 – ongoing recovery</p> <p>P3 – matching type of support to stage</p> <p>P15 – different experience dependent on stage</p>

## Appendix L

### Participant Pen Portraits

<p style="text-align: center;"><b>Sarah</b></p> <p><b>Age:</b> 35  <b>Gender:</b> Female  <b>Ethnicity:</b> White British  <b>Time involved with RCE:</b> 1 year</p> <p><b>Overview of storytelling experience:</b> The TMS course was Sarah's first experience of telling her story in a structured way, outside of clinical settings. She used a storybook format, with photos and succinct phrases around them – to reflect her creative personality. TMS storytelling was an emotionally challenging but liberating experience. She had not shared her story with others since, but felt she could if she wanted/needed to.</p> <p><b>Presentation at interview:</b> Sarah appeared to feel quite anxious within the interview setting ("mind going blank", 'hunched over' body language, initial difficulty with eye contact). Showing empathic listening through reflecting back the things she had said, or sharing some of my personal experience of attending the course, seemed to support Sarah to feel comfortable in the interview setting and to elaborate on her responses.</p>	<p style="text-align: center;"><b>Paul</b></p> <p><b>Age:</b> 71  <b>Gender:</b> Male  <b>Ethnicity:</b> White British  <b>Time involved with RCE:</b> 2 years</p> <p><b>Overview of storytelling experience:</b> Paul disclosed his psychotic experiences early in the interview. He described an extensive history of feeling that others did not believe him in relation to these experiences (in both medical and personal settings). The TMS course was his first experience of telling his story in a more structured way. His story focused on what he termed his "strange experiences" and he used a spoken format. He described feeling that others on the course could not relate to his difficulties, and this appeared to have prevented him from fully expressing himself on the course. He considered himself to be "worse off" than others and came away feeling that telling his story had not achieved much. Therefore, he did not wish to share his story again in future.</p> <p><b>Presentation at interview:</b> Some signs of anxiety but able to develop rapport. Held an open stance.</p>
<p style="text-align: center;"><b>Mark</b></p> <p><b>Age:</b> 58  <b>Gender:</b> Male  <b>Ethnicity:</b> White British  <b>Time involved with RCE:</b> 6 months</p> <p><b>Overview of storytelling experience:</b> TMS was Mark's first experience of telling his story. He used a written story format, and spoke this out to the group in the final session. For Mark, the most helpful aspect of telling his story had been organising/making sense of his experiences so that he understood himself better. He had gained less from the actual telling, although had found it helpful to feel validated by others in the group. He did not wish to share his story with those closest to him, and felt unsure about telling it again outside of the recovery college environment. However, he felt he would do so if it was going to be two-way sharing or if telling his story was going to be of benefit to the other person.</p> <p><b>Presentation at interview:</b> Reflective and open, appeared to enjoy talking about his storytelling experience and did not require much additional prompting to elaborate on responses.</p>	<p style="text-align: center;"><b>Brad</b></p> <p><b>Age:</b> 46  <b>Gender:</b> Male  <b>Ethnicity:</b> White British  <b>Time involved with RCE:</b> 1 year 7 months</p> <p><b>Overview of storytelling experience:</b> TMS was Brad's first experience of telling his story in a structured way. He described previous clinical experiences of sharing parts of his story, but feeling that this was always restricted by professional agendas/time constraints/lack of recovery focus. Feeling accepted within the recovery college environment had been significant in Brad's journey. He told his story in chronological written format, and enjoyed the freedom of being able to tell his whole story and feel listened to/accepted/validated by others.</p> <p><b>Presentation at interview:</b> Brad spoke about his social anxiety early on and commented that the interview situation was a challenge for him, but one that he was keen to participate in. Despite his anxiety he was able to establish a good rapport and he reported to have enjoyed having the opportunity to talk about his storytelling experience and contribute to this research.</p>

<p style="text-align: center;"><b>Janey</b></p> <p><b>Age:</b> 50  <b>Gender:</b> Female  <b>Ethnicity:</b> White British  <b>Time involved with RCE:</b> 3 years</p> <p><b>Overview of storytelling experience:</b> This was Janey’s first experience of telling her story. Having suffered from depression for several years, she appreciated the time and space to express what this was like. She did this through a spoken story, using props and metaphors to describe her most difficult experiences and how she has managed them. Janey particularly appreciated the mutual telling; feeling heard herself, and enjoying hearing from others. She felt that this positive experience of telling her story on the course had given her the confidence to share her story more widely, but only if she perceived this would benefit/inspire the listener(s).</p> <p><b>Presentation at interview:</b> Janey asked for more information about my personal experience of attending the TMS course. It felt important to her to know more about the angle I was approaching this from, before progressing with the interview. She appeared to relax in to the interview as time went on, and was quite naturally reflective.</p>	<p style="text-align: center;"><b>Lisa</b></p> <p><b>Age:</b> 29  <b>Gender:</b> Female  <b>Ethnicity:</b> White British  <b>Time involved with RCE:</b> 2 years</p> <p><b>Overview of storytelling experience:</b> Lisa told her story via song. She had written this prior to the TMS course, but it was not until coming on the course that she played it to others and spoke about her story around it. Lisa described a painful history of abuse as a child, and experiences that had culminated in a diagnosis of borderline personality disorder. For Lisa, TMS was about expressing her hidden experiences/parts of self, and experiencing a sense of acceptance from others which in turn allowed her to become more emotionally connected with herself. She had told her story again since the TMS course, and felt that she would continue to do so because it was helping her to feel more emotionally connected and to accept the most difficult aspects of her experience, in order to build a meaningful life in spite of these.</p> <p><b>Presentation at interview:</b> It was clear that playing the song felt exposing for Lisa, but it was something that she wanted to do and talk about. She was able to develop a good rapport and was naturally reflective.</p>
<p style="text-align: center;"><b>George</b></p> <p><b>Age:</b> 58  <b>Gender:</b> Male  <b>Ethnicity:</b> Mixed British &amp; Asian  <b>Time involved with RCE:</b> 1 year 4 months</p> <p><b>Overview of storytelling experience:</b> George had attended the TMS course twice and reflected on the difference between each experience. His difficulties centred on being unsure of his identity and where he fits in culturally, which had led him to a deep depression and social anxiety. George described how the first time he told his story he could only do this through a YouTube video that resonated with his experience, as he felt unable to express it through his own words. The second time around, he put together a photo collage that began to put words to how confused he felt in terms of his identity, and how this was impacting on his life. He also began to include elements of hope and a future-focus. George hoped to go on the course again as he felt that next time he’d be ready to tackle some deeper emotional and relational difficulties.</p> <p><b>Presentation at interview:</b> Reflective nature, able to develop a rapport but difficulties expressing himself were evident at times.</p>	<p style="text-align: center;"><b>Judy</b></p> <p><b>Age:</b> 63  <b>Gender:</b> Female  <b>Ethnicity:</b> White British  <b>Time involved with RCE:</b> 6 months</p> <p><b>Overview of storytelling experience:</b> Judy described a long history of contact with psychiatric services and a diagnosis of schizophrenia, but the TMS course was her first experience of telling her story. She spoke it in chronological order, listing what had happened and when. Judy felt that telling her story had been beneficial in helping her to feel organised about all the things that had happened, and to have a new perspective on her difficulties through understanding how they developed over time. She felt unsure about whether she would share her story with others in future, for fear that they may view her as “unstable”.</p> <p><b>Presentation at interview:</b> Observably anxious (repeating “I’m not going to be any good at this” and requiring reassurance that there was no right or wrong, any experience was valid etc). Judy had difficulty elaborating on her responses and often could not find the words to describe her experience, but was clear that telling her story had helped her quite significantly.</p>

## Appendix M

### Focus Group 2 Participant Information Sheet

Date: 06.01.17  
Version: 4



#### **Focus Group 2 - Participant Information Sheet**

**Study title: A qualitative exploration of Telling My Story in mental health recovery.**

I would like to invite you to take part in a focus group. I am conducting a study that is exploring the role of forming and sharing stories in mental health recovery. The main study involves me interviewing students of the Telling My Story course to find out about their individual experience of forming and sharing recovery stories. This focus group has been set up to involve recovery college students in the analysis stage. Joining the focus group is entirely up to you. Before you decide whether to take part, I would like you to understand why the main study is being run, why this focus group is being held, and what taking part in the focus groups would involve for you. Please feel free to ask me any questions if anything is unclear, and/or to talk to others about the study if you wish.

#### **What is the research study investigating?**

This main study aims to look at the role of storytelling in mental health recovery. Specifically, it is interested in how the experience of constructing a recovery story, sharing this with others, and hearing others share their story impacts on the individual's recovery journey.

#### **What is the background?**

In recent years, mental health services have moved away from the traditional medical model that has focused on reducing symptoms, and are instead focusing on supporting people to find ways of living meaningful lives with or without ongoing symptoms of their conditions. Recovery colleges have been set up, with individuals attending as students, learning about recovery. Recovery-based interventions are led or co-produced by those with lived experience of mental health problems, and there's a suggestion within recovery research that what is needed in order to break down the stigma surrounding mental health is for those with lived experience to be able to share their stories. The 'Telling My Story' course at the recovery college is run by people with lived experience of mental health problems, and it aims to support individuals to construct a story about their recovery journey; making sense of what has happened and what it means to them.

#### **Why is the research study being done?**

Understanding what is helpful or unhelpful about forming and sharing recovery stories will help us to gain a better understanding of the role of storytelling in the individual's recovery journey. This can then guide the development of future interventions and contribute to our understanding of how recovery stories can be shared within our wider society to continue to reduce stigma around mental health. It may also guide the development of measures that can be used to evaluate courses like Telling My Story to see whether they are helping individuals.

#### **What service or intervention is being studied?**

The Telling My Story course at Recovery College East (Peterborough and Cambridge sites) provides an appropriate setting for exploring the role of story-telling within the recovery context.

#### **Why is this focus group being run?**

The chief investigator (CI) is running this focus group in order to share their interpretations of the main study interviews and obtain feedback on how this fits with participants' lived experience of

Date: 06.01.17  
Version: 4

using stories in their own mental health recovery. It is hoped that this will help the CI to reflect on how their findings fit with the lived experience of members of the participant group.

**What will I have to do?**

You will be invited to take part in a focus group of between three and six people, which will be facilitated by the CI. The CI will introduce topics for discussion, which the group can then discuss freely. The focus group will not be recorded on audio or visual device and it will not generate any data to be included in the analysis. Rather, its aim is to generate helpful discussion around the topic area, so that the CI can obtain feedback that will inform their analysis. The CI will make written notes on the discussions held, which will not include any identifiable information.

**What will happen after the focus group?**

The CI will reflect on the discussions held and consider this within their analysis.

**Who is eligible to take part?**

Recovery college students or staff who have attended the Telling My Story course at some point in the past, and were not involved in the interviews for the main part of this study. You will also need to be fluent in speaking and understanding English, in order to participate in the focus group.

**Where will the focus groups be held?**

At Recovery College East, Peterborough or Cambridge base (to be decided with focus group participants – the CI will hold the focus group at the location that is most convenient for participants).

**How long will each interview last?**

The focus group is expected to last for approximately one hour.

**When will the study end?**

The research process is underway and will last until March 2017, when the project is submitted for assessment.

**How will the study findings be fed back to participants?**

The CI will arrange a time to feed back the overall results to the recovery college and you will be invited to attend, with the opportunity to discuss results and offer feedback. You will also be offered the opportunity for individual feedback via telephone discussion, email or in writing if you would prefer.

**Who else will the findings be shared with?**

The findings will be shared within the UK Recovery College Network and the National Health Service. The findings will be written up as the CI's doctoral thesis project. Findings may be published in journals and therefore be publicly available. No identifiable information will be included in the findings.

**How have patients and the public been involved in this study?**

Service-user involvement is highly valued within this project. A summary of the project, the participant information sheet and the consent form have been through an independent service-user panel for feedback. The interview schedule will be developed collaboratively with students at the

Date: 06.01.17  
Version: 4

recovery college. The researcher will also meet with students of the recovery college during the analysis stage for service-user involvement. When the study has finished, there will be a feedback session at the recovery college, and the offer of individual feedback to each participant via telephone/email/letter.

**What are the possible benefits of taking part?**

There are no guaranteed benefits of taking part. However, it is hoped that contributing to research in this way will be a positive and enjoyable process for you. The CI values the involvement of recovery college students in the research process, to make use of your expert experience and conduct a study that is useful and relevant.

**What are the possible disadvantages of taking part?**

The focus group will require your time to travel and attend. The CI will endeavour to minimise this burden by running the focus group at the base that is most convenient for participants.

**What will happen if I no longer want to participate in the focus group?**

You have the right to withdraw from the focus group any point. A decision to withdraw will not affect your involvement with the recovery college in any way.

**What if I am unhappy with any aspect of the study?**

If you have a concern about any aspect of this study, you should ask to speak to the CI who will do their best to answer your questions (please see the contact details at the bottom of this sheet). If you remain unhappy and wish to complain formally, you can do this by contacting Ken Laidlaw (Programme Director, Doctoral Programme in Clinical Psychology, University of East Anglia, email: k.laidlaw@uea.ac.uk or tel: 01603 593600). You may also contact the Cambridgeshire and Peterborough Patient Advice and Liaison Service (PALS) on 01223 726789 or pals@cpft.nhs.uk.

**How will my information be kept confidential?**

Data will be stored in accordance with the Data Protection Act (1998) and University of East Anglia policy. Research data will be stored in either locked cabinets or on encrypted password protected media and will only be accessed by the CI and research supervisors. After ten years, all data will be destroyed. The focus group will not be recorded on an audio or visual device. The CI will make written notes but these will not include any identifiable information. Everything you say at the focus group will remain confidential. However, should you disclose any risk to yourself or others then the CI would need to pass this information on to the relevant professional.

**What should I expect during the consent process?**

The CI will provide you with this Participant Information Sheet and a Consent Form when you are approached about taking part. You can take this information away with you. The CI will then ask for your written consent at the start of the focus group, before any discussions are held. The CI will keep this written record. If you would like any further information at any point, please do not hesitate to contact the CI via the details at the bottom of this form.

**Who is organising and funding this study?**

The study is funded by the Doctoral Programme in Clinical Psychology at the University of East Anglia. The CI is a Trainee Clinical Psychologist on the Clinical Psychology Doctoral Programme.

Date: 06.01.17  
Version: 4

**Who has reviewed this study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by North West Liverpool Central Research Ethics Committee. It has also been approved by Cambridgeshire and Peterborough Foundation Trust Research and Development department.

**Further information and contact details:**

If you require any further information or would like to discuss participation further, please do not hesitate to contact the CI via the following details:

Chief Investigator's name: Kate Nurser (Trainee Clinical Psychologist)  
Mobile: 07804 552684  
Email: [kate.nurser@uea.ac.uk](mailto:kate.nurser@uea.ac.uk)

## Appendix N

### Focus Group 2 Summary Table

Theme	Summary of focus group discussions	Further reflections and follow-up
Highly emotional experience	<p>Participants could relate to ideas about the storytelling experience being “double-edged” – emotionally challenging, but also highly cathartic and rewarding.</p> <p>One participant, however, reported a totally positive experience and said he does not tend to get anxious. Another reported high anxiety, but described it as “good anxiety”.</p> <p>Acknowledged as particularly difficult for those with perfectionist tendencies who may feel pressured to get their story absolutely right.</p> <p>Discussed the emotional impact of listening to others’ experiences as well. Evident within the interview data, although comments on listening to others’ stories were more strongly in relation to feeling inspired.</p>	<p>Discussion of this theme highlighted the individuality in how it is experienced emotionally, but intense feelings reported by all.</p>
Importance of feeling safe to disclose	<p>All participants mentioned ideas relating to “safety” within the focus group introductions, when they were asked to give a brief outline of their experience of the TMS course.</p> <p>Similar language used in relation to safety and belonging, and some attachment-based language (“warmth”, “containment”, “trust”, “validation”).</p> <p>Participants could relate to difficulties sharing their story in environments outside of the course.</p> <p>One participant spoke of how over time, his story has given him a sense of safety within himself, which he described as “taking the TMS environment with him”. He has continued to tell his story in various settings and described how this feeling of internal safety has developed over a longer period of time.</p>	<p>Resonates with participant data. Interview data suggests some internalisation of validation from others, but not to the extent of “carrying safety with them” as reported by focus group participant. Perhaps this takes much more time to develop (if it is going to) – focus group participant further on in recovery.</p>
Renewed sense of self	<p>Participants focused on the idea of positive reframing and felt particularly strongly about this being a key part of the storytelling process.</p> <p>Also discussed how the renewed sense of self continues to develop. Ideas around an “ongoing journey”, with TMS starting the process of discovery and helping the individual to open up, so that they can then continue to do this beyond the course.</p> <p>Two of the focus group participants were further on in their journey than most interview participants (more time had elapsed since the course) so it was interesting to hear their perspective that the process of self-discovery has continued far beyond the course, for them.</p>	<p>Resonates with the participant data.</p>

Two-way process	The idea of self-other comparison being a negative process for some sparked discussion. All focus group participants had found the mutual relationship with others in the group to be beneficial, and felt that the course stripped their mental health problem of its label because it didn't matter what exact diagnosis/difficulty they had – it was about the shared experience of having a mental health problem per se and not being alone in this. However, they contemplated how some individuals who might be more attached to or defined by their diagnosis, might have difficulty attuning to the recovery approach that doesn't really focus on diagnosis.	Feeds into the ideas for future developments of storytelling interventions, as outlined in the empirical paper discussion and discussion chapter. Perhaps TMS storytelling is not suitable for all, or for every stage of recovery.
A novel activity	Participants liked the content of this theme. However, it was presented to them with the title “a novel performance” and they felt that the word “performance” made the storytelling process sound disingenuous, lacking in authenticity, when actually it was highly meaningful to them.	The word “performance” was not used in the theme title. The key concept of this theme is “novelty”, which was retained within the title.

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