What Matters with Personal Narratives?

Iris Altenberger and Rob Mackay
Robert Gordon University

Report on how personal narratives are used in the promotion of recovery and social inclusion by mental health service users in Scotland
December 2008
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Preface

“Hey Daisy darling don’t give them all you can,

why don’t you keep a few more cards in your hand?

I know you’ll only say a thing you believe to be true,

But there are people in this world who don’t think like you do”

With thanks to Karine Polwart
(see page 33 for explanation)
ACKNOWLEDGEMENTS

My biggest acknowledgement is to those twelve individuals who not only give willingly of their time but also patiently shared with us stories of recovery and stories of recovery telling. I am grateful for the interest they showed in this research project and the advice they offered. Thanks as well to the four key informants who spared their time to offer thoughts on the ‘bigger’ picture.

I would like to thank the Scottish Government for proving funding through the Small Research Projects Initiative and at a personal level to Angela Hallam for her understanding, patience and enthusiasm. I wish to extend a heartfelt congratulations to Iris Altenberger for all her commitment, interest, creative ideas and hard work in helping this project to reach fruition.

Closer to home a big thank you is extended to all those colleagues for their support. A special thanks to Professor Joyce Lishman for not only her moral support but also for the back-up resources that the School of Applied Social Studies has provided. We extend our thanks to Karen Stewart who did an excellent job on producing the transcripts, which for those occasions when our audio recorder was competing with the full might of the Glasgow bus service was no mean feat!

I would like to thank the service users and academics that serve on our project advisory group very much for their guidance, support and encouragement which was valuable at critical points in the life of this project.

I hope the way in which this report is written brings to life the issues, the challenges and the rewards encountered by the individuals we met.

Rob Mackay
Executive summary

We found there is a clear consensus by the participants as to the core purposes of story telling:

- promoting mental health awareness & well-being
- inspiring hope and promoting recovery
- countering stigma and promoting positive attitudes
- become experts through lived experience
- providing opportunities for personal learning and development

In the same way that recovery is understood to be a process or metaphorically a journey, so too are we suggesting that story telling is a process of ‘learning and development’; a journey of storytelling which is interlinked to recovery and each have a influence upon the other.

A central feature of recovery and story telling is the development of a positive identity in which a high level of personal awareness is necessary to cope with the highs and lows of a journey. We heard about the various aspects of support from the participants of which being part of a peer support group and recovery training was especially valued.

We suggest that the journey of story telling is a process that starts with creating the story from raw lived experiences and that over time the personal story is developed, amended and edited using a range of resources. The telling of the personal story can be presented in different formats and for different purposes but essentially the person needs the skills and personality to tell that story in a way that meets the objective of a particular event or media production and the needs of an audience. The story becomes the medium for delivering core messages, such as anti-stigma, recovery, I am the message and self-awareness. Following the telling of the story there needs to be a space for a de-briefing, review and re-editing of the story.

Becoming a public person through story telling and therefore losing anonymity was a major issue for participants. The consequences of being recognised in public were varied and effected people differently, but were perceived as predominantly negative by the participants. The loss of anonymity led to people using strategies to minimize the intrusion on their privacy and that of their families. Another issue was the lack of control they experienced with regard to the media. This led people to using strategies to protect their stories. Issues of risk and protection arose in which the consensus was that each individual needs to make a choice about whether or not to tell their story in public but that this should be an informed choice. Supports available to the storyteller were deemed to be an important factor; we suggest these need to be at a sufficient level to address any potential threats to their own mental health. There is support expressed for the idea of guidelines whilst at the same time a concern that these need to be implemented in a sensitive and flexible manner at the local level. We suggest that accessibility to such guidelines needs to be promoted through being posted online on a number of major mental health websites.
Section 1 Background and Introduction

The community care reforms heralded by the passing of the NHS and Community Care Act 1990 placed the empowerment of service users and carers at the heart of the rationale for this paradigm shift. The concept of ‘Voice’ is one important strand within empowerment (Mackay 2007), in which the service user tells their story (narrative) as part of the process of expressing choice, wishes and aspirations. The mental health service user movement in the U.K. has utilised personal narratives to influence public opinion as to the human experience of living with a mental health problem. Indeed, it has become something of a publishing phenomenon with a string of books attracting public attention and acclaim (Hart 1995; Read & Reynolds 1996; Jamison 1997). This interest in narratives can also be seen in the development of the Hearing Voices Network (UK) and the development of narrative therapy. (White and Epston 1990). Both of these approaches are significant as they claim to support people with the recovery process and the development of personal identities based around wellness and health.

There is a suggestion in recent years that people with mental health problems have become much more visible in Scotland. This appears to be most apparent at conferences but also public testimony is being used on training courses for professionals both at the pre-registration and post-registration courses either in person or through the use of DVDs or streamed video clips. There are also websites that feature a combination of written testimonies and video clips and the use of TV adverts which See Me Scotland has used extensively in its campaigns and its use of media volunteers. Then there is the written word, such as ‘Journeys of Recovery’ which is a collection of stories of recovery (Scottish Recovery Network 2006) and the occasional feature article that appear in daily newspapers.

This study therefore was interested to meet with people, who describe themselves as either recovered or in a process of recovery, who share their own stories across Scotland using a range of media platforms. We wanted to find out how they experience this phenomenon of ‘going public’ with their own lives; what helps the telling of the story, what hinders it and what are the dilemmas and issues they have encountered.

This report uses extensive excerpts from our interviews with the participants in order to breathe life into the reporting of our results. These excerpts are taken from the transcripts of the interviews conducted and that a minimum amount of ‘cleaning’ or ‘sanitising’ of these excerpts has taken place (Elliot 2005). We have removed pauses and utterances such as ‘umms’ and ‘errs’. We have used the device . . . . to indicate where we have cut out some of the dialogue because it was either repetitive or a different point was made. However, the words used by the participants have not been altered.
Section 2  Methodology

2.1  Aim and Objectives of this study

These aims and objectives were agreed with the project sponsor, the National Programme for Improving Mental Health and Well Being

Aim:  To explore and identify how personal narratives are used in Scotland to promote recovery and social inclusion by mental health service users

Objectives:

i) identify the core conditions that support personal narratives as part of the recovery processes
ii) identify unhelpful practices that have hindered the use of personal narratives
iii) identify the range of issues and potential dilemmas for those people whose ‘stories’ have been used in the public arena for the purpose of health promotion and education
iv) facilitate the development of research capacity by service users

2.2  Research Philosophy and Design

The design of this project was positioned within anti-oppressive research (McLaughlin 2007), which was committed to engage with the research participants not as objects but as people. This impacted on the processes adopted from the design of the project to the dissemination of the results. An open and transparent process was more likely to be effective in involving people who could regard research with suspicion. In this way the research project could address the principle of beneficence (Alston & Bowles 1998) in that involvement might offer something back of worth.

An Advisory Group (Appendix 1) was established which reflected a range of skills including service users and researchers. The project was granted ethical approval by Robert Gordon University.

A qualitative approach was chosen, which allowed a rich and in-depth understanding of participants’ experiences of sharing their personal narratives and the issues surrounding them. The research methods employed included:

♦ Initial telephone interview and questionnaire
♦ Semi-structured individual interviews with service users
♦ Focus group involving the same individuals
♦ Telephone interview with key informants

The research process was informed by grounded theory which is used across a range of social science disciplines. The data generated by the research processes is used inductively to generate concepts and theories as opposed to testing established theories. As Strauss and Corbin (1990 p.24) put it: “the grounded theory approach is a qualitative research method that uses a systematic set of procedures to develop an inductively derived grounded theory about a phenomenon.”
Whilst the researchers had some theoretical knowledge mainly in the area of mental health, recovery and narratives, an in-depth literature review was not conducted prior to data collection. Rather the research has been grounded in what the participants shared and so the theorising has come later as the researchers made sense of the data we have gathered.

The researcher provided Scottish Recovery Network and See Me Scotland with an information sheet (Appendix 2) about the research and contact details. These organisations circulated the information sheet on to individuals who had shared their story in the public and thereafter participants contacted the researcher direct by telephone or by e-mail. This provided an opportunity for more information sharing (Appendix 3) and dates set for the interviews. Participants were also made aware that the interviews would be audio taped and transcribed in full. Total confidentiality was assured (Appendix 4).

There were twelve people who took part in the individual interviews in six locations across Scotland. The interviews were between one hour and two hours long and were all conducted by the same researcher with the same research assistant present who audio taped the interviews. The interviewers were guided by a schedule (Appendix 5). Factual information was obtained through the use of a questionnaire (Appendix 6). A summary of the interview was written up and posted to each of the participants to which they could provide feedback. All agreed with the final version of this summary. The digital recordings of each interview were then transformed onto paper by an independent professional transcriber, who produced full unedited scripts that provided the researchers with the raw data.

A workshop took place at Stirling University to which all participants who took part in the semi-structured interview and phone interview were invited. Four people participated in this event. One person could not attend due to our inability to meet travel and childcare costs, three due to ill-health and one due to another commitment. The researchers analysed the emerging themes from the semi-structured interviews in order to develop a focus group discussion. The aim of the focus group was to deepen our understanding of these themes through a structured programme (Appendix 7).

Four key informants were approached on the basis that through the work of their respective organisations each of them has been at the forefront of contributing to the transformation of mental health policy and practice in Scotland. The purpose of involving these individuals was to assist in understanding the wider context and contemporary issues that in their view relate to the story telling experience. The following are the individuals contacted:
Simon Bradstreet, Director, Scottish Recovery Network (hereafter referred to as key informant 1).
Ron Coleman, Trainer & Consultant, Working to Recovery Ltd. (hereafter referred to as key informant 2).
Gregor Henderson, Director, National Programme for Improving Mental Health & Well-being (hereafter referred to as key informant 3).
Allyson McCollam, Chief Executive, Scottish Development Centre for Mental Health (hereafter referred to as key informant 4).
(Appendix 8)
A semi-structured telephone interview (Appendix 9) was conducted.

2.3 Data Analysis

Aspects of the grounded theory approach were used to analyse the data, which was managed using Nvivo Version 7 software. This has involved a rigorous and systematic process of analysing the transcripts over months and including the period of writing this report.

2.4 The Participants

Of the twelve participants who took part in the semi-structured interview, nine have had their stories in print, four have been on the radio, five have been on television, seven have presented in conferences as well as classrooms, five have shared their stories in self-help groups and four have shared their stories in other forms such as websites, art shows and the workplace. Nine of the participants were actively sharing their story in public whereas two have ceased to tell their story in a public domain. Six participants have been sharing their story between zero and five years, one participant has been between five and ten years and three have been between ten and fifteen years.

For further details please refer to (Appendix 10)

2.5 Limitations of the study:

The fact that the participants within the study were self-selecting could be seen as a limiting factor in terms of the diversity of story telling experiences. This might be a reflection of the sensitive nature of the issues under discussion or the way in which information about the project was presented to potential participants.

Within the self-selected sample there is a predominance of female participants, which could have lead to gender specific data.

The ages of our participants is another issue as none of them are younger than 26 years but also none of them are older than 55 years. The majority of the participants are in the 36 – 55 years bracket. The implication is that the research has not investigated the story telling experience of adults in the 16 – 25 years bracket.

The adoption of Grounded Theory (Strauss & Corbin 1998) has been very useful as it has provided us with a central focus on the evidence emerging from the interviews. This provided the opportunity to challenge each others interpretations and so offers confidence as to the reliability of our systematic approach to the analysis of the data and hence our findings. A summary of each interview was agreed with the participants. So with regard to the validity issue, we are comfortable with the suggestion by Brown and Kandirikirira (2007 p. 15) that “perceptions of validity need to be radically re-conceptualised to include persuasiveness of the accounts, correspondence (cross-checking with the story teller), coherence of findings and their pragmatic use.”
Section 3 Personal Narratives and Story Telling

The aim of this research is “To explore and identify how personal narratives are used in Scotland to promote recovery and social inclusion by mental health service users.” A logical place to start therefore is a consideration as to what is the meaning of personal narratives or stories. It also considers the impact on the story teller and whether the act of sharing a personal story has a therapeutic effect linked to personal development.

The idea of stories is not a new or a difficult one for most people; we have grown up listening to stories being read to us from members of our families or teachers. Some of us may also have been told stories about our parents, aunts, uncles and grandparents by other family members. We may also have had stories told about us as we have got older – some of these may have positive associations whilst others may recall times of unhappiness and real distress. And then there are stories that we tell about ourselves in relation to the experiences we have had throughout our lives. It is this aspect that we are concerned about in this report.

Reading the social sciences literature tells us that ‘telling stories’ is not simply the preserve of the playroom but has a deeper meaning for all of us. There is a frequent assertion that people are interpreting beings, who make sense of the social world and create meaning through the telling of stories (White 1995 Elliot 2005 Lawler 2002). The following quote expresses well what is claimed about the meaning of stories in all our lives:

“We are all teller of tales. We each seek to provide our scattered and often confusing experiences with a sense of coherence by arranging the episodes of our lives into stories. This is not the stuff of delusion or self-deception. We are not telling ourselves lies. Rather, through our personal myths, each of us discovers what is true and what is meaningful in life.”
(McAdams, 1993, p11)

Elliot 2005 suggests that narratives can be understood to have three key features:

- Chronological (related to a sequence of events over a period of time)
- Meaningful
- Social (produced for a specific audience)

In addition, there are claims in the literature that personal narratives have a therapeutic or healing effect on the person telling and re-telling their own personal narrative (McAdams 1993 White 1995 Freeman Epston & Lobovits 1997). For some people – and there are plenty of historical examples such as Saint Augustine – writing their own auto-biography helps to put past events not only in a certain order but also strengthens the reflective process of establishing a positive and vitalising perspective on the self. It might be this has been part of the process for some of our participants and we will return to this issue later.

For some people this process is aided through a helping process with another or others. Sometimes this takes the form of a ‘talking’ therapy or counselling. In this context we asked the participants about ‘Narrative Therapy’ and it was apparent none of them had heard about this empowering way of working with people and groups.
From this perspective a narrative has a particular meaning and according to Morgan (2008):

“The word ‘story’ has different associations and understandings for different people. For narrative therapists, stories consist of:

- Events
- Linked in sequence
- Across time
- According to a plot

As humans we are interpreting beings. We all have daily experiences of events that we seek to make meaningful. The stories we have about our lives are created through linking certain events together in a particular sequence across a time period and finding a way of explaining or making sense of them. This meaning forms the plot of the story. We constantly give meanings to our experiences as we live our lives. A narrative is like a thread that weaves the events together forming a story.

The participants, through the individual interviews, expressed their thoughts as to the meaning they attach to their own story telling experiences. In the following section we have included some excerpts to illustrate a range of meanings about personal narratives.

3.1 Meaning of personal narratives

These excerpts are taken in response to the question we asked about the words or phrases they use to describe narratives. The underlining is ours to indicate specific phrases used by the participants:

i) Robert Stevenson comments were:

“I think story is a really important word in this context, because actually you are telling your life but you are turning life into a story. And your life often does not fit with the story . . so you craft your story out of your lived experiences. And what hinders it is that your life does not fit with models or concepts or ideas or philosophies, because it’s messy, because all of our lives are messy And so one of the factors that hinders us is that when we first start we are just given that raw experience which has loads of messages in it, but it hasn’t been shaped.”

For Robert not only is the word ‘story’ preferred but he also uses this within a literary context. So as with a good book the writer or story teller needs to work with the raw experience of life and through the “craft” or writing transforms this into a credible story with a clear message. There is also the suggestion that this is a learning experience for the story teller over a period of time.

ii) Cheryl Watt’s comments were:
“it’s not from later life to date, my life story is from a small child up, because there are a lot of things happened then that are relevant to the mental health problems I have today. So that’s it . . mine's is really a life story.”

For Cheryl she is clear her story has a time (or temporal) dimension as she moves between her childhood and her adulthood. Her recovery story is thus positioned within the bigger story of her life.

iii) Julie Tullie’s comments were:

“sharing experiences I would probably (call it) and it’s been a huge part of my recovery. . . . and the first time I remember sharing my experience was about five months after I got out of hospital.”

For Julie having the opportunity to share her experiences with others who had undergone similar experiences was affirming.

iv) Gwen Brankin’s comments were:

“I would call it a presentation because that’s what I have been trained to do”

For Gwen her role as a See Me media volunteer provides her with a focus for sharing her experiences of mental health problems and recovery.

v) Maria Croft’s comments were:

“a narrative means to me . . . telling a story . . or recounting details of things that have happened in your life again and putting it together in a formulaic way so that it makes sense and has a beginning, a middle and an end . . . and follows a pattern and has meaning for other people listening to it”

For Maria, who has written books and songs, the structure of a story is important and relevant. She is also thinking about the impact a story will have on an audience.

vi) Deborah Blau’s comments were:

“Recently I have questioned the word story in it and some of the service users I work with have not felt happy with the word story. So I am beginning to look at it . . . sometimes I think of it as a narrative but I am not sure that everybody would understand what that was . . . I have tended to call it my recovery story up until now and now I am not quite sure”

Deborah’s comments reflect the reflective conversations she has had with others in which there is a healthy questioning of meaning attributed to concepts. It may also be a reflection of her own internal conversation and that for somebody who has been sharing her own story for a number of years that her own understanding of personal stories is shifting.
Section 3.2 Discussion

In this section we have explored what is meant by personal narrative or story sharing through the social science literature and from the expressions of the participants. We discovered that the participants use a range of inter-connected words and phrases; “story”, narrative life story”, “life story”, “story telling”, “sharing experiences”, “presentations”, “narrative” and “recovery story”.

It could be argued that these stories are different in the sense that they don’t come from the pen of an author or a script writer but they come from an autobiography—namely the person who has lived through the experience that is being shared. But a further aspect is that these narratives are culturally different from the norm of exchanging stories about everyday events such as journeys or holiday experiences. These are authentic stories of human experience expressed and shared by people who have experienced personal, social and cultural problems. Deep feelings and thoughts of emotional anguish and pain have been experienced along side being a ‘patient’ and/or a ‘client’ and/or a ‘service user’.
Section 4 Findings

In Section 4 we are reporting on the findings that have emerged from our analysis of the individual interviews and the workshop. These are directly related to the four research objectives:

i) identify the core conditions that support personal narratives as part of the recovery processes
ii) identify unhelpful practices that have hindered the use of personal narratives
iii) identify the range of issues and potential dilemmas for those people whose ‘stories’ have been used in the public arena for the purpose of health promotion and education
iv) facilitate the development of research capacity by service users

The findings have come from a grounded analysis process in which we used the Nvivo software package (version 7) to assist us. The findings are divided into seven categories and cover the following areas:

1. Personal Identity & Recovery
2. Storying with a purpose
3. Dilemmas and Issues
4. Personal Impact and Self-awareness
5. Support, Training and Guidelines
6. Finding out about research

Section 4.1 Personal Identity and Recovery

We were interested to learn from the participants as they how perceived their identity in relation to mental health problems, recovery and the language they used in introducing themselves to an audience and how static or dynamic that might be. Our underlying hypothesis was that such words or phrases not only are a reflection of personal identity and self-perceptions, but also is indicative of a personal narrative in process.

In the course of the individual interviews we asked the participants to describe how they introduced themselves to an audience and provided them with a list of options on a printed sheet. We now include excerpts from all twelve participants to indicate the range of responses we received and would suggest that these need to be framed within an understanding that recovery is a process that is unique to each individual. This has been done as a way of introducing each of them as unique persons to the reader.

Mary Morrison:

“I mean you have got words down here, you have got like service user, I mean I struggle with that all the time. Everyone struggles with that. I mean obviously I do a lot of mental health writing and there are certain words that I struggle with all the time trying to find another word. Please invent a mental health thesaurus. And it’s just like, yes I use services because I use the bus,
therefore I am a service user. But service user it has to be a mental health service user, but then again why should that be?"

Siobhan Clark:

“I would normally class myself as a voice hearer . . I never say I am a person with a mental health problems because I think that’s quite degrading and I think it doesn’t help. In many ways it can make people see you as a victim or a patient and I am neither. I am a person in recovery which means that I have a quality of life, which means that I am identifying myself as a person of value”

Robert Stevenson:

“So I might say I have a mental illness, a mental health problem, suffer from mental ill health, emotional distress because I think none of the words actually fit and most of them have got faults within them. I have got no problem with being a patient because sometimes I am . . . I am fed up with being a user, but it's the only word we use, sufferer I don’t really use at all, I think that’s a bit demeaning, but survivor I sometimes . . . I used to be tempted in the past with the survivor label but I also think that’s a bit of a distortion and I sometimes think it’s either too confrontational or has different connotations to what it’s really about. I don’t use recovery although I would say I have been on the recovery journey, and I would use a person with mental health problems, and I would use person, I think the bit about person is something that I am moving to more and more”

Cheryl Watt:

“I do use service user, I am not particularly keen on it . . we use patient all the time . . mental health patient that’s ok . . person with mental health problems, yeah that’s ok. Person in recovery from mental health, yeah. And a person, yeah, we are all people and I am using that more and more . . But I am also a trainer in recovery, I can use that now, I am now a wage earner sometimes.”

Muriel Green:

“. . and also if I am under acute stress I will become psychotic, I will have a psychotic episode. And I would explain that’s what it is but I would say you know that . . I have a mental illness but I am not a person with mental illness or a person in recovery . . . I would call myself a person.”
Julie Tullie:

“... I said at that point I am recovered from depression. That quite surprised me that it came out so spontaneously, it was obviously in my sub-conscious this was how I was feeling that I had recovered and I was in that space. Whereas at different stages I have described myself in recovery. I have described myself as a service user, I think ... it depends what context as well, like I have done a four day recovery training which was for social workers and carers. ... and there I introduced myself as a service user.”

Laura Walters

“I would be somebody who ... who has experienced basically severe mental illness I would say ... so somebody who has experienced, I don’t like the word survived really ... No because I am past it, I think I have recovered, it’s in the past rather than in it ... but it’s not a big issue in my life you know I often don’t talk about it, because time has passed and I see myself as cured thanks. That’s great.”

Gwen Brankin:

“This is (first name) that you see, not (first name) who has manic depression. ... and the fact I had manic depression I think is something that enriches my life”

Kay James:

“I suppose the nearest one probably would be a person who has had to use mental health services but has been to change that relationship to promote my own recovery”

Maria Croft:

“I am (name) and I suffer from bipolar disorder ... I say I don’t have bipolar disorder ... I say I am not bipolar, let me get that right.”

Deborah Blau:

“I think part of my recovery has been that ... I have changed how I think of myself as a service user even though I am and technically still use services. ... it doesn’t seem an important part of my identity now although ... I obviously think it is but I don’t see it as the primary way ... I now use person for myself and as far as possible when I am talking about people I am working with”

Allan Stewart:

“A person with mental health problems. I do use the word service user; I don’t have a problem with that. I certainly use person in recovery and person is
probably most appropriate . . because everyone is an individual whether they have got mental health or not.”
Section 4.2  Storying with a purpose

Storying with a purpose emerged as a major core category from the individual interviews in response to questions we asked the participants as to what they considered was the purpose of sharing their personal story in public. This relates to two of the research objectives:
- Identify the core conditions that support personal narratives as part of the recovery process.
- Identify unhelpful practices that have hindered the use of personal narratives

Our analysis suggests this area consists of four sub-categories:
- the objectives of story telling
- giving back
- core messages
- working your audience

Section 4.2.1  The objectives of story telling

In the course of the individual interviews we asked about the experience of sharing their story with a wider audience including what each of them considered to be the purpose. We have underlined what we consider are the essential elements. The following are typical of the replies we received:

Siobhan Clarke:

“So I see by talking to the CPNs and students you can actually enable them to . . . instead of coming with fixed views, you can actually help them to look at it in a more balanced way. And I think it takes away the fear.”

Robert Stevenson:

“so how they can improve the way they react with us, view us and help us. It’s a way of letting the general public know about something that is relatively taboo”

Mary Morrison:

“. . . what I use my story my story mostly for if you want to say, I use it as a way to make examples so that people can maybe relate to it better. And that for me has been the most important thing . . . it tends to be to people to kind of grasp concepts rather than people who are in that situation”

Laura Walters:

“. . . that might just create that little spark that makes a difference”
By analysing the statements by all the participants it is possible to place these phrases into a number of related objectives:

1. **Promoting Recovery**
   “a recovery story in our message”, “expressing an idea or a concept”, “positive”, “getting my message across”

2. **Promoting Mental Health Awareness**
   “educate”, “enable”, “make examples”, “expressing an idea or a concept”, “getting my message across”

3. **Challenge Stigma**
   “takes away the fear”, “know about something that is relatively taboo”, “expressing an idea or a concept”, “getting my message across”

4. **The speaker is the message**
   “never seen users being articulate”, “comfortable”, “confident”

5. **Part of personal journey**
   “affirm”, “comfortable or confident”

### 4.2.2 Giving back

The phrase “Giving Back” was used spontaneously by a number of the participants in the course of the interviews in response to our question about why the participants put themselves in the public spotlight. We have selected a range of excerpts to illustrate the perceived meaning of giving back.

Alan Stewart;

“It’s just giving back (our emphasis). It’s giving back to either individuals in a similar situation, helping out carers, and sharing an empathy, an understanding of what it may have been like . . . in a peer way what it may have been like for me and trying to appreciate sort of what it might be like for them.”

Maria Croft:

“I used to go in and I do still go in and visit the ward (psychiatric) . . . and say . . . that’s fine you know . . . I just wanted to show them this is me well and you are owing part of that . . . because they don’t get to see the good part you know and I think that’s important.”

Kay James:

“Giving back I think doesn’t go far enough to be honest. Giving back can mean going back to the shops or whatever, but giving back for me actually means making a significant difference, giving somebody a bit of quality of life by enabling them to take the steps they need. It’s not something you can do to other people so I am reluctant to say giving back. I think it’s more a case of enabling.”
4.2.3 Core Messages

We asked the participants to comment on what they would regard as the core messages they are communicating. By core messages we meant that taking account of the range of formats and contexts with a range of audiences the points that consistently are at the very centre or core of what they would like the audience to be left with. We have identified four core messages that emerged and these are:

- Anti-stigma
- Recovery
- I am the message
- Promoting self-awareness

**Anti-stigma** refers to words and actions that are designed to challenge the stigma associated with mental illness and to promote greater knowledge and understanding of individuals who have experienced mental health problems. This idea is best illustrated through the following excerpts:

Cheryl Watt:

“And I think getting out there and showing that yeah you can string a few words together you know. That you don’t look totally alien and so you are doing a little bit of anti-stigma work there as well. . . it breaks down barriers.”

Julie Tullie:

“sometimes entrenched in the past and the fear and stigma that went with mental health in the past, asylums and things . . that you know if you have people that are willing to listen to somebody’s truth, someone’s reality, someone’s lived experience, and put all these notions aside, then you know that really enables you to get through to them and get the message across that this is the reality, this is the lived experience”

**Recovery** refers to the perspective that recovery from mental illness is more than just alleviation of symptoms but is an individually based move towards wellness and a satisfying lifestyle. This is illustrated through these excerpts.

Kay James:

“I think the key message in the story are just that even for myself, who was in the system for a period of twenty years it is never too late, there is always hope. And it helps when other people believe in you”

Muriel Green:

“I am in recovery from mental health problems because mental illness is so diverse . . I am in constant recovery and I have got a routine now for recovery if you call it . . but I don’t call it recovery I call it getting back to work and looking after my little boy you know.”
“I am the message” refers to the assertion by the participants that they are living proof of recovery and that each person has an important story to share. These excerpts illustrate this sub-category:

Gwen Brankin:

“I am talking about something that I have lived, that is part of me, that makes me up as a whole person. And that I think is the biggest message you can deliver because it’s something that . . . look see me, what I have done, this is me and what can be achieved.”

Kay James:

“I think that the way I do the narrative . . . my own actual story is to try and show what it felt like when I was maintained within a system, or wasn’t given choice where thing were being done to me, where I didn’t have the knowledge or experience to ask questions.”

Promoting self-awareness refers to the idea that people with recovery stories have a message for everybody in society about using self-awareness in order to maintain a reasonable level of well-being. These excerpts illustrate this point.

Cheryl Watt:

“I have also had a lot of professionals approach me afterwards and say well I have had that or I have experienced that myself. And it’s making it easier for them to open up because a lot of professionals are scared to admit in their workplace that they have a problem.”

Maria Croft:

“the chorus (in my song) is “its ok to be frightened, it’s ok to be on your own, . . . and it’s just saying look it’s alright, this happens to people. . . And that’s on the website. I have written the meaning of the lyrics and stuff.”

4.2.4 Working your audience

This section concentrates on the live situation, which typically would either be a Conference or a training event. It focuses on how the participants perceive their role with an audience, how they attempt to communicate their core messages and their use of what is happening in the room.

We asked about the impact their stories have on the audience and what that means for them as trainers or facilitators:

Maria Croft:

“I did a library session where the audience was just not responsive at all . . .
Mum said to me so do you remember that time when you were in hospital and such and such happened? . . . we got talking about it and then we were talking about going on public transport when I was ill . . . we got the discussion going and we worked it (our emphasis) because we were more experienced than they were. You have to understand that, you are more experienced than your audience is so . . . you have to get around that for a little bit”

Robert Stevenson:

“What we have found over the years is that many of us have actually got used to our stories and they have turned from experience into story. And yet they have a huge effect on some of the professionals who are in the room with us who may be personally affected, or may be very moved, and so you need to create a safe environment where you have a facilitator who makes sure that everyone feels comfortable, where you have ground rules for the way you express things. . . . so you need something that is participative, inclusive, collaborative, where you are all learning together and where you are challenging perceived ways of thinking and ways of acting.”

Gwen Brankin:

“you have got to know who your audience is, and what message you are trying to put across so that you deliver that message.”

The use of creative and especially visual materials was important for some participants as the main medium for the telling of a story as is illustrated by this excerpt:

Julie Tullie:

“I see that in the visual as well, in the art, changing the way people look at things and then the things that you look at . . the things that you look at sort of change . . . it’s like if people are in a really bad sort of space and they start seeing things differently you know through the art work then at the end of the art class they might feel differently about the problem that they were facing.”

Another finding was that the participants showed commitment towards communicating a positive message about recovery. The following excerpts are designed to illustrate the beliefs that underpin this commitment.

Alan Stewart:

“But I try and to put . . just give a factual spin on it, if it’s negative, don’t highlight the negative aspect and try and end on a positive aspect. And try and give a balanced story.”
We asked the participants about the possible impact an audience might have upon them. For some they have had the experience of realising on the spot that people were in the audience who had been their former care-givers. The following excerpts illustrate their response to this situation.

Deborah Blau:

“So very much who is in the audience would make me... I don’t think it would help for me to just to say how awful psychiatrists are. Because I think they would just discredit me... so I am quite influenced by that.”

Kay Jamison:

“I have been in training that I didn’t particularly want some of the audience to be in because they had given me a pretty hard time... but you know it’s surprising what a smile can do and how that can change things... because I have actually been involved in training a lot of the staff in the wards that I have actually been a patient in... it is very hard for them to realise how things have changed and they have all come back and said I need to change things on the ward, the potential, we need to have a completely different approach... . . and that makes it all worthwhile.”

Section 4.2 Discussion

This section raises the question as to the purpose of story telling. Our analysis of what the participants shared with us suggests there are five purposes:

1. Promoting Recovery
   The positive advocacy of recovery from a mental illness emerged as a strong theme in which participants considered they have benefited from listening to others recovery stories. The view was that such stories inspire hope and contributes to people taking charge of their own recoveries. Key Informant 1 expressed it like this:
   “through modelling recovery... giving out a lived example of how it (recovery) can happen and that is massively important.”

2. Promoting Mental Health Awareness
   This is the view that personal story sharing is a good medium for illustrating a range of social issues that are not only relevant to mental health problems but also have something to say about the importance of self-awareness and mental well-being. Key Informant 3 referred to personal narrators as “well-being champions” and that they have an important role as health promoters.

3. Countering stigma
   This is the view that by providing an individual’s personal account of stigma, exclusion and discrimination it counters and challenges generalised attitudes and beliefs which are said to be rooted in stereotypes.
Key Informant 4 expressed a cautionary point of view that whilst such individual examples can help to challenge stigma, much more work needs to be carried out to enable us to achieve a greater level of knowledge understanding as to effective processes involved in changing public attitudes and beliefs.

4. Experts through lived experiences
This is the view that having service users as public speakers at conferences reminds everyone who are the experts and indicates the re-alignments that are taking place, with regards to role, relationships and power.

5. Providing opportunities for personal learning and development
This is the perspective that telling and sharing personal stories in a public setting is a journey of learning that not leads to an increase in technical skills but also in the area of personal growth and development. Opportunities may be training courses, peer support groups and conferences for example.

The participants commented on their experiences of working with a live audience (section 4.2.4). Those who had been doing this for a number of years were clearly confident about their ability to work an audience in a respectful and caring manner. For some they had accumulated experiences of a range of audiences they had developed a range of strategies that they could draw upon in an on-the-spot manner and draw upon their own particular skills and creative talents. A particular issue that some of the story-tellers have faced is recognising some members of the audience as either past or current care-givers. Our observation is that our participants have mostly had the confidence and skills to deal with this situation, but how might this be for somebody new to sharing their story in public? Maybe this scenario is one which potential story tellers need to be alerted to so they can think of possible strategies.

The key informants were helpful in highlighting a couple of general issues. One comment speculated as to the risks posed by “slick P.R.” methods in using personal stories to promote a particular message. This might involve glossy photographs or film and limited text. The other issue is that the recovery message delivered through personal stories may not connect with everybody’s lived experience and indeed some may perceive “a happy-clappy” feel to it.
Section 4.3  Dilemmas and Issues

Within a section of the semi-structured interview, as well as within the workshop, story tellers were asked about what dilemmas and issues they had faced within their story telling. This relates to Objective 3 of this research project “identify the range of issues and dilemmas for those people whose ‘stories’ have been used in the public arena for the purpose of health promotion and education.”

The analysis of the responses identified “dilemmas and issues” as a main category. It consists of the following sub-categories:

- Losing anonymity
- Control over the media
- Considering family and friends
- Setting boundaries

Participants faced various issues and dilemmas when telling their story in public. The choice of going public also created various resulting issues. Participants saw issues from a negative perspective rather than from a positive one.

4.3.1  Losing anonymity

There was a strong consensus that participants felt that they lost their anonymity when going into the public. They became more visible and were approached by members of the public. The following excerpts illustrate this experience.

Maria Croft:

“.well I am much more visible now especially around (name of home town) that I used to be which I am not sure I am entirely comfortable with.”

Muriel Green:

“I have found though is when you do come out in a newspaper people will go to you and start telling you about their mental health problems, or mental illness and”

Siobhan Clarke mentioned:

“I make myself vulnerable each time because I open up the floor and say you can ask me anything. And…even sharing…just saying the words I hear voices makes you vulnerable to…vulnerable to other people’s views and stereotypes.”
A concern was highlighted by some of the participants that once a story has been put out in a public arena that it cannot be changed even though the person concerned has moved on. This is illustrated by these excerpts.

Robert Stevenson:

“But I do have a story that might help you in your research, where one of our members…gave a story about a feature article to the local paper about schizophrenia. And was really pleased about it, and then later went to college and found that that story was being used as a training tool for students in the class she was in. And she was really really upset . . . her story had changed over the years and she didn’t want her fellow students to see her in the story of a few years ago.”

Mary Morrison:

“I do slightly worry about people I have met who are amazing individuals, who have great skills but I just think they are going to burn themselves out and have to go and hide for a few years. . . and people always remember their story, and they are never going to get to change it.”

4.3.2 Considering family and friends

Participants considered that their story telling, which led to a loss of anonymity might have a negative impact on their families and friends lives. They agreed this was a major dilemma for them and therefore they addressed this issue by trying to protect their family as well as consulting them. This excerpt illustrates this dilemma.

Muriel Green:

“You know my main concern is my son because he is a child, . . .I don’t seek permission from him and I am also aware that he cannot possibly be aware of the wider consequences of me sharing a story. But . . . he is of my primary concern, and that’s why I won’t do the tabloids and things like that because he gets bullied enough and he doesn’t need that.”

The workshop also came to the conclusion that the family needs to be considered before going public and that there might be negative consequences for the family. It was also thought that a person needs to “work through” the possible consequences the family could face, if she/he goes public. So participants sought permission from their family and friends before going public:

Julie Tullie:

“….in the latest mental health first aid DVD I spoke for the first time about my attempted suicide. . . I ran it past my mum and my brother just to see how they felt about speaking about that. And my mum said just…that’s fine with me, she was quite happy for the truth to be known.”
4.3.3 Control over the media

The participants spoke about their experiences of sharing their story in print, on DVDs and the Internet.

Story tellers felt and experienced that they did not have control of the story that was used by the media. There were a number of issues as illustrated by these excerpts:

Deborah Blau:

“It’s the sort of lack of control you have even with the DVD that… I mean I know several user groups in Scotland have made DVDs and they are very publicly available. I feel… well I find that difficult but… because you don’t know who’s going to see it and its… you have no control over what it has got to.”

“….you might think well only people who are vaguely interested would go on to the Mental Welfare Commission website but it’s the fact that you can Google somebody and…”

Julie Tullie:

“So I think the press is the most scary thing that I have done.”

Laura Walters:

“I sent them a photo someone had taken with a glass of wine or something and they cropped the glass of wine out. I never thought it out but I wasn’t happy the editor changed it so much, never let me see it before it was published and I didn’t like the tone of it.”

One participant with experience of working in the media industry considered that story tellers need to be aware of the intention a newspaper has in seeking to publish a story:

Mary Morrison:

“The line of intention as in like so you work for a certain paper that has a certain you know remit, your advertising is sold on the fact that you are selling to a particular audience; therefore you must reach that audience. That audience expects certain things from you, certain repetition of belief systems, certain language use, you are going to keep feeding that because that’s your job and many is the time that I have had the argument about oh the media is bad and its done this, this, this and this.”

It was found that some story tellers tried to control the medium of sharing their experiences by actively using various strategies:
Julie Tullie:

“They change the order of the words and how the quotes appear out of context. . .which is ultimately I suppose why I prefer to write my own articles in a sense, because I can then divulge the information in the way that I want it to be interpreted.”

Deborah Blau:

“I think . . .for me to know what the context is, to know who the audience is . . . and to have some control over that, so conferences and that were sort of easier.”

4.3.4 Setting boundaries

Participants also spoke about that they had to decide how or if at all they would open up to a particular group of people. This setting of boundaries allowed story tellers to protect themselves. These excerpts come from two experienced story tellers.

Siobhan Clarke:

“If I have got a group of really hostile people I am not going to open myself up so much as I would with a receptive group. Because I don’t want to end up feeling vulnerable so if I get a hostile group then I will tell them very matter of fact the facts but I won’t tell them as many personal things as I would a group that was open to…”

“…it’s a little bit of both, 90% of the time I would say that I am very safe with myself; I don’t share things that I am not happy with sharing.”

Kay James:

“And its something about you have to be actually quite clear about what you are offering. And being quite clear with your boundaries and not being pulled into saying more than you actually want to because it’s very easy to disclose something that you are not really that comfortable for the whole world to know, that you can’t actually take it back.”

Section 4.3 Discussion

An important finding of this research is that participants faced a dilemma where on one hand they wanted to share their experiences with the public, while at the same time at a personal level they did not want to be known and recognised as public personalities. When losing anonymity participants singled themselves out and openly declared themselves to belong to a particular social group of people who have experienced mental health problems. Key Informant 3 was of the opinion that losing anonymity has a potential risk effect because it may become widely known in the public domain that somebody has or has had, a mental health problem that this has the
potential to be counter-productive such as an increased risk of discrimination, which may impact on the person’s mental health.

Participants had a strong sense that their story telling might have a negative impact on their families and friends. As participants themselves lose anonymity so do their families and friends as well, by being associated with the story tellers. Participants tried to protect their families using different strategies such as protecting their identity.

Another significant finding was the perceived lack of control of a personal story across a range of media platforms. An interesting issue is the extent to which names can be accessed on the Internet by simply typing a name on a search engine such as Google. This is relevant given the amount of personal blogs and posting of personal stories across a range of mental health websites.

Setting boundaries was an issue participants highlighted when looking at story telling. Participants had a feeling that they had to set boundaries to protect themselves emotionally. Therefore it can be argued that the participants who were interviewed had a feeling of being self-aware of their emotions and therefore knew how much they could convey to the public.

We speculate that participants used this self awareness to make decisions about boundaries taking account of the purpose of the session and the target audience.
Section 4.4     Personal impact and self-awareness

This section is drawn upon the findings that come out of our analysis of what the participants shared with us about the personal impact of telling and sharing personal stories. These issues relate to the third research objective of “Identify the range of issues and potential dilemmas for those people whose ‘stories’ have been used in the public arena for the purpose of health promotion and education.” Reference will be made to processes that might be called therapeutic and how for some this leads to enhanced personal awareness. The previous section on Dilemmas and Issues indicated that self-awareness is regarded as a protective factor.

Personal Impact and Self Awareness consists of five sub-categories:

- Storying personal identity and therapeutic processes
- Self-awareness as an enabling factor
- Emotional impact of story telling
- Perceptions of other service users
- Future plans

Section 4.4.1 Storying Personal Identity and Therapeutic Processes

There are assertions from many sources that using personal narratives has healing or therapeutic effect on the storyteller. We sought to explore this phenomenon, not in the sense that formally this was personal therapy but rather in an indirect manner, could the telling and re-telling of a personal story to others have a therapeutic or healing effect? In reviewing and analysing the transcripts of these interviews what became clear is that some participants chose to answer the question in terms of their own recovery journey whilst others focused more on their experiences of sharing their story with others:

Recovery journeys:

Julie Tullie:

it is part of the narrative journey the poetry . . . you are kind of asked to explore different avenues of thought that you haven’t gone down before. And it makes you think about yourself and where you are in your recovery journey. And you know . . its part of the moving on and moving through. It’s part of the passage.”

Siobhan commented about the experience of sharing her story within a peer group:

“it’s a very liberating experience being able to tell that story and to share that story with others who have got similar stories. . . you can identify with each other and the big thing that’s in that group is acceptance. There is total acceptance of the person and people are encouraged to tell their stories because it’s seen as telling stories is therapeutic, it’s been helpful, it’s been something that is a positive experience”
Therapeutic processes associated with story telling:

Siobhan Clarke:

“. . one is that you can actually tell your story, you are not just telling your story to someone else but you are also telling your story to yourself and you can make sense and you can see areas that well actually I had never thought of that before”

Alan Stewart:

“I think initially getting a story together or having to talk about your experience actually in some ways validates or clarifies where you have been .. it makes you rationalise it out personally, so I think it actually does something cathartic, it’s something that can if you want to work through, that can be healing”

Section 4.4.2  Self awareness as an enabling factor

A strong theme that emerged from the workshop was the need for a story teller to develop self awareness especially before going ‘public’ but also an ongoing process.

Kay James developed this idea in writing:

“Sharing your story enables the opportunity for you to ‘reframe’ the experiences that you have had. Too often when going through challenges in life other people can tell you what you are feeling and experiencing. . . The important thing is to feel listened to, not to be judged and to be accepted for who you are”

Some of the participants also referred to self-awareness within the individual interviews:

Allan Stewart:

“so there are times when you should (public speaking) and there are times when you shouldn’t be doing it. And that’s a bit about being honest to yourself and whoever you are presenting to or working for”

Siobhan Clarke:

“I am much more self aware than I was years ago . . And I just think it’s made me a stronger person. I think its also giving me more ability to deal with voices when they are bad. Because when they are bad . . I have still got those articles and I will go back and read them.”
Section 4.4.3 Emotional impact of story telling

The stories that are being shared, as indicated in the previous section, can have a powerful impact on an audience. What we heard from the participants was that for the story teller however many times they have told the story there is always an emotional memory attached to an event in the past. These excerpts illustrate some of this experience:

Robert Stevenson:

“but sometimes things hit you . . I felt this well of emotion come up and my throat tightened . . but it was a surprise to me that what has become a story actually still has a huge impact sometimes when you tell it.”

Julie Tullie:

“as part of the narrative story telling experience . . you are going to have to go backwards and relive experiences . . which is going back into space that you have kind of come out of. But I have found over the course of time it’s got easier because the distance from it is getting bigger.”

Section 4.4.4 Perception of other service users

The participants commented on their perception of other service users in a variety of ways. The following excerpts are a challenge to what was perceived by the participants as people being stuck in a comfort zone.

Muriel Green:

“. . I said well I never felt part of a user community, service user community, I said and you have got a choice, you grow up and you make the choice. Do you want to be a service user? Do you want to have a life?”

Gwen Brankin:

“I think there is too much of the mental health service user land so to speak. Where people don’t move on with their lives, they are stuck in the comfort zone of having a mental health problem so they feel comfortable with that. Well no you can achieve something with your life.”

A different point of view by some participants was expressed in terms of recognising that stories of recovery can offer hope and inspiration to other people who may be in the early stages of their recovery. A strong sense of mutuality came over as is illustrated with this excerpt:

Allan Stewart:

“there is mutual stuff going on if you can relate to your audience and there are people that are nodding and everything then hopefully it’s a learning
experience. It’s a thinking experience, people go away and think Jesus you know what if I did that”

**Section 4.4.5 Future Plans**

Significantly for some of the participants thinking about themselves in positive ways including looking to the future:

Laura Walters:

“people had asked me about writing a book . but there will come a time when I can do it I am sure . . . it’s getting nearer.”

Cheryl Watt:

“I take it (public speaking) seriously, it’s a stepping stone for me to get back maybe into full-time employment. . . I mean that’s in the future, I mean for me to get this far I have achieved . .that was less than two years ago I did that training for the trainer’s course and recovery. And we did our dreams and nightmares; I have achieved everything on my dreams chart.”

**Section 4 Discussion**

The major issue that this section has illustrated is that the telling of personal stories or narratives has a resonance that goes beyond the conference hall or the recording studio. The telling of these stories has a uniquely personal association for the storyteller and this process was described by different participants as “cathartic”, “re-framing”, “healing”. This might suggest a process of meaning making or ‘re-authoring’ (White 1995), whereby people on a journey of recovery can build alternative and preferred identities for themselves. The participants appeared to value having an enhanced understanding of a series of past events and have achieved greater self-awareness as to their lives in the past and the present. Heightened self-awareness has been identified in other studies as contributing to the development of a positive identity. (Brown and Kandirikirira 2007).

The experience of recovering from mental health problems has been likened to a journey and indeed the Scottish Recovery Network produced a booklet called “Journeys of Recovery” (2006). In the same vein, because telling a personal story or narrative is a process of learning and development we suggest this can also be likened to a Journey of Story Telling.
We suggest that it is fruitful to explore the relationship between the Journey of Recovery and the Journey of Story Telling as illustrated in Figure 1.

![Figure 1. Journeys of Recovery & Story Telling](image)

We suggest there is a direct and mutual interaction between the Journey of Recovery and the Journey of Story Telling, in which each circle of influence relates to the other. The personal accounts of the participants are testimonies to the empowering effect of telling one’s story in an accepting environment throughout the recovery process. It may be claimed this is experienced as healing and in that sense can be seen to be therapeutic.

At the same time for some of the participants a line needs to be drawn when the story teller is placed in the position of a facilitator or trainer and then the purpose of telling stories is different because it must relate to the objective of a particular conference or training session. If an individual is experiencing individual difficulties then the proper place to address this is in the therapy room and not from the conference podium according to this point of view.

The participants at the workshop considered that when a person decides that he or she wants to tell his or her story in public there are risks in the beginning stage of the Journey of Story Telling. These risks include that where a person is passionate about telling the truth as they see it that they may over-expose themselves and inadvertently may get into tricky and confrontational situations. The Scottish folk singer Karine Polwart puts her finger neatly on this dilemma in her song ‘Daisy’ and one stanza illustrates this:

> “Hey Daisy darling don’t give them all you can,  
> Why don’t you keep a few more cards in your hand?  
> I know you’ll only say a thing you believe to be true,  
> But there are people in this world who don’t think like you do”

The participants at the workshop were also of the view that whist speaking the truth about mental health issues is important this has to be tempered with an awareness of power and the potential for discrimination. Their view was also that in sharing
personal stories it is wiser for reasons of self-protection not to show all ones personal cards.

The workshop participants were of the view that the recovery process needs to have got underway prior to somebody telling their story in public for the first time. Their view was that before telling the story in public the person must have developed self-awareness through the telling of their story with others in an accepting and non-judgemental environment. The example given was of peer support groups. The participants stressed the importance of supports that need to be in place.
Section 4.5  Support, Training and Guidelines

The story tellers within the semi-structured interview were asked about enabling factors for their story telling in public. This relates to the first two research objectives. Analysis of their responses identified Support as a core category with four sub-categories:

- personal learning and training
- emotional support
- financial support
- best practice/guidelines

4.5.1  Personal learning and training

Within this section participants expressed their views of training for story telling and how this would support their efforts. Participants also shared how they learned through observing and practising story telling and being made aware of the potential consequences of story telling was also perceived as support by the participants.

There was a consensus that participants found training in various practical skills such as public speaking important but also that the impact can be empowering. Several participants made reference to the impact that taking part in WRAP or Recovery courses has made and talked about these as turning points in how they thought about their lives and their recovery.

Gwen Brankin:

“Other than any training that might be needed whether it be the way people present their stories, ...whether it be a story online, or whether its talking in front of an audience, or whether its doing a PowerPoint presentation,...”

Deborah Blau:

“I can see that...well yeah for the people I work with . . training seems to have an incredibly empowering affect almost regardless of the context. We have done a couple of trainings, different things, one was recovery training for trainers and a number of service users took part. And...moved on incredibly in their lives as a result of a one week residential course on recovery...on recovery training.”

Learning through observation and practice in doing story telling sessions was also thought to be important, as is reflected in these excerpts.

Cheryl Watt:

“....And I have done it with little preparation and I have done it with a lot of preparation and sitting reading over, taking time reading over and preparing
well and the difference that makes. If I am prepared then I can cope better you
know I prepare in my mind possible questions that people might ask. And I
think it calms me down as well and if I have my notes organised as well it
seems to go a lot easier and it’s less rushed.”

Within the workshop participants also felt that a person learns through the experience
of sharing her/his story especially with peers. It was felt to be very useful to observe
how other story tellers present their stories to the public.

Alan Stewart:

“The fact of the matter was everyone did, and they all did a very good job and
that’s something about the power of peer support and wanting to…wanting to
learn from one another. An enormous amount of learning should happen if
you do it right, an enormous amount of learning and joint learning, because
every time I tell my story whatever people pick up on then I am always
learning.”

Participants thought that a person who has lived through the experience of telling
stories should give advice to their peers, especially if she/he was concerned about the
mental health of the story teller. It was thought that peer support allowed sharing of
the experience as a team. One comment at the workshop was that:

“. . peer support can provide an opportunity to look at the experiences they have
had and ‘reframe’ them in a way that enables them to move in the direction of
their choice. I do not believe that this needs to be in a public way, it can be done
through private conversation and in the way that is chosen by the person
themselves.”

There was a strong consensus that people who share their stories should be supported
by being made aware of the possible effects their public story telling could have on
their life. This is illustrated within the following excerpts.

Robert Stevenson:

“We will provide training to our members on the pitfalls and the ways in
which they can involved in being awareness raisers. So that’s quite important,
so the setting is there and they have a chance to look at things, where things
might go wrong. For instance, where you might get too far down the
emotional route and have to leave the room, or where you might be too angry
to give a story, or whatever so we do that”

Mary Morrison:

“…so I don’t know if you can train someone, you can make them aware of
some of the pitfalls and I think people did… People did make me aware of
some of those things so that…in a way is sort of training I suppose.”
4.5.2 Emotional Support

Emotional support when telling their stories was also identified as a sub-category. Participants felt that on the occasions they established a bond with an audience that they therefore experienced emotional support from the audience.

Siobhan Clarke:

“...it’s a very liberating experience being able to tell that story and to share that story with others who have got similar stories. And...it almost...you almost become like identified as a group, you can identify with each other and the big thing that’s in that group is acceptance.”

There was a consensus about participants having emotional support through somebody else structuring the story telling session, such as in the role of a chairperson or a facilitator.

Deborah Blau:

“I think the chairperson if there is that kind of...definitely has a role to play, I think that’s really quite important, and I have been on a panel, I find that quite difficult. And you know you get asked questions. “

Robert Stevenson:

“...you have a facilitator who makes sure that everyone feels comfortable, where you have ground rules for the way that you express things.”

There was agreement that emotional support is considered very important. The emotional support was seen as coming from family, friends and colleagues.

Deborah Blau:

I now do it a lot, they have had a partner or a friend who is nothing to do with mental health but who has actually been present. And they haven’t made a big deal of it or anything but I have just noticed um...and...you know...I think...yes I think I do because if a colleague is with me, actually yes I think emotional support...I think probably I do need to talk somebody about it afterwards. Whether it...whether its just...somebody who is in my life anyway, a friend or...but a colleague

It was also felt that emotional support is provided by story tellers to each other.

Gwen Brankin:

“...whether its people doing it buddying up, so you have got two people each with a mental health issue, but they feel more comfortable doing it together. So one tells their story, the other tells the other and then they…it’s a common theme, maybe that would give people more encouragement to come forward.”
4.5.3 Financial Support

The financial aspect of story telling also featured in the accounts of the participants.

Where financial support is offered, for some participants this created a pressure to achieve, although the feeling this may lead to a loss of control of the story.

Muriel Green:

“And there were all these agencies phoning up wanting to say make money on your story, can we get your story and you can make money off it? And I rejected that because I felt that A. you would lose control and B. it would . . .probably counteract the. . .I am trying to think of the word, the…the actual…I think they would focus on things like psychotic and psycho and you know these things.”

Robert Stevenson:

“…we have been having a debate over the years about whether we should pay our awareness raisers. And with some exceptions the great majority of the view is that they don’t want paid and the reasons they have said for that is that…first of all if they were being paid to do awareness raising sessions they would have to make a commitment to do it. It would create a pressure to deliver a high quality.”

There was a consensus that financial support is indicative of how agencies value the contributions of story tellers.

Cheryl Watt:

“I just feel that you are getting paid . . .and you are getting treated properly you will work hard and I mean I put in…for anything I am getting paid for, even though I have done it 100 times before, I will read over it, I will prepare, I will be there in plenty of time to set up.”

Laura Walters:

“…..now I am left with the feeling of I want to be able to be recognised as somebody who has the ability to share her story but also to be recognised as somebody who has the skills to be a trainer and the skills to be able to stand up for others”
Participants also experienced problems with the benefit system in the context of financial gains when telling their story.

Julie Tullie:

“They said please send us wage slips and I just thought get real you know!”

Robert Stevenson:

“Then there is the basic benefits problems which really frustrates some people who say well you know if you give me a payment I have got to declare it. And if I don’t declare it I am doing something illegal so why pay me in the first place.”

There was also a strong consensus between participants that expenses should be provided to the story teller.

Laura Walters:

“I think it would be unfair to expect me to pay for accommodation in a B&B or something like that. And…I know that cars get thirty pence a mile or something but even just covering the cost of the petrol would be good.”

4.5.4 Best Practice Examples/Guidelines

The participants were asked as to their perceptions about guidelines, ground rules, good practice as well as best practice. Participants did refer to all of these terms. For example, the Scottish Recovery Network on its website has a document it terms “Guidelines and Considerations” and this applies to any person who might choose to submit their story for inclusion on the SRN website. This includes a number of promises by SRN as well as indications of what they consider they are not able to do. Within the workshop it became apparent that participants could not agree on one particular term relating to guidelines or best practice examples but there was agreement that guidelines/best practice/ground rules are of a great support for people who share their story in public.

Maria Croft:

“I think guidelines are a good thing it’s like everything else I suppose, I mean guidelines are good if you are starting out and you don’t know where you are, and you are not sure where the land lies. They give you solidity and the feel for what you can say and what you can’t say, they give you comfort.”

Deborah Blau:

“…just so that people have a chance to think about it, or know so that they are informed, so it’s an informed decision.”
Participants talked about how such guidelines should be applied in practice and strongly argued for a flexible and sensitive approach:

Siobhan Clarke:

“I personally don’t think it’s a good idea I think . . . general ground rules that’s fine, that’s good but every situation is different and I think the guidelines need to have that flexibility within them to do that because people tell their story in different ways. . . . if they got guidelines drawn up that included the service users when they are drawing up those guidelines that’s very good. But there should also be local guidelines that are much less strict so that the person telling the story has more creativity, has got more space to tell the story the way they want to tell it.”

Muriel Green:

“I feel that…you are kind of doctored in a way but your story has to reflect these themes on recovery and things like that.”

Maria Croft:

“…..I think once you have done this for a while . . . and you have done it…done it well, to the extent that people are responding to you positively, I think that’s very important. The conferences or whatever you have been speaking at feel that you are doing a good job as well, then maybe you can just gently push the boundaries of the guidelines a little bit, just feel your way with bits and see how it goes.

There was a consensus amongst the participants that after being made aware through guidelines of the consequences of sharing their story in public, story tellers should have the right to make the decision if they still want to share their story in public.

Kay James:

“I think that if the preparation work is done and the person is deemed well enough to be telling their story then that’s the same as anyone else. That has to be…you couldn’t suddenly turnaround ten years later and say well actually I was really pissed that night, I wasn’t really as it was, its something about the preparation to make sure that people are completely aware of what they are doing and the implications of what they are doing.”

Robert Stevenson:

“I think although we are giving our voice out there is an element where you own your voice, and you need to decide what you are going to do with it. But you need to have the information available to you to know what is going to happen that”
Section 4.5 Discussion

A major finding is that the notion of Support is accorded a high importance by the participants. As this section has discussed there are a number of issues relating to Support some of them complex but at the heart is the idea that a storyteller should have effective and continuous relational and emotional support that contributes to a feeling on their part of being valued and respected.

A current consideration is that the suggestion there should be readily available to potential and current story tellers documents (electronic and paper) that help to inform the decision to story tell in public settings. These are variously described as ‘Guidelines’ or ‘Good Practice examples’ or ‘Groundrules’. This is justified by its supporters as an essential act of duty of care by public authorities; this was expressed by two of the Key Informants.

We found although there was a lack of agreement about the term to be used to describe such documents, there was strong support expressed for the principle of general guidelines/best practice/ground rules being in existence although some questions as to the application of these in practice. There was a strong feeling that these need to be interpreted flexibly at the ground level. Key Informant 2 expressed real concern this might become a control issue by powerful institutions and that “guidelines might be the thin edge of the wedge.” Key Informant 4 recognised the need for guidelines but argued there needs to be a balance to ensure the control of the story is retained by the story teller.

The issue of people’s benefits being affected by payments received for story telling activities has been called the “Benefit barriers to involvement” by others (Turner & Beresford 2005, Commission for Social Care Inspection 2007). This means the way the benefit system works that prevent people getting involved in public services. Both these major reports highlighted major deficiencies within the Benefit system and called for the benefit rules to be made more flexible. For example, fees received should be looked at month by month and not week by week. This problem was also highlighted by Key Informant 2 and is a significant finding of this report.

It is our observation, that the concept of support is understood by the participants in terms of empowerment and this applies to training. Our sense is that “training” as a concept has been re-framed by service users to have a broader meaning than what is conventionally understood by training through the use of accredited courses. Some of the participants referred to courses that they have been on and seem to have found stimulating and on occasions inspirational.
Section 4.6    Finding out about research

The fourth objective of this research project was to “facilitate the development of research capacity by service users”. This took the form of exploring with the participants issues and questions concerned with ‘research’. This included the meaning of research for them, their experience of being involved with research and their advice on disseminating the results of this research.

4.6.1 Service users’ relationship with research

We asked the participants about any previous involvement with research either as a participant or as a researcher and followed this up with a question about attitudes to research.

A significant finding was that seven of our participants had been or are currently involved in a range of activities that can be classed as research. Most of this involved seeking out people’s views by a combination of speaking with people and/or using questionnaires. The information gained was then used for purposes of evaluation. When asked a large majority said they would be interested to know more about the methods and ethics of research.

Participants were asked about their attitude to research:

Siobhan Clarke:

“I think research like this which is much more qualitative, much more subjective you will hear people’s true stories and people will tell you things you wouldn’t find in randomised control trials”

Julie Tullie:

“an interesting kind of area for service users to be involved in, to feel that they are not the ones that are under scrutiny all the time. They are the ones that can do the research, its enabling, much more enabling”

Deborah Blau:

“it (research) does have a history of exploitation around it doesn’t it? . . . what’s in it for me? Because it seems to be for somebody else.”

4.6.2 What ‘research’ means

Participants were asked the question about the word research and whether they had a preference for alternative words or phrases. The following excerpts are representative of our findings:

Laura Walters:

“exploring life experiences”
Allan Stewart:

“Research is slightly jargon and I think if your average service user to get involved in research would think WOW! So it may have a negative effect on getting people to be involved, thinking research and they will get sceptical about it . . . what else could you call it? Information gathering . . . just keep it simple.”

Julie Tullie:

“As an artist it sounds too scientific (!) . . . untapping the truth“

4.6.3 Potential research topics

This was discussed at the workshop and a number of topics were generated by the participants:

- NHS funded alternative therapies to prescribed medication
- Management of change within services
- Building resilience and increasing coping capacity throughout the population
- Use of respite/shared care accommodation
- Individual growth and development
- Impact on carers of training and recovery approaches
- Educating mainstream services as to peer support

4.6 Discussion

We observed that the participants were all interested to talk about research either from the point of view of projects they had been involved in or from the point of view of wanting more information.

This was a positive orientation. Another dimension was a wish to see research done that has meaning in the lives of people and is able to record facts. For some there was a perception that there is a power dynamic in the relationship between researcher and the researched person and that there is now an opportunity in Scotland for a research initiative involving service users. There are some useful working examples in England of service users being active in mental health research. One example is Suresearch which involves service users in all aspects of research and has a strategy to develop research capacity (Davis 2005).

There was a general view from the participants that the word Research conjures up images of scientists in white coats working with test tubes in laboratories – and that would be off-putting for most service users if they were approached to take part in a research project. Preferred words include:

- “look at your story”
- “information gathering”
- “untapping the truth”
- “exploring life experiences”

But mostly there was a preference for plain English to be used to communicate information and understanding about the goals of a research project and what it is about.
Section 5  Discussion

The headline findings of this report are that:
- Personal stories or narratives of mental health problems and recovery have a number of purposes and these are linked to core messages.
- Story tellers, by going public, lose anonymity which is an issue not only for them but also for their family, friends and colleagues.
- The telling of stories causes further reflection on past experiences of mental health problems and can in supportive circumstances contribute to a re-framing of experiences and a move towards a preferred positive personal identity.
- The telling of stories in the absence of certain factors may for some be a high risk activity which may exacerbate mental health problems.
- Support is the major protective factor against such risks and consists of four elements; emotional/relational, financial, training with peers and guidelines/groundrules/examples of best practice.

Recovery and Positive Identity
A turning point is the active engagement with the process of recovery: a journey that leads individuals to re-frame their experiences and moving towards a positive identity. We have heard from the participants that for them the act of finding and sharing their personal story with others has had a cathartic and healing effect. The gaining of greater self-awareness through these personal narratives was highly valued. The use of personal narratives in our view needs to be recognised as a core element of the recovery process. There requires to be a valuing and recognition that personal stories are no mere ‘idle chatter’ but are the very stuff by which people take charge of their own lives and begin the process of building positive identities. It is one thing to share personal experiences with trusted others but quite another to do this in a public forum. This makes the decision to speak about one’s personal experience at a conference or be interviewed by a newspaper as a crucial step. In view of this we suggest it might be very useful to pursue a conversation with interested parties and organisations about how the use of personal narratives may be promoted and encouraged within mental health services in Scotland.

Deciding to go public
There are a number of issues facing people who are contemplating sharing their stories in public. This raises issues of risk and supportive factors for the mental health and wellbeing of story tellers. Will this be a flourishing or a languishing experience for them? As we have heard there are occasions when the experience of sharing in public personal experiences can carry risks and even for people who have considerable experience of storytelling it can have on occasions unexpected outcomes. This report identifies that the loss of anonymity is the biggest dilemma that participants face and that this may expose them to discrimination and challenge their own mental health. We do not think that the responsibility for protective measures lies wholly with service users and therefore agencies, public institutions, employers, universities etc. have an ethical and moral responsibility to take very seriously the question of inviting service users to share their story publicly. We suggest a useful starting place is to look
at the evidence there already is as to what works in the area of involvement and participation. Carr (2004) reports on a piece of research she carried out and includes a statement on how to make things better and these include some of the following:

- Aims and objectives should be clear
- Getting people to participate takes time and money
- Be aware of the relationships between the practitioner and the service users and the power involved
- Be flexible about different ways of working
- Ask service users how they would like to be given feedback
- Make sure all staff understand the value of having service user involvement and have the support to make it successful

We suggest that whilst there is support for the idea of guidelines there is some ambivalence and even anxiety as to the application of these at a ground level. It is recognized these may be very useful for inexperienced story tellers but there are potential issues of story tellers being controlled or influenced by powerful agencies both in terms of the message and how that is delivered. It is to be hoped that a constructive process of involvement and an open dialogue will help to illuminate the issues and encourage a positive way forward. In view of lack of agreement as to different titles used (guidelines; examples of good practice) our view is that it would be very helpful for people actually to view what documents are already in public circulation. A suggestion we make is that these documents should be placed online on several major websites so that these can readily accessed by individuals and organizations.

An informed reflection of these service user involvement issues suggests that a productive form of analysis is to consider these at three levels:

- **individual**
  an individual’s personal and interpersonal circumstances.

- **social**
  the cultural, social and political beliefs that are dominant in a society.

- **structural**
  the organisational policy, procedures and allocation of resources that are decided on by those institutions and individuals with political power and authority.

By adapting the model produced by Barry and Jenkins (2007) we can in Figure 2 illustrate some of these issues and begin to relate various elements that have featured in this report.
<table>
<thead>
<tr>
<th></th>
<th>Supportive Factors</th>
<th>Risk Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Individual level</strong></td>
<td>Recovery process</td>
<td>Low self-esteem</td>
</tr>
<tr>
<td></td>
<td>Self awareness</td>
<td>Low level of self-awareness</td>
</tr>
<tr>
<td></td>
<td>Positive identity</td>
<td>Focused on symptom alleviation</td>
</tr>
<tr>
<td></td>
<td>Social skills</td>
<td>And not on recovery</td>
</tr>
<tr>
<td></td>
<td>Relational connection with key person in co-ordinating agency</td>
<td>Discrimination</td>
</tr>
<tr>
<td><strong>Social level</strong></td>
<td>Supportive informal network</td>
<td>Socially isolated</td>
</tr>
<tr>
<td></td>
<td>Included in peer support group</td>
<td>Not discussed mental health issues with family and friends</td>
</tr>
<tr>
<td></td>
<td>Diversity valued</td>
<td>Diversity not recognised</td>
</tr>
<tr>
<td></td>
<td>Participated in at least one training course</td>
<td>Not part of a peer support group</td>
</tr>
<tr>
<td><strong>Structural level</strong></td>
<td>Safe &amp; secure living environment</td>
<td>Uncertain living arrangements</td>
</tr>
<tr>
<td></td>
<td>Positive training experiences</td>
<td>No training courses</td>
</tr>
<tr>
<td></td>
<td>Certainty re expenses &amp; fees being paid</td>
<td>Not being given guidelines</td>
</tr>
<tr>
<td></td>
<td>Consistent &amp; safe processes used in line with guidelines</td>
<td>Being asked for information by Benefits staff</td>
</tr>
<tr>
<td></td>
<td>Verbal and/or written feedback</td>
<td>Oppressive procedures &amp; practices</td>
</tr>
</tbody>
</table>

**Figure 2**  
Examples of supportive and risk factors  
(Adapted from Barry and Jenkins 2007)

This table in a simple way contrasts the two positions and indicates the range of issues that must be addressed positively by a potential story teller and by agencies. The objective for the storyteller is an enhancement of their own mental well being as part of a satisfying and fulfilling life. For this to happen in our view across each of the individual, social and structural levels there needs to be a preponderance of supportive factors over risk factors to make the decision to proceed with sharing a personal story in public a safe and feasible one. This will enhance the possibilities this will be a flourishing experience for the individual. A particular challenge may be the involvement of harder to reach groups such as older people, teenagers and those from ethnic minorities.

There has to be a process of sharing information with the potential story teller in which not only are they appraised of the particular event but also are advised as to possible adverse consequences of ‘going public’ For this reason the principle of informed consent is suggested as the foundation for story telling.

**Story development and story telling**

Service users through sharing personal stories can make relational connections with the public by shining a bright light on what has been a dark place; this connection happens because the audience is privileged to be invited in to somebody else’s real and authentic world. Experience of story telling may impact positively on a person’s identity and enhance his/her sense of well-being. To be on a journey of recovery is one thing and then also to enter a journey of story telling in public adds complexity, challenge and richness to the whole process. The journey of story telling involves a developmental process which is represented by Figure 3:
Support and Training are the central pillars in relation to both recovery & story telling as these offer many assets; acceptance, trust, other people’s ideas, different perspectives, inspiration, energy and a safe place to try things out and develop oneself. The processes used are that of empowerment whereby people reclaim control of their lives and use their own words to define themselves or as some might say to re-frame a much more positive identity with increased levels of self-awareness. We think this self-awareness is broader than the individual level and opens people to the world of ideas and action (Dalrymple and Burke 2005).

We are of the view that being part of such a culturally rich learning experience is a protective factor when a person moves towards sharing their story in public. Conversely if somebody starts story telling without the above cultural learning experience then the risk factor increases. We have heard during this research of the benefits of experience and how there is often a progression over a period of time. We speculate that out of raw lived experience may come an act of creation that converts this into a cohesive and meaningful story. The choice of a medium for sharing that story clearly has huge meaning for the individual person whether that be speaking with no notes, reading from a carefully crafted script, art work, poetic works, newspaper articles, audio clips and video clips etc. The core point is that the person needs to be in control of the medium and feel comfortable with it. We heard accounts of how the story is refined over the years and so maybe with experience the story becomes less cathartic and more focused as a means to deliver core messages and keeping in mind the objectives of a session and the needs of a particular audience.
Further research

Clearly in a study such as this which is limited in resources and time, there were a number of research questions that we encountered but were not in a position to follow up. The following are the most salient research questions:

- What is the extent and effectiveness of informal story sharing within peer support groups and self-help groups?
- What are effective strategies in encouraging and promoting greater diversity of people who tell their personal stories?
- What are the pathways that people follow to enter story telling in public and is this interest maintained or not?

Conclusion

As people who use mental health services increasingly use their personal stories to promote recovery and provide an anti-stigma message, it is important to ensure that best practice in this area is recorded and made available in an easily accessible format. This report highlights the issues and dilemmas associated with ‘going public’. It records the considerable commitment by the individual participants and suggests that training and support are key elements in supporting the process of story development and story telling.

Rob Mackay  
Applied Social Studies  
Robert Gordon University  
Garthdee Road  
Aberdeen  
AB10 7QG  
E-mail r.mackay@rgu.ac.uk
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## GLOSSARY OF TERMS

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guidelines</td>
<td>We have used guidelines as a broad term to include information, examples of best practice, ground rules and statements of expected responsibilities and limitations</td>
</tr>
<tr>
<td>People with Mental health Problems</td>
<td>We have used ‘people with mental health problems’ as a general and inclusive term.</td>
</tr>
<tr>
<td>Service user</td>
<td>We have used ‘service user’ to indicate a person who uses mental health services whether those be provided by the public and independent sectors</td>
</tr>
<tr>
<td>Story teller/Story sharer</td>
<td>We have used ‘story teller and ‘story sharer’ as terms to describe where a person elects to share aspects of their own personal lived experience in a public format, often with a live audience.</td>
</tr>
<tr>
<td>Storying</td>
<td>We have used the verb ‘storying’ to describe the act of story telling</td>
</tr>
</tbody>
</table>
LIST OF APPENDICES

1. Membership of project advisory group
2. Information sheet 1
3. Telephone questionnaire (participants)
4. Information sheet 2
5. Research questions used in interviews
6. Interview questionnaire
7. Workshop programme
8. List of key informants
9. Telephone questionnaire used with key informants
10. Table of story telling experience
Appendix 1

Membership of Project Advisory Group

Michael Coull  Aberdeen Mental Health Users Network
Colin Macduff  Lecturer in Nursing, RGU
Angie Mutch
Val Sheach Leith  Lecturer in Sociology, RGU
Jenny Spratt  Researcher, Dept. of Education, Aberdeen University
Appendix 2

Using Life Stories as part of the Recovery process

Research Study

Information Sheet

Would you like to help with an important research Project?
Your views and experiences are important . . . .

WHAT IS IT ABOUT? This research aims to explore the use of personal stories or narratives within the recovery process. It will do so by asking people who have shared their own recovery stories in print, film and on the Internet. The research is especially interested to find out the best conditions for the telling of these narratives and how these are used more broadly. An important aim is that this research project involves service users in an open and transparent way so that the work of the research project is shared and owned jointly.
WHY THIS RESEARCH? This research is being carried out at this time because there is an increasing use of narratives, especially as a way of raising awareness as to mental health issues. This research aims to find out and explore the different ways that narratives are told and used, including issues of confidentiality.

HOW CAN RESEARCH MAKE A DIFFERENCE?

*This research can make a difference through highlighting the personal experiences of narratives and the issues. You have the experience and the skills in telling your story. It is important that this is acknowledged and valued through this piece of joint work. As such YOUR co-operation in agreeing to take part is to be very much welcomed. The findings will be sent to the Scottish Executive who are funding this research and these will be widely circulated throughout Scotland.*
HOW & WHEN? This research will involve questionnaires, interviews and a group discussion. The information gathered will be treated confidentially and no individual will be identified by name in any report arising from the research. Those taking part will be given the opportunity to see and comment upon the final draft of the research report. The research will take place between July and December 2007.

If you would like more information please feel welcome to contact:

Rob Mackay  
School of Applied Social Studies  
Faculty of Health & Social Care  
The Robert Gordon University  
Garthdee Road  
Aberdeen  
AB10 7QG  
Tel: 01224-263212 (direct)  
E-mail r.mackay@rgu.ac.uk
Appendix 3

Telephone Questionnaire

1. Contact details
Name ........................................
Address ........................................
‘Phone No.  ......................................
E-mail ...............................................

2. Experience of sharing a personal story
- in print Yes/No
- on radio Yes/No
- On video or TV Yes/No
- classroom speaker Yes/No
- Conference speaker Yes/No
- Self-help groups Yes/No
- Other Yes/No
  Specify

3. For how long have you been sharing your story?
0 – 5 years
5 – 10 years
10 – 15 years
20 – 25 years
25 – 30 years

4. Are you still active in sharing your story? Yes/No

5. Availability for the research?
- would you be available for 1 – 2 interviews? Yes/No
- would you be available for a group type of Discussion With the other research participants? Yes/No

6. Notes
Appendix 4

‘What works with personal narratives research project’

Information Sheet 2

Thank you very much for agreeing to take part in an individual interview on the use of narratives or life stories. The interview should take about 90 minutes and involves meeting myself and Iris Altenberger (research assistant). The meeting is to be audio taped and we will analyse this to produce our results. It is possible (although not automatic) that we may ask for a second interview. Following the meeting, we will write and provide you with a summary of the key points that we think you made in the interview. You may wish to comment on these. We will take every care to ensure that in the final report that the anonymity of every research participant is protected. We will send you a draft copy of the final report and invite you to make comment in relation to accuracy of information.

Follow-up Workshop
You are invited to take part in a follow-up Workshop that is taking place on Friday 2nd November at Stirling University. This is offered free of charge.

Expenses
Robert Gordon University is prepared to meet the travel expenses of research participants in attending for the research interview. Evidence of the travel expense incurred needs to be produced to the researchers, e.g. bus or train tickets or receipts. Mileage incurred by car travel to the meeting place may also be paid. Payment will be arranged as soon, as is practicable.

Counselling support
The researchers are aware that talking about mental health issues is a sensitive and personal matter. We endeavour to ensure this is a positive experience and at the same time recognise it is possible it may raise further issues for participants. If is felt that these issues could be usefully explored in a counselling environment then the research team can provide information as to counselling resources in Scotland.
**Research team**

Rob Mackay is a social worker who has worked in mental health since 1973 across hospital, community and voluntary sector settings. He has been involved with others in establishing informal support and advocacy services in the Aberdeen area. He has had contact with service user and carer groups in the Grampian area over many areas. He has worked for the Robert Gordon University for the past 13 years and has particular interests in relation to mental health, service user involvement, advocacy, narratives and empowerment. He has been heavily involved in promoting service users and carers as co-educators of social work students. He is the lead researcher in this research project.

Rob Mackay
August 2007
**Appendix 5**

What Matters with Personal Narratives?

Research question – What does using a personal narrative mean to you?

<table>
<thead>
<tr>
<th>Objectives</th>
<th>Questions</th>
</tr>
</thead>
</table>
| Identify the core conditions that support personal narratives as part of the recovery process | The what, where, how & whom of telling stories  
What enables the telling of a story in a way that connects with other people?  
What is the impact on the story teller of telling his/her story in these conditions? |
| Identify unhelpful practices that have hindered the use of personal narratives | What disables and hinders the telling of a story?  
What is the impact on the story teller of telling his/her story in these conditions? |
| Identify the range of issues and potential dilemmas for those people whose ‘stories’ have been used in the public arena for the purpose of health promotion and education | What are the pros and cons of going ‘public’ with a personal story?  
How can somebody exercise control of personal information over time once it is in the public domain? |
| Facilitate the development of research capacity by service users through this project | What processes and resources would enable the participation of service users as equal partners in the research process? |
Appendix 6

Interview Questionnaire

Personal Information

Contact details

Name ........................................
Address ......................................
‘Phone No.  Home .........................
Mobile  .........................
E-mail  .........................

Age band (please circle)

16 – 25 years
26 – 35 years
36 – 45 years
46 – 55 years
56 – 65 years
66 – 75 years

Gender (please circle)

Male
Female

Employment status

Are you in employment? (please circle)  Yes/No
Can you indicate type of work and job title?

........................................
Appendix 7

What matters with personal narratives workshop?

Friday 2nd November 2007
10.30 a.m. to 3.30 p.m.
The Iris Murdoch Centre
Stirling University

Programme

10.30 a.m. Arrival & saying hello to each other!
Coffee & tea

11.00 a.m. Introductions & purpose of the day
‘Let me tell you a story’
narrative activity

11.45 a.m. So far so good!
(Feedback on this research project)

12.00 Journey from service user to presenter
Exploration of processes leading up to individuals sharing their
personal experiences at a conference or training event. Use of
guidelines.
An activity

12.45 p.m. LUNCH (provided inc. coffee & tea)

1.30 p.m. Journey from service user to presenter continued

2.30 p.m. Your questions to be researched?
An activity to find out the questions you would like asked
about recovery.

3.15 p.m. How was this day for you?
A review of this workshop

3.30 p.m. Coffee, Tea & Cake
# Appendix 8

## LIST OF KEY INFORMANTS

<table>
<thead>
<tr>
<th>Name</th>
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<tbody>
<tr>
<td>Simon Bradstreet</td>
<td>Director, Scottish Recovery Network</td>
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<tr>
<td>Ron Coleman</td>
<td>Trainer &amp; Consultant, Working to Recovery Ltd.</td>
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<tr>
<td>Gregor Henderson</td>
<td>Director, National Programme for Improving Mental Health and Well-Being</td>
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<tr>
<td>Allyson McCollam</td>
<td>Chief Executive, Scottish Development Centre for Mental Health</td>
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Appendix 9

Telephone Questionnaire

1. Do you consider there is a growing trend in Scotland of service users sharing their recovery stories in public? (conferences, training events, dvds, websites, TV programmes, newspaper articles)

2. What is your explanation for this trend?

3. What do you consider is the purpose of such public sharing of recovery stories?

4. If we accept this trend is likely to continue, what needs to happen to support best practice in this area across the country?

Rob Mackay
### Appendix 10

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<th></th>
<th>Julie Tullie</th>
<th>Maria Croft</th>
<th>Gwen Brankin</th>
<th>Muriel Green</th>
<th>Siobhan Clarke</th>
<th>Deborah Blau</th>
<th>Cheryl Watt</th>
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