REVISITING THE NARRATIVE RESEARCH PROJECT: A FOLLOW-UP STUDY OF MENTAL HEALTH RECOVERY

Dr Sue Cowan and Dr Jennie Guise
Working Well Together Ltd

May 2011
Acknowledgements

We would like to thank all the participants, who gave so generously of their time to share their views and experiences with us. We are also indebted to Lucy Mulvagh, from the Scottish Recovery Network for her invaluable administrative support.
# CONTENTS

1. INTRODUCTION.............................................................................................................. 1
   1.1 Background .................................................................................................................. 1
   1.2 Aim ............................................................................................................................... 2

2. METHODS ............................................................................................................................ 3
   2.1 Recruiting participants ............................................................................................... 3
   2.2 Data collection ............................................................................................................ 3
   2.3 Analysis ....................................................................................................................... 4
   2.4 Ethical issues .............................................................................................................. 4
   2.5 Demographics ............................................................................................................ 4

3. FINDINGS ............................................................................................................................... 6
   3.1 Introduction .................................................................................................................. 6
      3.1.1 Understanding the quotations ............................................................................. 6
   3.2 Issues related to telling the story ............................................................................... 7
      3.2.1 Summary of findings .......................................................................................... 7
      3.2.2 The importance of telling the story ....................................................................... 7
      3.2.3 The emotional impact of telling the story .......................................................... 8
      3.2.4 The impact of stories of recovery on other people ............................................. 9
      3.2.5 Key issues ............................................................................................................ 9
   3.3 The process and nature of recovery .......................................................................... 11
      3.3.1 Summary of findings .......................................................................................... 11
      3.3.2 The start of recovery ............................................................................................ 11
      3.3.3 The progression of recovery ............................................................................... 12
      3.3.4 Recovery and self-identity .................................................................................. 14
      3.3.5 Key issues ............................................................................................................ 15
   3.4 Relationships with services ....................................................................................... 16
      3.4.1 Summary of findings .......................................................................................... 16
      3.4.2 The impact of services on recovery ...................................................................... 16
      3.4.3 Disempowerment in relation to services ............................................................ 18
      3.4.4 Redressing the power imbalance in working with services ................................ 18
      3.4.5 Key issues ............................................................................................................ 19
   3.5 What helps recovery .................................................................................................. 20
      3.5.1 Summary of findings .......................................................................................... 20
1. INTRODUCTION

1.1 Background

The Scottish Recovery Network (SRN) was formally launched in 2004, as part of what was then the Scottish Executive (now Scottish Government) National Programme for Improving Mental Health and Wellbeing. At that time, the SRN had a specific role to play in supporting one of the four aims of the Programme: to promote and support recovery. However, although the National Programme has now come to an end, the SRN continues to play a key role in mental health improvements in Scotland through promoting recovery-oriented approaches and awareness-raising.

In 2007, the SRN reported on a study of narratives of mental health recovery (Brown & Kandirikirira, 2007). This research sought to build on the evidence base of other narrative studies of recovery, conducted predominately in the US and New Zealand (e.g. Jacobson, 2001; Lapsley, Nikora & Black, 2002) by exploring the experience of recovery from mental health problems of 64 individuals in Scotland. In particular, it was anticipated that information from these stories would assist other people with long-term mental health difficulties on their own recovery journey. It was also envisaged that this evidence would help carers, communities and professionals to gain a better understanding of what factors help, or hinder, recovery from long-term mental health problems. The study findings have underpinned the work of the SRN, and formed the primary evidence base for the development of nationally disseminated recovery training materials. In addition to the final study report, other materials published on the basis of the findings of the study include a booklet of individually summarised narratives called ‘Journeys of Recovery’ (Scottish Recovery Network, 2006), and a booklet of tips and strategies informed by the research called ‘Routes to Recovery’ (Scottish Recovery Network, 2007).

It is now six years since the narratives that formed the basis of the original study were collected. Although the original research was never designed to be extended, it was felt that a study that followed up those participants who took part in the original narrative project would be of considerable interest and value to a range of stakeholders.

Dorrer (2006) has pointed out that longitudinal outcome studies of mental health recovery have tended to use outcome measures that are inconsistent with service users’ perspectives on what constitutes recovery. In particular, they have used traditional objective psychiatric outcome measures, such as a reduction in psychiatric symptoms or number and duration of hospital admissions. Although quality of life outcomes could be viewed as more compatible with the ways in which service users define recovery outcomes, where such measures have been used they have tended to be researcher, rather than service user determined.

---

1 Henceforth referred to as ‘the original narrative project/study’ or the ‘the original project/study’
2 Realising Recovery Training Materials (SRN & NES, 2008); discussed further on p.18
The current study addresses these limitations through the use of a narrative approach. To our knowledge, this is the first narrative follow-up study to be conducted of mental health recovery.

1.2 Aim

The aim of the study was to explore the ways in which participants’ recovery journeys have developed since their involvement in the original narrative project.
2. METHODS

2.1 Recruiting participants

It was not possible to contact directly the 64 participants whose narratives were included in the original narrative project. This was due to the fact that the original study’s compliance with data protection requirements meant that their contact details had not been retained by SRN.

A call for participants (Appendix 1) was put out on the SRN website and circulated in two electronic and postal newsletters to members of the SRN mailing list. In addition, four consecutive weekly advertisements were placed in ‘The Big Issue in Scotland’ and a flyer was put in delegate packs for the SRN national conference.

The only criterion for inclusion was that people had to have participated in the original narrative study. People who were interested in taking part in the follow-up were asked to contact SRN, in the first instance, for a participant information sheet (Appendix 2) containing further details about the study. Thirteen people were sent information sheets, and all responded indicating their wish to take part. However, one individual withdrew the day before the scheduled interview and another did not attend the interview. Thus, the final group of participants comprised eleven individuals.

2.2 Data collection

Interviews took place in Dundee, Glasgow and Edinburgh. Participants elected which location they wanted to attend for interview.

The study employed a narrative approach. Interviews were unstructured, although all began with an opening question whereby participants were invited to discuss why, having taken part in the original narrative project, they had decided to participate in the current study. With this exception, there were no set questions that were asked of all participants. Instead, in recognition of the individual and unique nature of each person’s recovery journey, follow-up interviews took the form of a conversation in which the interviewer encouraged the participant to talk about how their recovery had developed since they told their story for the original narrative project.

In order to prepare for each interview, the researchers familiarised themselves with each participant’s original interview transcript. This meant it was possible to ask about specific points of interest that came up in each participant’s original interview, if they were not raised spontaneously by that participant in the follow-up interview. Interviews were, therefore, conducted in a relatively informal manner and took the form of an everyday conversation with the emphasis very much on each participant’s perspectives and experiences.

3 ‘The Big Issue in Scotland’ is a weekly entertainment and current affairs magazine, the sale of which supports homeless and vulnerable people.
Interviews were open-ended and lasted between fifty minutes and one hour and fifty minutes. However, the majority lasted around an hour. All interviews were audio-taped and transcribed verbatim.

2.3 Analysis

Data were analysed using a modified version of 'Framework' (Ritchie & Spencer, 1994). Framework is a method of qualitative analysis developed at the National Centre for Social Research for use in applied policy research. Analysis was aided by the use of NVivo 8, a qualitative analysis software package. The analysis involved reading and re-reading the interview transcripts, the development of initial coding categories and later emerging themes, and the use of constant comparison of emerging categories and themes within and across transcripts. The final themes were then used as the basis for selecting text that could serve as exemplars.

2.4 Ethical issues

The study was conducted in accordance with the code of ethics and conduct of The British Psychological Society (The British Psychological Society, 2009).

Individuals who answered one of the calls for participants were sent a participant information sheet, providing details of the purpose and nature of the study. In addition, they were invited to contact SRN for any further information they felt they needed prior to deciding whether they wished to take part.

Those participants who attended for interview were provided with an interview information sheet (Appendix 4) which provided further details about the process. They were also given an opportunity to ask any questions they had about the study before finally deciding whether they wished to participate. Those who decided to participate were asked to sign a consent form (Appendix 5). Participants were informed that they could withdraw from the study, and withdraw consent for the use of any data collected, without the need to give a reason, at any time.

During the interview, participants were asked to reflect on their experiences in relation to recovery. It was recognised that not all of these would necessarily be positive, and that some participants might find talking about such experiences upsetting. Therefore, a counsellor was made available, should participants feel they needed to speak to one post-interview.

Once transcribed, interview data were returned to participants who were invited to review them and to clarify any issues or remove information that, in retrospect, they would rather they had not shared. All data were stored securely in accordance with data protection legislation. All names and identifying information have been changed to protect the anonymity of participants.

2.5 Demographics

Demographic data for each participant were collected using a short questionnaire (Appendix 3).
The final group of participants comprised eight women and three men, all aged between 35 and 64 years of age. Seven were in paid work and two in unpaid work. Four were receiving support from statutory services. Five were currently being prescribed medication. Eight participants indicated that they had a current diagnosis. These included a range of diagnostic categories, the most common of which was depression.
3. FINDINGS

3.1 Introduction

The framework analysis of interview transcripts resulted in the identification of six key themes:

- Issues related to telling the story
- The process and nature of recovery
- Relationships with services
- What helps recovery
- Problematic implications of recovery
- The role of work in recovery

The themes cannot always be separated entirely from each other – there is some degree of overlap in the ideas that were expressed.

Each of the above themes will be discussed in turn. These sections begin with a brief review of literature relevant to the area, where this is available. This is followed by a summary of our findings, illustrated by extracts from the transcripts. Each section ends with 'key issues' which provides an analysis and discussion of how the findings relate to the existing literature.

3.1.1 Understanding the quotations

The quotations that follow in this section are taken word for word from transcripts of the interviews. In brackets after the quotations, we have provided initials to indicate which participant was speaking. These are not the participants' own initials, to preserve their anonymity. After the initials we have provided the line number from the transcript. This gives some indication of where in the interview the quotation appeared.
3.2 Issues related to telling the story

Story-telling is regarded as a natural human process that helps people to understand their lives and themselves (Sarbin, 1986). We construct our stories about our lives in such a way as to bring meaning and a sense of coherence to our experiences and our sense of self, and to integrate our thoughts and feelings. Once we have given structure and meaning to our experiences, the emotions that accompany those experiences are more manageable (Pennebaker & Seagal, 1999). At times of transitions in our lives - for example, as a result of trauma, mental or physical illness - our self-identity is threatened. The stories that we once told can then fail to bring the necessary order and coherence to our lives (Frank, 1995). We therefore need to tell our stories in different ways, and reformulate our self-identity so that we can again make sense of our world and our place within it. In recognition of this, story-telling, in which the therapist supports the client to re-author his or her story, is often used as a therapeutic tool within psychotherapy, (McLeod, 1997).

3.2.1 Summary of findings

In the course of speaking to participants about why they had decided to come forward for a follow-up interview, we explored issues around telling their stories of recovery. We found that the issues that arose related to three areas. The first was the importance of telling their story. The second was the emotional impact that telling the story had on the narrator. The third issue related to the impact that stories might have on other people.

3.2.2 The importance of telling the story

Some participants described telling their story as being significant in their moving forward:

For me personally, the first research was so powerful and so important to my journey of recovery (TS 52)

It was a bit of a catalyst I think, I could see a light at the end of the tunnel (CY 86)

Other reasons were given to explain the importance of telling their story. It provided some opportunity to reflect on past events. They were sometimes then seen as more real, and the story seemed more coherent than perhaps it seemed as it was unfolding:
I thought long and hard about it, but I thought that this is an opportunity to reflect on the last five years. To think where I’ve got to and what the differences are (KB 45)

You kind of take a process of change pretty much in its stride and you don’t often reflect kind of – what is happening here, what has happened, what has changed – and taking part in the study kind of meant that you sit down and look at that (FD 99)

It makes it real. If I read my story in a book then I wouldn’t believe it, you know, there has to be a limit to how much misfortune can happen to people, and how many bad experiences a person can have in their life (HN 1420)

Some participants found that the fact of being asked, listened to, and heard by others was of value in itself:

I had literally been paying people to do therapeutic work, and part of that was being able to tell and make sense of my own stories, so there was such a contrast to have someone offer that invitation even in the context of a research study. So that felt very, very powerful at the time… I wasn’t doing it for therapeutic reasons, but it was something of a milestone to participate in something that was more public because most of the other work I had done was in a therapeutic context (IS 84)

Recovery stories were described as important because they provide a record of what happened, with the narrator as author:

An opportunity to get things down (KB 106)

For me, the initial interview was something like having a focus to sit down and write things out in my own words, my own understanding of where I was and how I got to be there without other people interjecting, like – no, no, it was like this or it was like that. I was actually able to express things the way that I had perceived things, rather than being influenced by other people. So I think for me, that was really important (TS 68)

3.2.3 The emotional impact of telling the story

The process of telling their story was described at times as upsetting, although this was sometimes seen as cathartic:

Even though it was anonymous, which made it an awful lot easier, it was also quite unsettling and in some ways destabilising in terms of symptoms (IS 95)

I just didn’t find it a helpful experience and I was quite distressed afterwards (OB 822)
I think I found the original narrative very cathartic, it was upsetting at times but in the end it was cathartic to share instead of internalising everything (CY 47)

3.2.4 The impact of stories of recovery on other people

There was a strong sense that telling recovery stories could help other people, by giving them hope and making them aware of strategies they might be able to try:

It felt good to think that someone could be helped, or it would give hope to someone or it would inspire someone to rethink the way that they’re living their lives (HN 1393)

I thought it would be a good idea, so if other people like are listening to it, they can actually see that there is light at the end of the tunnel (HB 38)

I think when you talk about your experiences to other people it gives hope to other people that what you’ve been doing has helped you, and maybe they could try and do the same as what I’ve been doing (HB 317)

I think it’s important to put the message out that recovery can happen (CY 40)

People realise that once you’re down there, you don’t have to stay there (ED 69)

If what I’ve gone through helps someone else, it’s all worthwhile (ED 104)

However, there was some concern about the level of expectations that might be raised in relation to recovery, and also that the impact of recovery stories on professional practice might be limited:

I also have a very substantial wariness about the sorts of expectations that can be raised by the word recovery… I struggle a bit in terms of the kind of changes that might be likely to be possible and the kind of expectations that might be raised in terms of the levels of changes that might be possible for everybody (IS 234)

People can tell their own personal journeys in anything, but was what was said, or what was explained, taken and actually put into practice? (HI 456)

If there’s anything that can be done to help people understand, and also from the professional point of view, some of the professionals like GPs still find it very difficult to understand (DF 44)

3.2.5 Key issues

From participants’ accounts, telling their recovery story can be a difficult, but personally useful exercise. Although the stories were not told in a therapeutic context, it may be that the act of telling them enabled participants to better make
sense of their experiences and themselves. This might, in part, explain the impact telling their stories had on helping participants to move forward.

A large part of the discussion around telling recovery stories related to the impact this might have on other people. There was a feeling that these stories could provide hope and guidance, but that they could also be demoralising for other people with mental health problems. A similar issue emerged in a study conducted by Tilley and Asquith (2008) about the story of recovery in Edinburgh and Scotland. They found that some people felt under pressure to recover, and that not recovering could be seen as failure. In addition, while telling their story was acknowledged to be beneficial to participants themselves, there was some concern that the stories might not influence the practice of some professionals.
3.3 The process and nature of recovery

There has been considerable discussion and attempts to define what is actually meant by ‘recovery’ (e.g. Anthony, 1993; Deegan, 1988; Onken, Craig, Ridgeway, Ralph & Cook, 2007; Resnick, Fontana, Lehman & Rosenheck, 2005; Warner, 2004). However, tensions remain between the humanistic view of recovery and the biomedical model that has traditionally informed psychiatry, and whether recovery is a process or an outcome (Stickley & Wright, 2011). Thus, there is no single, agreed definition of recovery on which consensus can be reached. Instead, it is generally agreed that the definition and meaning of recovery will vary from person to person (Allot & Lognanthan, 2002; Hatfield & Lefley, 1993; Repper & Perkins, 2003) based on the values that an individual has developed as a result of their life experience (Allot & Lognanthan, 2002; Hatfield & Lefley, 1993). The Scottish Recovery Network provides a description of recovery that is based on the original narrative research project:

“Recovery is being able to live a meaningful and satisfying life, as defined by each person, in the presence or absence of symptoms. It is about having control over and input into your own life. Each individual’s recovery, like his or her experience of the mental health problems or illness, is a unique and deeply personal process.” (Scottish Recovery Network, 2006: 1)

3.3.1 Summary of findings

The process of recovery, and what it meant, was different for everyone. Some people found the metaphor of a journey or a road was useful. Participants spoke about how recovery might start, and how it progressed. They also discussed recovery in terms of the impact it could have on self-identity:

3.3.2 The start of recovery

Participants described the start of their recovery in terms of personal motivation, sparked by insight, frustration or the need to do something different:

So what happens is the day that you start realising I suppose is the best word, as to how you’re feeling… the journey starts (HI 394)

Well, I was so desperate to get out of it, and me being desperate that’s what I’ve done, I went and done all these things that I’ve achieved (HB 599)

There was this feeling of – there are things I would like to do – and I think I kind of lost or buried kind of any kind of sense of spirituality and desire, kind of, who I want to be, what I want to do… it was this kind of, emerging aspirations (FD 348)
For a while, I had been pretty low, and again it’s repeating old ground, didn’t want to go out, the usual kind of stuff at that time. And we were out a lot with the dog and I just happened to see that (an ornament) in somebody’s garden and I can’t explain it but it tweaking my interest… and that for some reason I can’t explain, that’s where things started to turn round (ED 406)

3.3.3 The progression of recovery

Generally, recovery was described as a long and ongoing process:

It’s not that you’ve recovered and that’s it, everything is okay and your garden is rosy because it doesn’t work that way (HN 768)

It still feels a very long road (IS 154)

You don’t really come to the end of the journey, I don’t think (ED 501)

I can’t see the end of the journey (HI 395)

I think that will be a lifelong thing (CY 287)

Some implications arose from discussions of the ongoing nature of recovery. It involves conscious effort on the part of the individual with mental health problems. This is a fact that is not always recognised by others:

A lot of it is self-help, trying to keep involved in things and doing things that are positive (HI 431)

Recovery is about being able to move forward, it’s about being able to direct how you move forward, it’s about managing life no matter what happens (TS 283)

I think it’s up to each individual, because at the end of the day it’s been up to me and what I’ve been doing (HB 596)

Just because you are discharged doesn’t mean that you’re okay or that you’re coping without a lot of effort (DF 294)

It’s bloody hard work and I once said to a doctor that this was hard work… and she said, what are you talking about? What do you mean? This keeping well is what I meant (OB 1247)

In addition, progress should be seen, and appreciated, in the small steps that move people in the right direction:

For me, recovery could be as simple as not having to take so many tablets or being able to do the shopping by myself or taking my dog for a walk… it’s the small things… Aim for the sky and you’re likely to get burnt, aim for a foot in front of you and it’s much easier to achieve (HN 1165)
It starts with a tiny step… and then it was another step… it was just step by step, things came back to what you class as a kind of normality (ED 474)

The jigsaw is beginning to move into place… but there were a million pieces and you can’t put a million pieces back together in one go (DF 483)

I’m the kind of person that I want to run, I don’t want to walk, but I realised quite quickly that there was a process here, and that I had to take every step at a time (CY 154)

Sometimes, progress seems to come to a halt. An awareness of this can help the individual to view it as an opportunity to rest and take stock, rather than a failure:

I think part of recovery, particularly in terms of mental health, can involve periods of being stuck (IS 240)

There’s something about, sometimes part of that journey is pausing, and it’s never too late to pick it up again because it’s not a constant. I don’t think. Like the nature of life, you have to pause and pausing is about reflection as well (TS 328)

(Using the metaphor of a road to describe recovery) I’ve got choices, whether I want to stop and let the traffic by or whether I want to go to the beach (KB 676)

It is also important for some to come to terms with the fact that for participants, illness always seems to be in the background, with the sometimes frightening prospect of setbacks:

To a degree, I have recovered. But I think it’s always there, once you’ve had something like that, I think it can be there, and if you let your guard down too much, or if there’s a problem in your life, I don’t know that it would be very difficult for it (illness) to jump back in (ED 113)

The journey looks like a long and lonely road… like through a wilderness, and you’re groping all the way along to stay on that track, and not fall over into the muddy, miry pit (DF 418)

If I became, you know, very unwell again… that is my fear, you know, but my hopes are that because I’m learning, and I’ve got this far at the moment, that they are just a passing place or a little bit back to the start again, rather than to places that I have been in the past (KB 1150)

You have this dread if you like, of going back, right down the slope (DF 735)

However, participants said that the nature of these setbacks might be different from before:
The whole thing set me right back to when I was very ill… the memories of being as ill as that… but I did manage to get through that, and I didn’t you know… well I did go back to the doctor and that, but I didn’t take any medication that was offered at the time (KB 805)

I also know that there are times when I do fall apart… and it’s maybe not as often, it isn’t as often, I mean there’s no doubt about that (DF 100)

In the winter, I had another breakdown and ended up back as an in-patient, and it’s taken me since then to get back on my feet again. It seems to have been a longer bounce back for me… this time, my self-confidence took a huge smack, and it took me a lot longer to stick my head back up above the parapet (HN 120)

I think the difference is, that the times that I fall to that extent are far less, and don’t tend to last as long, but are they better?… When I’m actually at that point of lying catatonic in bed in hospital, unable to move or eat or drink or talk, then in many ways that feels the same as it has always done (TS 181)

As we can see from the above extracts, some participants regarded recovery as a lifelong journey. However, from the point of view of others, complete recovery is possible:

If there was a time came that I actually got a job even five hours, ten hours a week, I think that would… make me feel that I had recovered… I do think that people can recover (HB 587)

For me, kind of the term recovery is embedded in a philosophy and a culture of illness… and I’m not ill. I haven’t been ill for ten years. Well, I was probably in recovery for maybe five years of that… I’d lost a lot of abilities to cope with day-to-day functioning, whether it was picking up a telephone or getting on a bus, whether it was dealing with how I felt when I woke up one morning. I don’t have any of those disabilities, and therefore I’ve got at least, and I think a lot further, at least the level of wellness that I was before I had my health problems. I actually think I’m a lot better now than I was pre-illness (FD 153, 431)

3.3.4 Recovery and self-identity

Some participants spoke about recovering who they once were, and others described a change. One aspect that was important was the development of a self-identity where they were not defined primarily in terms of their mental health difficulties:

I don’t look at myself as a… sick person any more. You know, I don’t think that way now (ED 724)
I will never, ever take it for granted again – that’s me, I’m at the end of the journey, I’m cured, I’m the old person I used to be – no, that person has gone, that life has gone, this is a new life, a new person with new skills (CY 486)

Now I think that recovery probably is that you still have… you have scars but you don’t see them, and you can live with those scars, you know (KB 1375)

I don’t want to define all of my life in terms of what I’m recovering from, so I want to continue to grow and develop (IS 203)

I’m fed up of thinking of myself within the mental health framework and recovery is linked to that… what I’m probably more interested in is: I am who I am, I have experiences, I have past, difficult life experiences and I’m not static. I am developing self-awareness and growing as a person (OB 909)

3.3.5 Key issues

While the uniqueness of each participant’s recovery journey was evident in their individual narratives, there was some consensus across participants in relation to certain aspects of that journey. Recovery was spoken about mainly as a long process, a road with dips and bumps. For some, this was a lifelong journey, while for others it was possible to be completely recovered. This reflects the tensions in the literature between recovery as a process and as an outcome (Stickley & Wright, 2011). The impetus for starting the process came from the individual. Continued progress, over time, involved a good deal of personal effort, both in practical and emotional terms.

As noted earlier, illness can have an impact on our self-identity. It can result in a need to reconstruct our identity in the context of the ‘new’ story of illness, in order to bring coherence to how we make sense of our world and our place within it. It is perhaps not surprising, therefore, that recovery had an impact on participants’ self-identity, as they moved beyond ‘illness’. The reformulation of a self-identity in which mental health difficulties are no longer to the fore is likely to restore structure and meaning to someone who is on a recovery journey.
3.4 Relationships with services

In recent years, there has been considerable emphasis on the need for services to develop a recovery-oriented focus. This has, to a large extent, been the result of national policy developments. These have included the Scottish Government’s vision for mental health service improvement - Delivering for Mental Health (Scottish Executive, 2006a) and the national review of mental health nursing ‘Rights, Relationships and Recovery (Scottish Executive, 2006b).

Delivering for Mental Health contained a commitment to develop a tool to evaluate the extent to which the activities of mental health services supported recovery. This resulted in the launch of the Scottish Recovery Indicator in 2009 (Scottish Recovery Network, 2009). The nursing review’s Delivery Action Plan (Scottish Executive, 2006c) also contained a number of recovery-focused objectives, including the development of a national framework for training mental health workers in recovery-based practice (NHS Education for Scotland & Scottish Recovery Network, 2007), and a set of national recovery training materials called Realising Recovery (NHS Education for Scotland & Scottish Recovery Network 2008). These have now been widely disseminated across Scotland and it is worth noting that the primary evidence base for these learning materials was the original SRN narrative research study.

3.4.1 Summary of findings

Participants described the significance of services, in terms of the impact they could have on recovery, both good and bad. Several spoke about the ways in which they could be disempowered by the system of service provision, and things that could be done to redress this power imbalance.

3.4.2 The impact of services on recovery

Some participants felt that it was hard to access the help that they needed. A number of reasons were given – including the difficulty of finding a GP who had an adequate understanding of mental health problems:

I had got a much better GP to help me contact other services and... this person had a better understanding of mental health, which is the seventh GP that I have spoken to since I wasn’t well. So it was the first time I was actually getting somewhere (HI 52)

My original GP, that I had known for years and had been exceptionally good with all my children… when it came along to me being ill, just didn’t know or understand… there are an awful lot of these GPs that really don’t seem to understand that you’re not just making it up (DF 826)

Participants appreciated the involvement of professionals who had appropriate attitudes and values, in particular a non-judgemental approach. One difficulty potentially relating to this is that, having found the ‘right’ professional, it can be hard when that person moves on:
I didn’t feel that I was talking to someone who wasn’t on the same wavelength and this is all because I’ve had a GP that was willing to take that step to understand mental health as an illness, and not stigmatise you or show you the door (HI 74)

When I got referred to the Consultant Psychiatrist, that’s when I really started feeling that things were fitting into place. He had much more of an attention span when you were speaking. He’s actually writing down what was wrong with you and never criticise or stigmatise you. It didn’t matter what you said to him, he was very open in how he answered you (HI 157)

I’ve found a psychiatrist that I trust, and now she’s going. I don’t like it… It’s taken me twenty-something years to find a psychiatrist that I actually like and that will listen (HN 522)

The psychiatrist that deals with post-traumatic stress that I go to, he’s actually getting referred to the wards to work… it means I have to go back to a psychiatrist that doesn’t deal with PTS (Post Traumatic Stress) (HB 269)

Participants spoke about the benefits of diagnosis, in terms of getting access to the right treatment and other support, and also as a means of validating their feelings:

The PTS actually got a bit better because of this type of treatment, whereas if I’d had it (the diagnosis) years ago, I would have probably got better sooner (HB 266)

There are benefits to having a diagnosis, to being part of the system, to seeing yourself as being mentally ill, but then that conflicts if you’re someone who thinks differently. To be able to access the support you need or want without a diagnosis, you won’t get it (OB 1154)

For me, being able to relate to a diagnosis eventually after all these years then empowered me to then find out more about it and gave me that sense of – I now know – I feel my feelings have been validated, I feel my experiences have been validated, and I now have the capacity to look at how to manage in this situation (TS 219)

Some participants felt that services are not always set up to provide the right kind of support at the right time:

The focus is on – let’s see how bad they get before they have a crisis, and then we might kick in with some medication or something else (OB 1119)
I did feel myself slipping back and I went to the doctors and said – I know that I’m slipping downhill, please can I get some help before I reach the bottom. I did get some help, in inverted commas, I had two people, a doctor and somebody came out from the mental health unit and interviewed me… and told me that there was nothing that they could do to help me, because I wasn’t ill enough (DF 244)

I couldn’t get psychology, which I’d fought for three years for, and thought – stuff this, and went and sought counselling elsewhere (OB 1012)

3.4.3 Disempowerment in relation to services

An important aspect of relationships with services is the potential power dynamic. People with mental health problems may be dependent, to some extent, on services for treatment and other types of support. Participants had not always found this a positive experience:

You’ve actually got to teach yourself the problem, you’ve got to understand it yourself, but you can’t medicate yourself, that’s where people come in who are qualified (HI 470)

I just thought that I’d grown past mental health services or psychiatric services, I thought - I can't stand having this relationship with a CPN (Community Psychiatric Nurse) - because I just feel patronised. I don’t like these appointments with the psychiatrist, because really it’s a medication check (OB 999)

I would very much say that in the past, the services had turned out to be abusive, in the sense of the power dynamic and preventing me having my own mind and restricting my freedom (TS 107)

3.4.4 Redressing the power imbalance in working with services

Participants spoke about the importance of having choices. Making choices was seen to be important in taking back control.

I think it’s important that it’s people’s choice, and that if people choose to work in a recovery-oriented way, then that should be an individual choice (IS 238)

I’m able to ask for the support that I actually want and there’s a great deal of choice about whether or not I take the support that’s offered (TS 112)

I was keen for the change to happen and I also became more vocal in relation to writing a WRAP (Wellness Recovery Action Plan) and actually being able to say – actually, this is how I’m going to take control of my life (TS 526)

However, as implied in the last extract, taking back control involves responsibility for the choices made, and their outcomes. This was noted by other participants:
I think probably for the first half of my illness I didn’t want to have to do anything, it was everyone else’s responsibility, and that was fine. I was okay being unwell while it wasn’t my responsibility, because whatever I did, it wasn’t my fault… I can go into hospital and get them to fix it or get them to give me sanctuary. That was fine for four or five years, and then I started to feel uncomfortable with that… so I started to take part in treatment programmes, become an active participant with treatment, with psychiatrists, with psychologists, and becoming proactive about trying to get well (FD 327)

I think that’s part of my difficulty with services was that I never bought into it. I was quite heavily medicated, and at times I wanted it, but on reflection back, that was always just a way of me not taking responsibility, life was too difficult (OB 987)

I also think that there’s something about being able to get a message out to people who do use services, this whole idea about personal responsibility, about what people need to do and the decisions that people need to make, and that just because you’re a service user does not mean you’re not accountable. I think that that’s a message that really needs to be sent out loud and clear to people, that this is actually a two-way process (IS 607)

3.4.5 Key issues

Mental health services have a major role to play in supporting recovery and this has been recognised in key mental health policy statements (e.g. Scottish Executive, 2006a, 2006b). Participants expressed an appreciation of the involvement of professionals who had appropriate attitudes and values. Some participants, however, felt disempowered by their relationship with services. The extent to which recovery policy has been translated into practice, therefore, appears to be variable. In particular, the extent to which recovery-focused practice has been disseminated into primary care, as reflected by some participants’ experiences of GPs, appears to be limited. Participants valued having choices and control, which enabled them to play an active role in their own support and treatment. As noted earlier, this is regarded as a key element that must be present in order to support and promote recovery. While none of the participants spoke of any disadvantages associated with having a diagnosis, a number identified benefits. This is an issue that has been shown to be more contentious amongst other groups of service users (Highland Users Group, 2009).
3.5 What helps recovery

As noted previously, there is no universal definition of recovery. A degree of consensus has, however, been reached in relation to the key elements that must be present in order to promote and support recovery. These include: hope, meaning and purpose in life, choice and control, the development of self-management techniques, risk-taking, relationships, social roles and meaningful activities.

Stickley and Wright (2011) found that activities and social roles were key factors. These activities might be, but did not need to be, therapeutic in themselves. They might involve, for example, participation in sport, the arts, or work. Onken and colleagues (2002) report similar findings in relation to meaningful activities, but in addition noted the importance of personal resourcefulness, self-care, self-agency and empowerment. This section describes the factors that participants spoke of as helpful in their recovery. A significant amount of discussion related to work, and this is therefore examined separately.

3.5.1 Summary of findings

A number of circumstances, strategies and skills were described that can help in recovery. Some participants spoke about the need to somehow address (or at least not to ignore) issues that are not directly related to mental health, such as the feelings of loss and shame that can accompany illness. Several participants talked about the need to develop self-awareness and knowledge of how their mental health difficulties affect them. It was useful for some to draw on past experiences to develop this awareness.

A number of skills were mentioned, that helped participants to manage some of the challenges they faced. Some participants found it useful to take part in an activity that could provide some kind of respite, or enhance self-esteem. Aside from the things that they could do, participants talked about the role of relationships with other people in their recovery.

3.5.2 Addressing issues indirectly related to mental health problems

Some participants spoke about the need to work through difficulties that resulted from, or might have contributed to, their mental health difficulties:

*I think it’s something that is often missed in the sense of recovery, I think that if you face challenges for a considerable period of your life, even when you’re turning things round, when you’re taking steps in your journey and you’re being self-directed, there’s still, for me, an awareness and a rawness of the things that you’ve missed and the things that you’ve lost by the years of being ill, and I think that should never be undermined (TS 385)*
I think that’s one of the things that I’ve had to deal with, how I feel about myself. I don’t think that’s just about my mental health experiences, I think that’s what led me up to crisis and developing quite severe mental health issues (OB 227)

3.5.3 Developing awareness

The concept of self-awareness had resonance for many of the participants:

Just prior to the actual narrative research I had taken these first couple of steps to developing some kind of awareness, and wanting to explore further in my own mind, rather than being led or directed by other people… There’s something about, with insight also comes acceptance and with acceptance comes the ability to move forward. So, insight is part of a crucial process… insight into yourself, your situation, the challenges you face… that’s not to say – okay, I have a mental illness, I can’t do this, I can’t do that (TS 82)

I’m still a vulnerable person and I know that, so I suppose in a way what I’m doing is recognising the warning signs, not personalising everything and doing the best job I can… I’ve learned that, after taking the risks without actually being prepared, that it’s so easy to slip back. So, I think that’s self-preparation, the learning process. It was a necessary step (CY 358)

I think for me to fly is not a good thing, for me to sedately drive along the speed-bumped road, that’s all right (HN 1197)

Asking for help is always one of the biggest things I’ve had trouble with. I’ve always for some reason thought of that as some sort of failure if you’ve got to ask for support or help, and you know, now I’ll do that (KB 998)

As long as I’m doing things at my own pace, where I can control it, that’s all right. The minute that someone tries to put some control over me, I can’t. Maybe that’s part of learning to live with what you’ve got (DF 622)

It was also important for participants to know about their illness:

You actually go through a learning process where you have to learn your illness. It’s a personal thing to everybody, no two people’s illnesses are the same (HI 154)

We sat and worked out when my admissions were and all my admissions were in the winter months, autumn, winter time. Low mood thing, I mean we watched it and I kept a diary and everything… I ended up getting one of those lamp things… and it’s been all right, I’m on a lower dose of antidepressants than I was last winter (HN 513)
I suppose having had the opportunity to pay attention, and learn to manage my symptoms, rather than having them dampened down. I can see changes, and I think that’s given me the opportunity to kind of read what’s going on in my body. I’ve been able to become much more self-aware, and that’s actually helped with self-management (IS 299)

3.5.4 Developing skills

One participant had learned to store up good experiences and draw on them as a resource in times of difficulty:

Looking back I see it as a huge achievement… I don’t think you get much more, a bigger challenge than that… the fact that I got up in front of all those people and spoke, that was bigger to me than flying across the world… yeah, one of those experiences that you bank and maybe bring out later, to reflect on (HN 235)

A couple of months ago I found the report that I wrote when I came back and I was reading it through and remembering how I felt and what the experience had given me and it was like – oh yes, that’s a good one, keep that one. So now the report stays in a little box beside my bed, so I’m feeling if I’m not doing well, or I’m not feeling confident about something, then I’ll take it out and look at it again and think – yes you can do it, don’t worry about it (HN 267)

It was also considered crucial to learn from less positive experiences, to try to face challenges as they arose, and to plan ahead in anticipation of potential future problems:

I never forgot the experiences, never forgot the bad times… but I think part of me forgot that I could crash and burn and if I did it would be quite spectacular (HN 835)

I’m not going to say I have a long-term kind of vision, but neither do I kind of take things on a day-to-day basis. I have an idea of what I want, you know, what I want to be doing and if problems come along then I can, I see them on the horizon and sort of tackle it before it becomes a problem, but if it does come along it’s like – deal with it (FD 465)

You see all the things I should have done before I went to hospital, I never did. All the things that I was advocating other people to do – advanced statements, living wills, all that stuff – I never did it, I just kept thinking that I had time, I was well and everything was great and then the horrible thing happened and I had no advanced statement (HN 1133)

That was a huge step for me, to face things rather than hide from things and now that’s just a basic, day-to-day part of living. If you are going to keep well and keep things in control, as much as you can keep things in control, then you have to face these things (CY 563)
Being involved in activities was seen by some as helpful:

All the voluntary work that I’ve done has got me to where I am because if I never had things like that going on for me, I don’t think that I would have survived my mental health, and I think that’s the most important thing that I’ve done in trying to keep myself well (HB 194)

I could go into the greenhouse and shut the door, potter away and one minute my wife’s saying – dinner time! – and you realise that a couple of hours have gone and for that wee time you were just focused on what you were trying to do… I think it’s important if you can snatch that wee while, where you’re focused on your own thing and put the rest of your worries to the back of your mind (ED 436)

One participant spoke of the particular value in being involved in an activity that was outside the area of mental health:

I’ve been doing a bit of voluntary work… and I also think the reason why it’s helped me is, it’s like I’ve been away from the mental health system, and I feel like - well I think that the best thing that’s been for me has been to move away from going to mental health groups, like drop-in centres or going up to hospital to do different groups and things like that (HB 56)

I think that you can get stuck in a rut with mental health, you can get stuck in a rut with it and I’m not in that position because I don’t want to be stuck in rut, I want to move on (HB 860)

3.5.5 The impact of relationships on recovery

In relation to others, participants discussed the impact, both positive and negative, of support from peers, and the help of partners:

I think being around people who experience mental health problems has probably perpetuated… in the sense of spending the amount of time that I did in the services that I did and what we talked about was our life, was mental health, how our life was, how awful it is, how crap the services are or talking about this member of staff or that psychiatrist and what medication, what benefits you’re on and we’ve got no chance of getting a job because we have mental health problems… it seeps into you (OB 283)

There was a self-help group, which is fine to a point but it also drags you down because if you’re quite a long way up and you go back to this situation with these people who are really, really ill then it’s not actually helping you because they’re looking to you for support and you’re not well enough to give them support (DF 782)
I think it helps if you’ve got a partner. Someone who has been in the same position as yourself so you can help one another because he knows what I’m like and I know what he’s like (HB 336)

I think that’s made a huge difference as well. I think, that family support, because she (partner) is my family, we’ve been together that long… she’s been amazing (HN 1117, 1123)

It’s lots better now than it was from five years ago, partly because I’ve met (partner) and he’s helped me. Having someone else there who really cares and is very helpful and somebody who will listen and somebody who believes in you… and someone who accepts you as you are, not as they thought you should be (DF 425)

One participant spoke of a need to broaden her social circle to include friends with interests in common that go beyond the area of mental illness:

I think part of my recovery in the future has to be looking at – how do I develop friendships that are sustainable, and that are around interest and a common ground that’s not related to mental illness? (TS 269)

3.5.6 Key issues

In talking about recovery, participants mentioned a number of issues that have resonance in the literature. The development of self-awareness was seen as important, as well as the need to improve knowledge of their illness and how it affected them. Some of the skills that were thought to be useful involved reflecting on past experiences, and using them to forestall problems in the future. Participants also spoke about the need to address wider issues, related to their mental health problems but in a less direct way. Some participants noted the advantages in seeking out activities, and social relationships that were not related to the area of mental health.

Participants mentioned the potentially negative influence on their recovery of spending too much time with peers with mental health problems. Specifically, they felt that this led to people focusing on their difficulties, to the extent that they began to feel hopeless about their situation. This highlights the need to develop specific competencies in peer support workers through appropriate training programmes.
3.6 Problematic implications of recovery

In the course of talking about the things that help recovery, some participants drew attention to areas of concern that were not directly related to an improved state of mental health. They might instead be thought of as potential consequences of no longer being categorised, or thought of, as a person with mental health problems.

3.6.1 Summary of findings

Some of the implications of recovery were in themselves quite problematic. These related to the fact that support could be withdrawn, and that it could involve changes in relationships with other people.

3.6.2 Withdrawal of support

Whilst it might be easy to view recovery as a positive experience, some participants found it difficult to adjust to living without access to services and other forms of support that accrue as a result of a diagnosis of mental illness:

*I thought, no, I don’t want this any more, yet when my CPN (Community Psychiatric Nurse) said – I think we’re coming to the end of our time together – I was more like – whoa! Where am I going to get my support from? This is it, recovery! You’re too well now for us so we’re going to stop this service, a psychiatrist wasn’t going to see me now because I wasn’t taking medication… So you think, what is there? Because for me and my thinking is, the psychiatrist is the passport to other things, they open the door to other things and if you don’t have that then you don’t get (OB 1063)*

*I’m slightly apprehensive, you know, that if I ever do need something that I can’t afford that I won’t get it because that’s not what’s provided. I have Disability Living Allowance at the moment, which I’m apprehensive about, because you know, if someone was to reassess me then I’d lose it because the evidence requirements aren’t there – I’m not seeing a psychiatrist, I’m not on medication, I’m not seeing a CPN (Community Psychiatric Nurse) (OB 1134)*

*I do think that it’s really important as well that when you’ve had the intensive sort of therapy side of it, that you have some sort of support, ongoing support, and I think that’s an area that people should be looking at as well, that you need a prop - or certainly I needed a prop… I mean, you have to stand on your own two feet, I know that, but I do think that there should be, like, somewhere where you could go back every six weeks or something, and just have a top-up of something (DF 125)*

*I don’t think that I’ve had any choice because I don’t come in any category, I don’t fill a box, I’m not ill enough (DF 232)*
3.6.3 Changed relationships with other service users

Some participants described a deterioration in relationships resulting from the fact that they were no longer identified with other service users:

I think that for many people part of that journey requires changing their network of friends, so that can be challenging as well. In the sense of if your social network was very much about people and things associated with the hospital and then your life takes a different direction I think that can be quite challenging, that period of being in no-man’s land. I also think that in relation to when you take up positions as in peer support workers, or you’re recognised as a trainer within organisations, that can alienate you as well from people that you’ve known for many years. I think it changes the dynamic sometimes so that people that have supported you in the past or you have supported in the past, that becomes a bit of an issue at times… Sometimes people who haven’t moved in their journey, sometimes it’s just too much, it’s just too painful for them to be part of a circle where other people are moving on and they’re unable to move on for any reason (TS 444)

These days, whilst it annoys some people, I describe myself as recovered and not in recovery… I think that the pressures were actually peer pressures to remain in recovery and not become recovered (FD 133)

3.6.4 Key issues

Two main problems were identified in relation to participants’ concerns about the possible consequences of recovery. A person who is recognised by others to be in recovery, or recovered, might have to manage without the support that was available in the past. There are also problems associated with other people’s reactions.
3.7 The role of work in recovery

Being in employment has been strongly associated with mental health recovery (Coutts, 2007; Stickley & Wright, 2011; Onken et al, 2002). The benefits are various, associated, for example, not just with the potential for greater financial independence and all that comes with it, but also with the opportunities that work can provide for positive social interaction and enhanced self-identity.

3.7.1 Summary of findings

From participants’ talk about work, it seems that it is often seen as a marker of recovery. They spoke about a number of positive aspects of work - it can provide structure, and a sense of meaning or purpose. Work can provide the opportunity for social interaction, recognition, and a feeling of belonging, and it can help a person to learn new skills. Paid work can enhance feelings of self-sufficiency and provide more choices, including those in relation to treatment. Getting the type of work they wanted was described by some participants as quite difficult, and this led to questions about whether or not it is wise to disclose previous mental health difficulties. There are also a number of risks associated with taking work, around the possibility of losing benefits and of becoming ill again as a result of not being able to manage.

All of the participants who were in work at the time of the study were involved in the area of mental health. They described some of the reasons behind this, and the benefits involved, which could include more understanding of participants’ needs in relation to mental health, as well as a boost to self-esteem. However, a number of problematic aspects were raised. These related to the challenging nature of the work, and the fact that becoming a worker could alienate people from friends who are service users. A more significant problem relates to the fact that people are often employed because of their lived experience. This can mean that the individual’s value to the organisation is closely related to his or her experience of mental health problems. For some people, who had not previously found that their experience of mental health difficulties was a source of positive interest to others, the associated boost to self-esteem had an almost addictive quality. This could lead them to over-work, to the detriment of their mental well-being.

3.7.2 Positive aspects of work

Some participants drew attention to the role that work can play in enhancing self-esteem:

Well it gives me a bit of pride in myself. Always been one that wanted to stand on my own two feet, not live off the state. You know, to me the work ethic, in our age group, was very important (ED 321)

Work gave me that sense of meaning and purpose… it’s given me that sense of self-worth, self-respect (TS 298)
(Work gave me) **self-worth**… and that’s hugely important… it had been completely depleted (KB 493)

I got nominated (as Active Citizen of the Year), that was by the council… that was because I was going out and doing public speaking, going to conferences and I was doing talks and things like that, and also going to an art group and doing all the arts and things like that, and someone had nominated me because obviously the work that I did, they thought was really good. That was a big boost to me. I found that really… I just couldn’t believe it. I thought – oh! And when I got the letter I thought – oh, not me, I wouldn’t get anything like that. But I did (HB 133)

(Work is important) for my self-esteem, for my recovery, for my self-esteem it’s like the cherry on top. I’ve done all the hard yards by getting myself back to where I can walk and talk at the same time and function well in society… it’s important for anyone’s self-esteem (HN 947)

For many participants, there was a multitude of benefits associated with working:

I know for me in terms of having structure and focus for time, I’m generally better when I’m in work than at times when I’m not… the structure of work and the opportunity to have an external focus, the opportunities to be interacting with other people… and also other things like income which enable other choices for me, enabled me to pay for counselling, that I wouldn’t have been able to do on benefits the whole time (IS 338)

It’s even as basic as I mean, I get up in the morning, I know I have things that need done, I know that I’m appreciated for what I do, I get paid for what I do and I enjoy what I do (CY 167)

It’s given me an opportunity to make friends to have a part-time job again… to be part of society, to be part of lots of projects and it was a massive turning point even though it was at times really hard to get up and go and be amongst people, and gave me a purpose for the day… Having your own… earning your own money again, you know. I think even from the point of view of treating yourself to a hair-do, the fact that you’ve earned that money makes a difference (KB 149)

I’m uncomfortable around people and I still am, it’s just that I’m awfully good at being uncomfortable and hiding it and that takes a lot of practice. I think also there’s that kind of purpose, there’s that social, I suppose social skills and social interaction. I also think paid employment facilitates things that I want to do in kind of, normal day-to-day life… I have the means to manage my wellness. We’re going away for the weekend. If I wasn’t working, I wouldn’t be able to go away for the weekend (FD 927)
I felt good that I was being paid, I felt good that I could actually say that I had a job. It’s very embarrassing when people ask you what you do and you have to say that you don’t work… I feel a lot more validated as a human being. And in one sense I feel a lot more part of society because I have a job. I feel that I have a sense of purpose, I have a reason to get up and do things (OB 55)

(When you are not working) I think you miss the company... you miss the money (DF 542)

3.7.3 Problems associated with gaining employment

Some participants felt that they were discriminated against in the job market, and had considered the implications of disclosing their mental health difficulties:

Everyone wants a job or to feel valued in some way. To be part of society again because you were so excluded all the time. I don’t care what anyone says about ‘see me’ and all that guff, we’re still excluded, excluded from the job market you know (HN 974)

I was scared to go into work because who would employ me? What sort of job would I get? I didn’t want to do something like stacking shelves somewhere but I was very aware of the fact that I was fifteen or sixteen years unemployed, mental health problems, no qualifications – what the heck was I going to do? Plus somebody who didn’t have much confidence or self-esteem, so who was really going to employ me? (OB 360)

It’s because we’ve had so much trouble for so long if we disclose - to disclose or not to disclose. I had an interview with a job before the one I’ve got and I chose to disclose. I didn’t get the job and I could have done it with my eyes shut but I didn’t get it. Did that have anything to do with it? I don’t really know. I would always disclose because there are big gaps in my life where I’ve been away, you know. I can’t say if they ask, what did you do with those years – oh, I don’t know. For someone like me with the longer-term relapsing things happening, then it’s difficult to explain gaps in your career (HN 1057)

I think, most professional relationships that I have, I’ve gone in and said – I have a history of mental health problems – and kind of put it straight on the table, sold it as a skill and emphasised that it’s not a problem, and it’s not been an issue for anyone. I think we’re very fearful of that approach… What is the risk? I mean I’m not working, if I tell them, I might not be working. If I tell them and then they offer me a job, if any issues come along then I don’t have to hide it because they know about it (FD 767)

4 ‘see me’ is Scotland’s national campaign to end the stigma and discrimination of mental ill-health
I think that it’s really helpful when people can actually be honest… I think it’s actually quite important that people still know that I’m mad, that I have crises, crises that actually mean that I’m actually in hospital, but that’s part of who I am and that’s part of my journey (TS 484)

There was some feeling that the jobs available to people with mental health problems were of generally low status:

There’s so many ways you can convince yourself that you’re not… good enough isn’t the right word, no, that’s not the right word… capable of sustaining a job… I think that working for two hours once a week is plenty for some people. There are some people that will struggle to commit to that. There are others that are more than ready to get a full-time, proper job, in inverted commas, not one of the three Fs: filth, food or filing… it is true, you get jobs in cleaning, you get jobs in cafes and you get jobs filing things for people. I’m not a stupid person, I have qualifications (HN 1006)

I felt equal to anybody else around the table of the Board that I was on. It wasn’t a service user position it was… I was there as me, and I think that was highly valuable…I really didn’t want to work in a gardening project, I didn’t want to work in supported employment. I wanted a job that the people supporting people had (OB 1385)

Some participants felt that the decision to work had to be balanced against the risk of becoming unwell as a result, or of losing state benefits:

I’m thinking about doing something part-time and then I think – well, who will employ me after not having worked since I was 50 and if I was to start doing something, would I cope with it or would it lead me down the long, slippery slope? (DF 550)

If there was some kind of staggered approach… it wouldn’t be so difficult to return to the benefits that you were on if you started work, and it’s not working for you at that time (KB 306)

The whole process of going through, not the Department of Work and Pensions, but the organisation that is funded to support people back into work, was appalling. I hated it, I felt completely patronised. It was like they wanted to know too much about you. Then they started throwing money at me and I had to tell them I didn’t want it, I just wanted to ensure that I was going through a process to ensure that if I was to become well again, then I could get back onto that level of benefits again (OB 536)

3.7.4 Working in the area of mental health

Several advantages were mentioned in relation to working in the area of mental health. It allowed the opportunity to learn more about personal difficulties, and there was some feeling that participants were more likely to find supportive employers in this sector:
Well, you do learn more because of the type of work that I do. You’ve learned a bit more about mental illness, you’ve learned a bit more about issuing people with coping strategies. You talk about, to some of the service users, make sure that you have some me time, you know, a time for yourself, so while you’re giving that stuff out to people, you’re actually taking some of it in yourself. So probably my employment has helped me to gain more knowledge about my own problem (ED 645).

Doing something that I actually choose to do - I’m doing something that I hope makes a difference, I’m doing something that enables me to learn more about myself… (TS 306)

Things have been a bit difficult the past couple of months… but in one way it’s been actually quite incredible how I’ve been supported through that in my work. Times when I’ve thought – I can’t do this, I can’t come to work, I think I’ll have to leave because I’m not coping… but no, if I was finding that too hard just now, then they’d take that away from me. I just came in, did what I could and there were no pressures… I was just really grateful that I was within the organisation that I am within because they’ve given me the space to work though something… if I had gone off sick or anything, I wouldn’t have slipped back into work again. I just found a natural progression. I began to do more and more and more and thought – wow, how did that happen? (OB 739)

In applying for jobs, there is that question – who do you apply to, because you want somebody that’s going to be supportive, and that’s probably why I was thinking about staying within the mental health sector or support sector, because I thought they’d be a more supportive employer (OB 781).

Many felt that they could often make positive use of their lived experience. This in turn could increase their feelings of self-esteem:

I quite strongly hold the view for those of us who identify as having an experience of mental health difficulties, that there is a strong potential to give added value to the work that we do, from that added insight, if we’re able to work with the learning from that (IS 391).

I’m not different from any other support worker, it’s just that I have the added bonus of having lived experience with mental ill health, and I’m willing to share it… Some people are more open to the added value the peer support brings when they see the differences in how they’re working with our service users. In the six months, I’ve achieved more with some of our folks than they have in three years. I don’t have the boundaries that they do (HN 727).

This might sound very huge or big-headed but I’ve had people say, this has saved my life, and you know that is the most important thing you can do… you know, just coming in and listening (KB 483).
I also get the satisfaction of being able to see other people move forward, other people who have been in similar situations where they have been totally lost. They’ve been told, well people have made predictions about what they won’t do, and then to see them move forward, I can’t think of anything more rewarding (TS 308)

Difficulties could, however, arise. These were also related to participants’ experiences of mental health problems, in terms of the type of work, and also in terms of the impact it could have on relationships with friends who were service users:

I do still wonder if it’s healthy in terms of, you know, there’s more to life than mental health. Working within mental health, is it actually too close to my experiences? (OB 856)

I needed more balance, the work-life balance wasn’t there because it had subsumed my whole life, you know, it was all about mental health (HN 853)

In relation to when you take up positions, as in peer support workers, or you’re recognised as a trainer within organisations, that can alienate you as well from people that you’ve known for many years (TS 449)

The most significant problems, however, were related to the possibility of participants over-committing themselves to the point where it could become harmful to their mental health. This could be because of their perception that others think that they should know how to deal with their own difficulties, and should therefore be less prone to setbacks:

Sometimes I feel embarrassed to say that no, it hasn’t been a straight line, because I think that as (job title) in (country), then I should have the capacity to manage my setbacks in a way that makes the journey a bit straighter… you fight towards gaining a reputation and building up a business and then that sudden sense of loss. Will people believe in me? (TS 175)

Some participants felt that the positive value given to their contributions, and the boost this provided to their self-esteem, caused them to work excessively hard.

At the moment, I’m working so much, even at the weekends… so actually I’m very, very aware that I need to pause… and have more confidence to say to people – well, you want training, I’m not able to do it until… - rather than actually saying – yes, yes yes… and I mean, it’s something that has been picked up by my Consultant. He has concerns that I need to pace myself better… I think it’s also, if your self-esteem is tied up with the work that you do, then the feel-good factor is there, so why would you say no? (TS 346)

This could lead to an exacerbation of mental illness, and unfortunately employers were not always seen to provide appropriate support:
I was flying really high, things were going really well, I was quite well respected. People would ask me things, and want to listen to my opinion. It was an amazing time, but they sucked me dry, you know, and that is a danger when you are looking at getting service users involved in really high level, strategy work, that you get burnt out... I've been away for four years, and now I'm back out again, and people are surprised that I'm still alive, you know? So close friends knew that I wasn't well, and they came in to see me in the hospital, and came to see me at home, and phoned and asked about me, sent cards and stuff. See those other people, they didn't bother their arse. People I thought of as friends and allies. Because I wasn't there to have my brain picked any more. That's what it felt like anyway, then. What use was I... Don't fly too close to the sun, because it's very easy to get sucked in, and then once they don't need you any more, they don't even remember your name, which is sad. They've kind of set you on this pedestal and then started shaking it from the bottom (HN 795)

(On losing her job:) it was traumatic, and it came at the very, very worst time that it could have. When I needed support they let me down, and that's that (HN 619)

3.7.5 Key issues

Participants referred to a number of positive aspects relating to work and its role in their recovery. For example, as well as opportunities for increased financial independence, work can be a source of positive social interaction and enhanced self-esteem. They also spoke about some of the risks involved in taking on work, in terms of losing benefits and what might happen should they experience a worsening of their health. This is consistent with the literature.

In addition, our findings suggest that the type of work undertaken is significant. Some participants spoke about the issue of whether or not to disclose their history of mental health difficulties, in terms of the impact this might have on potential employers. However, in the mental health field, lived experience of mental health difficulties could be seen as a positive advantage. Some participants described the boost to their self-esteem and the job satisfaction they got from being valued in the contributions they could make. However, this meant that some were drawn to over-working, to the detriment of their own mental health. While many participants saw employers in the mental health sector to be more supportive than other employers, not all found this to be the case.
4. DISCUSSION

This unique and novel six-year, follow-up study has explored the ways in which eleven people’s recovery journeys have developed since they participated in the original narrative project. Six key themes were identified through the framework analysis:

- Issues related to telling the story
- The process and nature of recovery
- Relationships with services
- What helps recovery
- Problematic implications of recovery
- The role of work in recovery

In this chapter, our findings are discussed in more detail. Some of our findings confirm what we already know about recovery on the basis of the original narrative project. However, others extend our knowledge of recovery. These findings are discussed in turn below.

Consistent with the findings of the original narrative study, participants found telling their story to be a positive experience. It acted as a catalyst to recovery and was found to be cathartic. The process of recovery and what it meant to individuals differed. However, it was generally viewed as a long, ongoing process that was not straightforward in nature. Many journeys began with a triggering event or a decision to take control, and often progressed in small steps that gave people a sense of achievement as they completed them. The involvement of professionals - consistent over time – who demonstrated appropriate attitudes and values, having a GP with adequate knowledge of mental health issues, and being able to access the right support at the right time were seen to be particularly important. In addition, there was some general agreement about what helped promote and support recovery. These included: hope, meaning and purpose in life, choice and control, the development of self-management techniques and risk-taking, relationships, social roles and meaningful activities. Opportunities for work were seen as valuable because they brought with them possibilities for greater financial independence, for socialisation, skills development and purposeful activity, enhanced self-identity and self-esteem, and a sense of meaning.

A number of new insights into recovery emerged from the findings of this study that build upon the findings of the original narrative project. Our six-year follow-up study suggests that there is a more complex interplay amongst self-identity, relationships, social roles, work and other meaningful activities, and their relationship(s) to recovery, than was previously thought. These are discussed below.

Some participants expressed the need to seek out activities, friendships and other social relationships that were not related to mental health. This may be seen as a product of the impact that recovery had on their self-identity as they moved further beyond ‘illness’. In particular, structure and meaning could be restored through the reformulation of a self-identity in which participants were no longer defined primarily in terms of their mental health difficulties. In spite of this, all of the participants who
were in employment, which was seen as a significant marker of recovery, worked in a variety of roles in the mental health field. This presents something of a conundrum. Participants wanted to move beyond mental health issues, while at the same time the majority were working in this area. Four potential reasons for this are considered below.

First, it might be concluded that participants applied for jobs in the mental health field rather than in the wider job market, because they felt they would be less likely to be discriminated against. Indeed, a key issue for participants was whether they should disclose the fact that they had experienced mental health problems. People with mental health problems are under-represented in the workforce. This has generally been regarded as a product of inequalities (Coutts, 2007). Another explanation is that it may be the product of self-stigmatisation (Rüsch, Corrigan, Todd & Bodenhausen, 2010). According to this view, people with experience of mental health difficulties internalise the stigma they perceive society to hold against them. As a result, they do not apply for jobs for fear of not getting them due to discrimination. However, there was no evidence amongst our participants that this was the case.

Second, there was a view that by working in the mental health field, participants were likely to benefit from greater support and understanding should they become unwell. Unfortunately, this did not always appear to be the case. Indeed, a number of participants found that they were placed in situations in which they experienced work-related stress. On the one hand, people realised that the demands made of them were excessive and might be experienced as such by anyone. However, on the other hand, people were sometimes concerned that they might only be feeling stressed in their work because of their previous or existing mental health problems. This is perhaps not surprising, given that some participants described a continued fear of setbacks in relation to their mental health.

Third, working in some capacities in the mental health field was seen by some participants as providing an opportunity to enable them to draw upon their lived experience and expertise in relation to mental health difficulties, to the benefit of others. In particular, doing peer support work was viewed by some as marking a significant point on their recovery journey. While at times the role could be challenging, addressing and overcoming these challenges enhanced peer support workers’ own sense of recovery. Delivering for Mental Health (Scottish Executive, 2006a) contained a commitment to put in place a training programme for peer support workers. A number of people have now undergone this training and are employed in mental health services. The evaluation of the peer support pilot scheme found benefits to the approach for those using peer services and for the wider mental health system (McLean, Biggs, Whitehead, Pratt & Maxwell 2009). However, it should be noted that some participants in this study who were employed because of their lived experience of mental health problems found that, for the first time, their experience of mental health difficulties were a source of positive interest to others. This resulted in an associated boost to self-esteem that had an almost addictive quality, which in turn could lead participants to over-work, to the detriment of their mental health. The evaluation of the peer support pilot scheme (McLean, Biggs, Whitehead, Pratt & Maxwell 2009) found that some peer support workers took periods of time off sick due to the stressful nature of the work. However, in light of
the findings of the current study, the extra demands that people impose upon themselves in carrying out these roles might be a contributory factor to their work-related stress.

The fourth potential reason that participants worked in the area of mental health is that, for some, working with people who were also in the process of recovery gave participants the opportunity to see, by comparison, how far they themselves had travelled on their own recovery journey. However, other participants felt alienated by those who might have regarded themselves as being further ‘behind’ in their own recovery. Indeed, one participant expressed the view that he had recovered (and on reflection had done so when he took part in the original study), but had felt under pressure by others on their own journeys to say that he remained on his.

These experiences and views may be an example of the ‘in-group’/’out-group’ phenomenon predicted by Social Identity Theory (Tajfel & Turner, 1979). Social identity can be regarded as the sense of who we are based on our group membership – it gives us a sense of belonging to the social world. People come to identify themselves increasingly with their own group (the in-group), which provides them with an enhanced sense of self-esteem, and to accentuate the differences between the in-group and the comparison out-group. This can lead to in-group favouritism and discrimination against the out-group (Tajfel & Turner, 1986). It may be that alienation by other service users is more likely to be experienced by people working in certain roles. That is, they might be seen to have ‘moved on’ to the extent that they are no longer seen as one of the in-group of service users.

The number of people who took part in this study was small by comparison to the original narrative study, and no claim can be made with regard to what extent those who took part were either typical or atypical of the original group of participants. Consequently, it is not possible to make any claims as to how representative participants’ experiences are of those of the remaining original participants. Moreover, it might be concluded that anyone who had taken part in the original study who, from their perspective, had ‘failed’ to make progress on their recovery journey, might be unlikely to come back and tell us about it. Thus, the study may have been biased towards stories of ‘success’. However, if this has been the case, it could be argued that it has offered us more opportunity to explore the factors associated with the progression of recovery.

In summary, the current study has enabled us to explore in-depth with participants the ways in which their journeys of recovery have developed over the past six years. Our findings have confirmed some of those of the original narrative project, and their continued relevance. Our research has also produced some valuable, new insights in relation to the complex interplay amongst self-identity, relationships, social roles, work and other meaningful activities experienced by people who might be considered further down the road to recovery.

Our findings suggest that more attention needs to be paid to the potential impact on self-identity of progressing further down the road to recovery. Specifically, self-identity might become less closely defined in terms of having mental health problems. Whether this is cause or effect is not possible to say, on the basis of the findings of this study. This is an issue that would be worthy of further investigation.
It is particularly relevant to those individuals who are employed in roles where lived experience of mental health difficulties is a prerequisite – for example, peer support workers. Crucially, it might be more difficult for people in such roles to develop a self-identity that is less entwined with their mental health problems, and this might be significant in terms of their own continued recovery.

The current study has made a significant contribution to our further understanding of recovery. It is anticipated that the findings will be of relevance and practical utility to a range of stakeholders, including service users, service providers, policy makers, practitioners and employers.
5. REFERENCES


APPENDIX 1: Call for Follow-Up Participants

Did you talk to us in 2005 about your experiences of recovery?

In April and May 2005, the Scottish Recovery Network (SRN) travelled around Scotland gathering people’s personal stories of recovery from long-term mental health problems.

We hoped that information from these stories would assist other people with long-term mental health problems on their own recovery journey. We also envisaged that this evidence would help carers, communities and professionals to gain a better understanding of what factors help, or hinder, recovery from long-term mental health problems.

We would now like people who took part in this study to contact us so that we can find out what has happened since these stories were first told.

Would you be prepared to get back in touch with us?

Would you be prepared to talk to us about

- recovery in general

- your recovery story, your experiences since you first told us your story, what has helped or hindered your recovery, and the things that help keep you well?

If you are interested in allowing us to follow up on your experiences, please contact story@scottishrecovery.net or phone (Name) on (Number).

We will then contact you to arrange a suitable time and place to meet.

All expenses will be reimbursed, lunch will be provided and all follow-up participants will be remunerated with a £25 gift token.
Thank you for your interest in our research. Before you decide whether you would like to take part in the study, you should know something more about it.

What is the study about?
We want to find out how things have been for you in relation to your recovery from long-term mental health problems since you first told us your story five years ago. We would like to talk to you again about your experiences, where you now see yourself in relation to your recovery and what has helped or hindered your journey. We hope that the information from your story will assist other people with long-term mental health problems on their own recovery journeys. We would also anticipate that this information will help carers, communities and professionals gain a better understanding of what factors help or hinder recovery from long-term mental health problems.

Who is conducting the study?
The research will be conducted on behalf of the Scottish Recovery Network by Sue Cowan and Jennie Guise from Working Well Together (independent consultants).

What will happen if I decide to take part?
The research will take a similar format to the original study. You will be asked to take part in an interview, which will last approximately one hour. A week before the interview, we will send you a copy of your original interview, and a guide to the kinds of issues that will be covered in the follow-up interview. Interviews will be conducted between now and the end of February 2011 across a range of locations in Scotland, and you can come to the location that is most convenient for you. We will pay your travel expenses, and you will be remunerated for your time with a £25 gift voucher.

Is my participation confidential?
All interviews will be given in complete confidence and will be anonymous. No quotes or stories will be attributed to individuals. Before taking part in the interview you will be asked to provide written consent to take part, and for the interview to be audio-recorded.

What should I do if I think I would like to take part?
If you think you would like to take part, please complete the enclosed participant contact form and return it in the stamped addressed envelope to:

Lucy Mulvagh
Scottish Recovery Network
Suites 320-323, Baltic Chambers
50 Wellington Street
Glasgow, G2 6HJ

If you would like more information before deciding to take part, please contact Lucy Mulvagh at the SRN on 0141 240 7790. If you decide to take part and then later change your mind that is not a problem. You can withdraw from the study at any time without giving a reason.
### APPENDIX 3: Participant Background Information

**PARTICIPANT BACKGROUND INFORMATION**

*Revisiting the Narrative Research Project*

The purpose of this short questionnaire is to gather some background information about the group of participants involved in the study. However, you do not have to answer any question that you do not wish to.

1. **What is your sex?**
   - Male ☐
   - Female ☐

2. **Please indicate which age group you are in:**
   - 18-24 ☐
   - 25-34 ☐
   - 35-44 ☐
   - 45-54 ☐
   - 55-64 ☐
   - 65+ ☐

3. **Are you currently in paid work?**
   - Yes ☐
   - No ☐

4. **Are you currently undertaking any unpaid work?**
   - Yes ☐
   - No ☐

   If yes, please describe:

5. **What, if any, is your current diagnosis?**

6. **Are you currently receiving support from the statutory mental health services?**
   - Yes ☐
   - No ☐

   If yes, please describe:
7. Are you currently receiving support from any non-statutory mental health services?
   Yes ☐  No ☐

   If yes, please describe:

8. Are you currently being prescribed psychiatric medication?  Yes ☐  No ☐

9. Are you currently receiving any treatment/therapy/support, other than psychiatric medication?
   Yes ☐  No ☐

   If yes please describe:

**Name of Participant:**

Thank you for completing this questionnaire.
APPENDIX 4: Interview Information Sheet

INTERVIEW INFORMATION SHEET

Revisiting the Narrative Research Project

The aim of the interview is to find out how things have been for you in relation to your recovery from long-term mental health problems since you told your story as part of the Narrative Project five years ago.

To begin with, we will ask you for some background information in the form of a short questionnaire. The interview itself will be open-ended. However, we would anticipate that it will last about an hour. It will be audio-recorded and transcribed. The reason for this is to help us to remember what you have said.

The background information, the recording and the transcript will be kept in a secure place and will not be accessible to anyone outside the research team. Any personal material from the study that is used in project reports and publications arising from the study will be quoted anonymously and anything that could identify you will be removed. You may choose to terminate the interview at any stage and withdraw your consent for the use of information gained from the interview.

During the interview you will be asked about your experiences in relation to recovery. Not all of these will necessarily be positive and talking about these might be upsetting. We would anticipate that you have your own network(s) of support, for example, family, friends or mental health professionals, to whom you can talk. In addition, information is provided below about a trained counsellor who will be available should you want to talk about anything which came out of the interview.

We would like the interview to be as informal as possible, more like an everyday conversation. We may ask some specific questions, and we may ask you to provide more detail about some of the things you are talking about. However, since recovery is a very personal journey, it is your perspectives and experiences we are interested in so, in general, we will be taking a back seat.

Thank you for agreeing to take part in the study. Please feel free to ask any questions before we begin.

Telephone support following the research interview

The Scottish Recovery Network has hired a trained counsellor who is available should you want to talk about anything which comes up as a result of the research interview.
Anything you discuss would be confidential, and the aim would be to give you somewhere to talk things over in the first instance, to reflect on the experience of the interview, and to consider options for any additional support.

His name is [name], and you can contact him on his private number: [mobile number]. If he is not immediately available, please leave a message with your name and a contact number on which he can reach you. He will call you back as soon as possible, normally within 24 hours. If you need to talk urgently then please contact the crisis support numbers which will are noted below.

[Name of counsellor] has been working as a counsellor for twelve years and previously worked with a national mental health project and a local counselling service. He is a BACP accredited counsellor and a member of COSCA. He is also registered with UKRCP. He works within the BACP Ethical Framework for Good Practice in Counselling and Psychotherapy and is accountable to the BACP Complaints procedure.

[Name of counsellor] will be happy to talk to you about anything arising from the interview. He will discuss confidentiality with you if you call, including the privacy of your information and possible action which may have to be taken if there is a serious risk of harm to yourself or to other people. You will be able to ask him any questions you may have before talking about the things which have come up for you.

Crisis response services

Crisis response services vary across the country though they can generally be accessed via your GP, Social Work Services, NHS 24 or Breathing Space.

The following telephone helplines offer a national service:

**Breathing Space**
Phone: 0800 83 85 87
Breathing Space is a free and confidential phoneline service for any individual experiencing low mood or depression, or who is unusually worried and in need of someone to talk to. Lines are open 6.00 pm – 2.00 am each day and 24 hours at weekends.

**The Samaritans**
Phone: 08457 90 90 90
Email: jo@samaritans.org
Available 24 hours a day, providing confidential emotional support for individuals experiencing feelings of distress or despair, including suicidal thoughts.

**NHS 24**
Phone: 08454 24 24 24
NHS 24 provides comprehensive, up-to-date health information and self care advice for people in Scotland, and is often used by GP practices as their out of hours service.
PARTICIPANT CONSENT FORM

Title of Study: Revisiting the Narrative Research Project

Name of Researcher:

Name of Participant:  

| 1. | I confirm that I have read and understand the interview information sheet for the above study and have had the opportunity to ask questions. |  
| 2. | I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. |  
| 3. | I understand that my personal details will be kept confidential. |  
| 4. | I understand that the interview will be recorded and that anonymous direct quotes from the interview may be used in the study reports, related publications or in any awareness raising activities arising from this study. |  
| 5. | I understand that my data from this study will be anonymised and that only members of the research team will have access to the data and my personal information. |  
| 6. | I agree to take part in the above study. |  

Name of participant: 

Date  

Signature  

Name of person taking consent  

Date  

Signature