Involving service users’ stories in developing mental health services: the process of capturing, enabling and supporting service users' expertise and experiences

*A Participatory Action Research Project*

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SUMMARY

“Human beings, who are almost unique in having the ability to learn from the experience of others, are also remarkable for their apparent disinclination to do so” (Douglas Adams, 1991)

This paper reports on the process of a four year participatory action research study; a collaboration facilitated within the statutory mental health services by a mental health nurse manager working alongside six people whose identity moved beyond ‘service user’ to embracing that of co-researcher over this period. The main focus of the study was that the six ‘service user’ researchers interviewed 31 people currently diagnosed with severe and enduring mental illness and receiving input from the statutory mental health services. All interviews were audio recorded and transcribed verbatim. The transcripts were subsequently mapped and analysed by the research team using interpretative phenomenological analysis (IPA). In order that the people were enabled to undertake these roles, the study included a process of interviewing and appointing service user researchers followed by a programme of training workshops, provision of supervision and discussion group/peer support facilitated by the mental health nurse manager throughout the programme.

The purpose of this report is twofold; 1) to highlight the perspective of those involved as researchers on both the process and the impact of this type of involvement on them; 2) to identify significant themes from the service user stories and how these aspects can inform practice within statutory services.

IPA shares the view that human beings are sense-making creatures, and therefore the accounts provided and the quotes used in this report reflect the participants’ attempts to make sense of their experience of mental illness and mental health services. This paper discusses implications for service user involvement within the statutory mental health service, the potential for transformation at both an individual and collective level and the importance of how individuals engage with such agendas on their own terms.

Three main (meta) themes were identified by the researchers in regards to their experience of involvement - restricted lives, reframing the illness narrative and
involvement in developing the system. Four main (meta) themes were identified by
the 31 participants in regards their life story - experiences of mental illness, issues
around the mental health service, social/contextual issues and core/central/being
needs.

Each of these meta-themes contained a number of themes which are discussed.
The findings suggest that social isolation, lack of opportunity for reciprocity and
discrediting of self are barriers for any involvement activity within statutory mental
health services. The narratives further reveal the lived experience of mental health
issues and the services provided, emphasising the need for such narrative to inform
the service of the person’s whole identity as opposed to a focus on illness and
disorder - the human connection.

The report suggests that there is a need for acknowledgement of the capabilities of
service users with recognition that their former sense of agency may be subjugated
by the system. The system therefore needs to take these individual factors into
account within the process of any involvement activity in order that it moves people
away from an illness trajectory to that of transformation. The narratives obtained
provide a detailed and meaningful history which offer far more information to the
providers of services than “assessment” methods alone. These transcribed
narratives if made available within clinical records, would contribute to the strategy of
personalised care planning and genuine patient involvement in their own care plans.
The starting place of revealing the individual, beyond the illness focus enables a
personalised service to be offered and recovery realised.

Implications for further research, service user involvement and service delivery are
discussed.

BACKGROUND

Despite a long tradition of support for service user involvement, there is little
evidence that it is truly an integral and embedded part of the statutory mental health
services. User involvement continues to take a more passive form, where the use of
suggestion boxes, patient satisfaction surveys or consultation with service users in
the later stages of a project predominate. Studies have found that professionals
control the interpretation of involvement and the ways that service users are involved (Hodge, 2005; Rutter et al., 2004). This may have implications for the ability of user involvement to bring about fundamental change.

Although evidence of personal impact on those that become involved exists the nature of this impact is not well researched (Crawford et al., 2002; Hitchen et al., 2011; Minogue et al., 2009) and little is addressed regards these forms of involvement and impact on the ‘self’ in terms of recovery. Whereby effectiveness has been limited, it is the validity of user involvement that has been questioned and not how that process was implemented in the first place or what the different agendas were that influenced it.

Chronic Illness and the Self
Attention to the impact of chronic mental illness on the self has not been explored within the service user involvement debate.

It is important to revisit Charmaz (1983, 1987) who explores the illness trajectory of what happens when images of self are altered as a result of chronic illness. She addresses the aspects of “restricted lives” which relates to patients having insufficient information or treatment or relying on one practitioner or perspective limiting possibilities for increasing participation in their life. The unpredictable course of chronic mental illness, characterised by fear and uncertainty may result in some people voluntarily restricting their lives or drifting into isolation unintentionally. With such a fluctuating course people may feel they have to limit social activity, give up work or avoid others. This attempt to protect self results in great costs to their self–image. “Social isolation as a major consequence of a restricted life” has not been previously identified as an issue which can both be explored and addressed if service user involvement processes allow for and embrace diversity.

Reciprocity
Charmaz goes on to say that when people have withdrawn from the community as a consequence, family and friends may have to visit them. This requires extra time and commitment on behalf of their visitors and past reciprocity becomes altered and the
chronically ill are left behind. This loss of reciprocity is another significant feature highlighted in the process of service user involvement.

Discrediting Definitions of Self

"Experiences of being discredited, embarrassed or ignored or otherwise devalued also contribute to the growing isolation of ill individuals and to their subsequent reappraisals of self." (Scambler, 2003)

Another factor in the withdrawal from involvement in any social activity is the risk of potential discrediting. Importantly the discrediting definitions of self from health professionals become increasingly significant for an isolated ill person. Once a person is labelled with mental illness they must recover not only from severe emotional distress, but also from the role and identity of a person with mental illness. The label not only relegates people to a low status and diminished rights, but it also erodes a person’s confidence and initiative to pursue dreams and lead a full life of one’s own choosing. It is crucial therefore to attend to the idea that positive images of self reflected by even the briefest of interactions can help to maintain a positive self image.

The Mental Health Foundation recommended more funding to support user/survivor research in 2003, including infrastructure support and training especially in Scotland, Wales and Northern Ireland, where it reported that user/survivor research is less developed. In spite of these recommendations, Beresford and Branfield (2006, p 443) conclude in a study on developing incusive partnerships "that service users repeatedly state that the best way for them to have more say in the services which they use, and for their knowledge to become valid in the eyes of service providers, was through better and sustained involvement, as opposed to 'tick-box' exercises". This initiative provides great potential for that development locally and fundamentally underpins the philosophy and values within both recovery and personalisation agendas. These are highlighted for example within “From Vision to Action”: Reports that call for more personalised services (2010/2012) and Department of Health White Papers ‘Improving the Life Chances of Disabled People’ and ‘Our Health, Our Care, Our Say’ (Department of Health, 2005 and 2006). In order to do this, as stated in the personalisation agenda briefing (SCIE, 2009) you will need to have:
• **relationships** with people that are about respecting each other’s expertise, experience and assets and working together, sharing knowledge and ideas

• **conversations** with the people using services that are more open, exploratory and creative, looking at their life goals and the things that really matter to them

• **understanding** of people’s rights and entitlements – and the discrimination and stigma they may face – and the ability to share this understanding with them.

This research study by its very nature addressed all three of these criteria. It aimed to encourage truly innovative thinking and practice and be a vital channel for the transmission of growth of an ever-expanding range of user centered initiatives.

In the longer term it is anticipated that this research may contribute towards the very change of culture that the recommendations from Mental Health Organisations and Government Papers rely upon. Listening to service users is vital to developing a mental health system that is responsive to their needs, delivers effective interventions to the most vulnerable and reflects a true partnership between stakeholders. There is little point it would seem in involving service users if the outcomes do not reflect that involvement. "A marriage of two types of expertise is the essential ingredient of the best mental health care: expertise by experience and expertise by profession" (Faulkner and Thomas, 2002, pp 1-3).

**AIMS**

1. To gather data through the use of patients' stories that allows the service user to express their experience of the mental health system without any imposed direction from service providers.

2. To ensure these stories are not contaminated by service agenda or the need to please by having service users conduct semi-structured interviews with training and support.

3. By using this method it is hoped to reach those whose views would not normally be heard. While most service users want providers to take account of their views, only a small proportion are willing to attend regular meetings or provide ongoing input into the work of service providers (Coulter, 2002).
4. To enable the voices of the most disabled users, the 'silent majority' to be heard, to make a difference, influence service delivery and be a positive experience for themselves.

**Previous research has demonstrated the rationale for utilising narratives:**

1. Many mental health conditions are poorly understood and for which we need to establish a more accurate descriptive base grounded in first hand experience.
2. These are conditions in which the person is able to play an active role beyond adhering to a prescribed regimen, and understanding the nature of this role requires consideration of that person’s perspective (Davidson, Stayner and Haglund, 1998).
3. There are conditions from which many people are able to recover over time, but in ways and means not accounted for by the current mental health system (Davidson, Harding and Spaniol, 2005).
4. These are conditions which have been complicated and confused by problematic social conditions and as a result confined by asylums, stigma, poverty, unemployment, discrimination and a long list of disadvantage. Social and personal factors operate in complex inter-relation and where medicalised research has frequently failed to address all aspects of mental health issues.

**METHOD**

**Design**

Participatory action research (PAR) was chosen for this study as it provides a more dynamic method of research. For those persons within the research sample with enduring mental health problems, accessing local mental health services and who were unlikely to engage in “involvement activity”, who previously have had limited voice, it offered the opportunity to become activists and advocates by influencing the direction of mental health research. In order to:

“bring together action and reflection, theory and practice, in participation with those providing the service ……to pursue practical solutions to those of pressing concern to people, and more generally the flourishing of the individual persons and their communities” (Reason and Bradbury, 2008, p 4).
This approach resonated with this study whereby the collaborative nature of each stage of the research offers opportunities for participants. The focus of this report is on:

1) the “flourishing” of those individuals sharing their lived experience for the purpose of learning and peer support and developing skills and new identities as researchers.

2) the impact and experience of mental illness and mental health service responses.

This study incorporates principles of the participatory action research paradigm within three key processes. The first is that of hearing the service user 'story' (‘narrative’- the aim of this narrative to focus attention on the lived experience) and its effectiveness in identifying issues that are of direct relevance to the individual. The National Modernisation Agency piloted this approach, in order to learn how to use ‘patient stories’ to improve care. The study claimed intensive interviews with patients generated far more valuable ideas for service change than traditional patient satisfaction surveys (Mahoney 2003).

This research then goes further in that the narrative is heard by service-user researchers. There is accumulating evidence which illustrates that engaging service users in obtaining the narrative has enabled and strengthened validity of responses from other service users (Clark et al., 1999; Polowczyk et al., 1993) and as exemplified in "Knowing Our Own Minds" and "Strategies for Living" (Mental Health Foundation, 1997 and 2000).

Thirdly, in order that the people were enabled to undertake roles within this research project it included a process of interviewing and appointing service user researchers followed by a programme of training workshops, provision of supervision and discussion group/peer support throughout the research. The main focus for the research is the service user story, how it is obtained and mapped by the service user researchers and analysed using interpretative phenomenological analysis (IPA) to construct a framework for understanding the personal world of the interviewees and then translated into effecting change in services.
**Participants**

People who are using (interviewees and interviewers/researchers) or have used (interviewers/researchers only) local mental health services within Montgomeryshire, Powys (aged 18 and above). The sampling frame was approximately 400 persons (328 who are currently clients of Community Mental Health Teams).

**Procedure**

The methods chosen for this research are reflected in the participatory action research approach which involves the collaborative partnership between a user-researcher group established as part of this research and a Community Mental Health Nurse/Manager.

A launch day was organised in which to advertise the idea to as many service users both past and present, as possible. The number attending the day were double that expected and at the end of the day, any service user wishing to pursue the role as researcher or give their story were able to put their names on a list of interested individuals. The individuals who had expressed an interest were then sent information packs. There were separate ones for those wishing to be a researcher and those wishing to give their story (see Appendix 1). Those who had expressed an interest in the researcher posts had within their packs the job description which had the requirement of lived experience of mental health issues. People were asked to apply by sending a letter expressing why they would want to be involved in this role.

A small committee (n=3) was formed to shortlist the 14 applications received. 11 were shortlisted utilising the job description/person specification criteria initiated by Involve (Lockey et al, 2004). Those involved in shortlisting and interviewing were also part of the Stronger in Partnership Group - and having had lived experience of mental health difficulties themselves. Eight people were appointed as researchers. All eight completed the training however only six went on to complete the research project from interviewing through to analysis, writing of the report and dissemination.

Guidance and good practice standards from the NIHR (2010) was followed in the obtaining of honorary contracts for the service user researchers in order that NHS Indemnity would cover those conducting the study. Enhanced Criminal Records
Bureau (CRB) checks were also instigated at the outset of the training programme in conjunction with Human Resource personnel.

For the study, face-to-face interviews, adopting semi-structured interviewing techniques with each service user were used. It illustrates interpretative phenomenologist analysis commitment to an inductive approach, asking the service user (as an expert) to talk about the way they think about their experience, rather than using a priori hypotheses to make assumptions about how people think, as traditional health psychology has done. Similarly unstructured interviewing was adopted as a means of harnessing the capacity of the participants to set their own agenda; talking about their own priorities, in their own words. It was anticipated that in-depth information would likely be generated about opinions, attitudes and feelings (Hek and Moule, 2006).

A lot of consideration was given therefore to the fact that interviewing is a skill that needs developing (Hek and Moule, 2006) and therefore teaching. A programme which would give the researchers an understanding of the process, ethical issues and skills in listening required for the role was devised.

The ‘TRUE’ guidelines from the organisation Involve were utilised which had been devised from a study of training provision and participants experience (Lockey et al., 2004). During the training sessions a pilot study to test the interview schedule was practiced in advance and changes made to the cue cards needed for the interview. This enabled the researchers to refine the interview schedule prior to the main study so that they felt comfortable with it (see Appendix 2).

Those wishing to give their narrative were either contacted from the details provided at the launch event or via community mental health workers in the statutory or voluntary agencies. All interviews were undertaken at the two community mental health team bases. This was an ethical requirement of the study for safety and insurance requirements of the organisation. The interviews were undertaken in private counselling rooms. Refreshments were provided and the rooms set up to be as informal as possible. Interviews were audio taped and professionally transcribed. Handwritten notes were made whereby there were difficulties with the equipment.
**Data Analysis (Mapping)**

The interviews were audio-recorded and transcribed verbatim and the transcripts were analysed utilizing interpretative phenomenological analysis (IPA). The analytic process began with a detailed examination of each narrative, listening to the audio tape and reading the transcript before cautiously moving onto an examination of similarities and differences across the narratives. Thus resulting in “fine-grained accounts of patterns of meaning for participants reflecting upon a shared experience” (Smith, Flowers, Larkin, 2010). IPA was utilised in order to provide an inductive approach that not only allowed conscious reflection on this human experience but also challenge understandings which may be based around ‘othering’ people, or medicalizing and pathologizing behaviours.

The mapping process consisted of monthly sometimes fortnightly meetings and although this was critical to build the camaraderie it did not feel sufficiently regular to deal with the vast amount of material we had collated. To every mapping session the six researchers each brought in new types of knowledge. The relevance of the researchers’ direct experience of the service, treatment and often diagnosis under discussion added insight and depth to the whole process of mapping. As participatory action research involves not only keeping records which describe what is happening as accurately as possible but also collecting and analysing the group’s judgements, reactions and impressions about what is going on the mapping meetings which were audio taped became a source of important data in themselves. Additionally this process of consensual validation proposed by both Reissman (1993) and Lieblich et al. (1998, p 173), by which the “sharing of one’s views and conclusions and making sense in the eyes of a community of researchers and interested, informed individuals” could be established as the major criteria for validation of narrative studies of this type. Thematic analysis, as outlined by Reissman (1993) was carried out on the data. Initially the tapes were transcribed to provide a verbal account of the conversations. The transcripts were read and re-read in detail, and annotated on a line-by-line basis to generate codes. These codes were then analysed to generate themes into which they clustered. These themes were then progressively clustered into meta-themes as reported in the findings. Following this transcripts were re-scrutinised to check the relevance of the themes and to find illustrative quotes.
Transcripts were anonymised, and any personal information which could lead to an individual's identification is modified within the report. Quotes are not attributed to individuals, but are numbered according to the participant to which they relate.

Thematic analysis was chosen as it is a robust method for identifying, analysing and reporting patterns within data. It does not sit within a specific epistemology and does not seek to produce a theory, like grounded theory. It does however acknowledge the active role of the researcher in forming the themes and at the same time allow the participant's voice to be heard (Braun and Clarke, 2006)

**FINDINGS**
Following thematic analysis, the following meta themes and themes were distilled.

**Service User Researcher Meta Themes and Themes**
Table 1 refers to the themes from the six researchers involved and their experience of involvement as elicited from audio tapes of meetings and written accounts.

**Table 1: Service User Researcher Meta Themes and Themes**

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<th>Meta-Theme</th>
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<td>Need for Reciprocity</td>
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<td>Need for Recovery and Development</td>
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<td>Reframing the Illness Narrative</td>
<td>Definitions of self</td>
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<td>Self Knowledge and Self Acceptance</td>
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<td>Recovery and Hope</td>
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<td>Involvement in Developing the System</td>
<td>Hope for Service</td>
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<td>Different Relationships</td>
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<td>Having Value</td>
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<td>The Importance of Process</td>
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<td>Recovery and Moving On</td>
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Meta-Theme 1: Restricted Lives

The aspect of restricted lives and the resultant social isolation caused by mental illness and reactions to it emerged strongly within the researchers' own experience. The research study provided an environment for connection with peers and an ability to feel safe being themselves which were identified as key factors in addressing loss as a direct result of chronic mental illness. The ability to empathise and support one another was valued and enabled a focus outside of one’s illness, as was their recognition of the changes and development of each other over the period of the research process (four years).

1: Need for Connectedness

“Now the best thing for me has been the feeling of connection because so often you feel totally unconnected with mental health problems from everybody else but being with everybody in the team you feel very connected. Everybody knows what you’re talking about and doing the interviews and talking to people you just know where they’re at in a way that makes you feel normal somehow.” (Researcher 4)

“Elsewhere I still put a face on and feel the loneliest person on earth … here I can be myself.” (Researcher 6)

2: Need for Reciprocity

The need for equal relationships of give and take after the perception of being dependent on family, friends or the mental health service was fundamental in regaining self worth and value:

“The feeling of connection was strong … it was surprisingly so comfortable and comforting to do even when people were telling you tragic things it was the sense of trust and confidence they had to tell you … I feel valued for having had the opportunity to do it, like I have given something back.” (Researcher 3)

3: Need for Opportunities for Recovery and Development

Researchers were able to gauge their own progress, their own development over the four years. They were able to accept their own achievements more readily when highlighted by others in the group and were able to look back over the progress made. They were thus able to identify milestones achieved throughout the project
from being able to attend an interview through to being able to talk in front of 60 people:
“Seeing everybody still ‘fighting for it’ … the enthusiasm is more than ever … these are different people to the ones three years ago … I’ve been able to watch my team mates blossom!” (Researcher 2)

By hearing the narratives themselves it was identified that this provided an opportunity to learn, to reflect and ultimately be a step towards recovery and acceptance.
“I realised it didn’t just happen to me and therefore I was able to let go of blame and self recrimination.” (Researcher 3)

“And hearing those narratives on a one to one basis of such courage and survival from people who would be unlikely to be involved in any other sort of activity has inspired us who have listened and been another step in our own recovery.” (Researcher 1)

**Meta-Theme 2: Being Able to Reframe the Illness Narrative**
That shared by the researchers within the study went far beyond the medicalised view of mental illness but addressed restricted lives in terms of the loss of self whereby former self-images were observed to have been lost without the simultaneous opportunity for development of equally valued new ones.

1: **Definitions of Self**
Both the process of involvement and the stories narrated became that which humanized the people behind the ‘diagnosis’ or 'label' that previously had defined them. This was a fundamental challenge to any psychiatric stereotypes or assumptions previously made about them. It also respected and valued the experience of mental illness. Self reliant development is not possible with someone else's thinking, and the formidable status of formal knowledge with its associated power had created a sense of inferiority among those involved, making them surrender to or look up to the medical/nursing profession to promote their lives paradoxically they needed this support to recover their self confidence in their own
intellectual abilities. The following quotes illustrate for themselves the change in identity:

“We became visible” (Researcher 4)

2: Self Beyond the Label

“We have moved from being service users, to being researchers, a positive identity, which has motivated us all, yes we are useful, we have a purpose, we are being valued for helping to compile, an incredible piece of work, for many of us, confidence has returned, passion and purpose too, as well as an overwhelming feeling of pride, to be part of such an incredible project … For us, being part of a team, sharing, supporting, discovering and importantly, laughing together, has been incredibly affirming.” (Researcher 4)

3: Self Knowledge and Acceptance

“All that horrible stuff in your life can be used for a purpose.” (Researcher 6)

4: Hope for Self and Recovery

“I reached my peak at that conference … and told my family, they could not believe I stood in front of 60 people and presented … my dad cried and said he wished he’d have been able to see me do that.” (Researcher 3)

Meta-Theme 3: Involvement in Developing the System

Involvement was not only seen as contributing to personal recovery, but also recovery of the system. The opportunity to be working within the system on an equal footing, to learn more about what hearing the narratives feels like and develop empathy not only for those giving their stories but also to those listening and responding to them.

1: Hope for Service

“I am hopeful for the system being able to work alongside ‘professionals’ on an equal basis … being heard … look how far we have come.” (Researcher 1)
2: Different Relationships

“It shortened the gap between you and me and widened it between me and the illness.” (Researcher 2)

3: Having Value

“Yes, service structures, medication, practical help and meaningful occupation are all part of the recovery package, but the central theme for most of us is our lack of confidence and self esteem and for some of us our lack of and sense of identity at all. Listening, really listening to someone is a way of helping them to feel, perhaps for the first time in their lives, they have value just as human beings. And until you know that you do have value, you have not got any tools with which to build your own recovery, however helpful professionals are.” (Researcher 1)

4: The Importance of Process

All the researchers spoke passionately about the importance of the process- the key aspects of ensuring any service user involvement is rewarding for service users and of benefit to the service emerged (see Appendix 7).

“Thirty one interviews have been taken, mapped and themed, we have been quite simply amazed at the amount of information we have captured, the honesty and openness, and immediacy of the people giving their stories has been, inspirational, as well as humbling, and frequently very moving. We have presented, held workshops, and spoken at length about our project and our findings, and will continue to do so, as we believe our work and findings, have the opportunity to really influence the service we are all part of, and indeed pose some challenging questions for all involved.”

“But it is not only the findings that have inspired us, the whole process has been incredible, we have found that, not only for ourselves, but also for those giving their stories, that being given the opportunity to tell their stories, often for the very first time, has incredibly beneficial qualities, therapeutic, for many.” (Researcher 5)

5: Moving On and Recovery

“New life begins … you are not trying to recapture your old life … you are taking the good from the bad and moving on.” (Researcher 2)
This aspect was echoed by each of the researchers. Service user involvement as offering an opportunity to reappraise ones identity, allowing the experience of mental illness to be a utilized as a positive aspect, allowing for acceptance of who you are rather than what you thought you were.

**Service User Participant Narratives Meta Themes and Themes**

Table 2 refers to the themes that emerged from the 31 participant narratives.

**Table 2: Service User Participant Narratives Meta Themes and Themes**

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As it is crucial that the narratives given are represented honestly we decided in the writing of this report not to censure or edit out any of the themes identified as this would represent our interpretation of what was important to individuals. This does mean that the content is extensive; this in itself identifies the value of this type of collaboration and collation of 31 narratives, each one that can have its own action plan in terms of identifiable and measureable change to improve services and identification of that which is excellence in practice and otherwise may go unrecognised.

**Meta Theme 1: Experiences of Mental Health Issues**

Or as one person described it: “It’s just like a computer I mean they can break, the brain can break.”

It is not possible to include all the quotes extracted which represented each of the 14 different types of mental health conditions covered although each presented a lesson to be learnt and can be utilized for this purpose locally. The issues that emerged within all the narratives regardless of diagnosis were the “perpetual loop” of the conditions, perceived safety of the condition, fear, the loss and withdrawal from society involved and in spite of the difficulties caused by the conditions how people were able to recall exact detail, dates and specific incidences. These incidences recounted those experiences that both credited and discredited the self.

Quote 1 - “Some days I can’t go out because I’m so paranoid about other people and what they think of me. I got an awful lot of rituals and routines and my exercise I have to do every day and it takes me a certain length of time and I have to do certain
a certain route and all this type of thing and I eat once a day and it’s in the evening at 7 o’clock and it’s a certain number of things and all that kind of things but it’s all kind of, I don’t know, it’s not really living though it’s very safe I suppose my world but I can’t cope with it being anything else. I’ve got a routine that’s what I need.”

Quote 2 - “I was very frightened of moving forward again a) because it had been so long since I’d mixed with anybody and b) because who’s to say it isn’t going to happen all over again which I think is the sort of repeated pattern when I get depressed. I worry that I may be pushed too fast or something and then I’m not going to be able to cope and things like that.”

1: Abuse (sexual, bullying)
In spite of the extremely powerful and distressing detail in the 12 experiences of the different types of abuse revealed, it was clear from the narratives that people were willing and in fact needed to share this. The issue of openness, the need to share the most difficult times even though they had only just met the researcher illustrates the essence of utilising narrative as the starting point in any care.
Quote 3 - “I was 29/30 and everything I’d known, even though I’d run away from it and lied about it all of a sudden it was questionable and I didn’t, I suppose I fell down a big hole really because I didn’t know where to go, I didn’t know what to do, I didn’t know, the things I’d made up could be true, they could be right but you know really deep down everything I’d known as a child, that’s what’s right really isn’t it and because I’d never spoke about it, never questioned it I didn’t really know it was wrong, that shouldn’t have happened to me.”

2: Agoraphobia
Two narratives revealed detail of this and its impact on social withdrawal which emerged irrespective of diagnosis.

3: Alcohol/Drug Dependence
And withdrawal often came by withdrawing into self- a factor marked in regards to dependence issues. Two narratives referred to escaping painful feelings in regards to taking illicit drugs as did all four narratives in respect of alcohol dependence.
Quote 4 - “But drink and me don’t mix because I get really really depressed to a state I don’t want to be around. I can’t be happy, I get depressed because it brings back everything that I’ve tried for years to block out of my head.”

4: Anxiety - Panic Attacks
Anxiety and panic revealed a further aspect of withdrawal:
Quote 5 - “But as I’ve got better in one way I started to get really bad panic attacks so you know just going anywhere, across the road to the shop you know I’d get in a panic or any strange, well it didn’t have to be a strange situation even, people I know you know.”

5: Aspergers/Autism
A particular difficulty was the transition from child to adult, not knowing where help was to come from.
Quote 6 - “Provision is quite well catered for in the childhood sector in all areas from the schooling to the further education colleges but once they hit 18 and an adult you cross a barrier where they drop into a black hole and because they don’t know that they need help anymore when I was that age I needed help. You have to ask for help. I’m aware of that now right but unless you’re aware of it you can’t source it in the first place and sometimes you have to do things that you’re not necessarily comfortable with because you know that you can’t get anything unless you go through social services or something in order to access the various things.”

6: Depression/Bi-polar
12 separate narratives revealed great detail about their depression and bi-polar disorder. Such detail is not given in the corresponding clinical notes assessments, on CPAs and hence cannot be utilised to assist in any outcome measures.

People spoke of the long process before they seek help, with either a difficulty in recognising or accepting the presence of such feelings, a concerted effort to keep them at a distance and keep their perceived identity intact.

Narratives were not linear and neat; they did not form complete sentences and as such gave a clearer picture of how the course of events was experienced.
Quote 7 - “I mean the major things have really cropped up what, four years ago I had a bout of quite bad depression and I was off for about eight months then and then well, Christmas 2007 I was really suicidal and I just wanted to finish it all and something made me ring up the doctor and that’s what like put everything in motion you know.”

Quote 8 - “So with twelve years of that it’s been hard going as well. I suppose I just thought that being a man you’ve got to be strong, you have to take all these blows no matter what’s thrown at you but I didn’t realize all the other things that come with depression. The tell tale sign sort of things but I didn’t know.”

A particular feature of those persons suffering from bi-polar disorder was the insight evident in portraying the true impact of the illness. They frequently referred also to the changing diagnosis and medication to equalize the different parts of their experience.

Quote 9 - “I’d worked through a lot of the anger and frustration and stuff that sort of I feel after I’ve been high because you know being low is very, it’s not great, it’s pretty soul destroying. Being high is much more damaging to everybody around you, around me. Much more destructive and upsets many more people ... I had no idea what was happening I was just having a better and better time but I did start sort of clashing with people, you know people were, there were some people in the house who were, because I’m a pain in the arse when I’m high, I get very, I think rather opinionated and I get quite claustrophobic so I have the windows wide open the whole time even if it’s winter, I giggle the whole time you know which can drive people mad if they’re trying to be serious and I’ve got heaps of energy and unreliable and then it becomes very visual and I have psychosis and you know all the colours are beautiful and everything and people just get totally fed up with basically.”

7: Eating disorders

Three of the 31 narratives discussed eating disorders in great detail. Of all the narrative content these gave some of the most detailed, visual and distressing and destroying aspects of the struggle with a mental health condition. Two narratives were in the first person and one of them spoke not only from their own mental health experiences but also those of being the parent of a child who had died from the
disorder. They spoke in candid detail and with extraordinary insight into the aspects of control, safety, childhood, strategies and treatment.

Quote 10 - “Now I sort of, but it was very safe, and now I hanker after that time because all the responsibility was taken away. You know they told me that you will eat this and that you will put on weight at this weight and blah blah blah so someone else was in control. Now I have problems with eating but there’s nobody to help me. I’m on my own, there’s a whole supermarket of food and it’s terrifying.”

One person spoke of how the very ethos of the out of county placement they were referred into was in stark conflict with the very issues which had triggered the eating disorder in the first place creating more harm. Having this in depth narrative has the potential of avoiding such mistakes in the future.

Quote 11 - “It was an eating disorder unit with a Christian bias which was a nightmare. My biggest problem all my life has been caused by religion and having to follow the drum if you like.”

Quote 12 - “They need, they really need a facility in Wales for treatment so they don’t have to pay the high cost of sending to private hospitals. Unfortunately within the national health there don’t seem to be, apart from you have to be virtually dying, to be able to access national health treatment. Now I am a believer in the national health. I, one thing that I think anorexics in general feel, that they are not worth it. My big problem with private treatment I have, I thought they were wasting their money on me. I couldn’t see why at that time, I could be funded for over £3,000 a week. I felt that was a waste of taxpayers money that I wasn’t worth. I think it is a case of you lose self-worth, you think you aren’t worth any effort being put into you because you aren’t using it how you should be and I think it’s a difficult concept to overcome because it’s hard for the CPNs, for the health authority and even if you like to take it to government level for them to understand how people can want to help themselves but they’re unable to do so. I mean do you think I don’t wish that I could go to things and not think about how the heck am I going to avoid the eating, avoid.”

By far the greatest issue here was the lack of specialist help with this aspect of mental health and the need for a service that communicates the value, worth, respect, dignity afforded palliative care.
Quote 13 - “I mean an eating disorder is because of acute distress, because of not coping with your feelings and the way they treat it it’s like a punishment. I mean I went to a hospice-palliative care because I was involved with a bereaved parents group. In fact I started one and I thought maybe we could help them and they could help us and I went in and there was this beautiful, beautiful facility. Light and airy and absolutely gorgeous and my child had been stuck in that place with bloody nettles round the door.”

8: Obsessive Compulsive Disorder (OCD)
The impact of OCD and safety behaviours from three different narratives were referred to as well as the understanding of the development of the condition.

Quote 14 - “I felt a lot of pressure during GCSEs to do well because I wanted them to be proud and afterwards I went to do A Levels and the safety behaviour, sort of touching things, repeating things became more.”

9: Personality Disorder
A single narrative referred to personality disorder, whereby it was a shock to see it written as one of a multiple of diagnoses given. The reason for giving this diagnosis had not been explained to the person nor what the person was supposed to do as a result of being ‘given’ it.

10: Post-traumatic Stress Disorder
One narrative explored a 20 year history of post-traumatic stress disorder from the beginning incident to needing to relearn cognitive strategies and the impact on their life, work and family.

11: Post Natal Depression (PND)
Five separate narratives explored the impact of PND on them. Two people were admitted to a psychiatric hospital and all five spoke of the guilt, shame and fear of not having a bond with the child. Two spoke candidly about child protection or “losing their children” as a result.

Quote 15 - “I didn’t mention it to anyone because I didn’t realize I had it, I didn’t realize I just thought it was normal that when you have children that’s how you felt. I
mean I know it’s wrong now because that’s not the way I feel now so – that’s the way it was and I just had to get on with it and then I ended up losing the children.”

12: *Schizophrenic Illnesses - Hearing Voices*
Six people spoke of the experience of schizophrenic illness. The impact of hearing voices and the avoidance through to the coping strategies people employed.
Quote 16 - “And you wouldn’t believe it, I used to go in the supermarket, every single person in that supermarket I could hear them in my head, every voice and in the end I’d have to get out. I wouldn’t care if I had a trolley with me I’d leave that trolley and I’d have to get out. I’d got every voice in that supermarket I could hear buzzing in my head. And it’s like suffocation, it’s like I thought I’ve got to get out of here.”

13: *Self-harm (suicide attempts, eating issues, cutting, and overdose)*
Nine narratives spoke of self-harm. Although three people referred to specific suicide attempts with ongoing wish to escape life, a further six spoke of repeated overdoses to harm themselves, not necessarily to die, examples given in the narratives were cutting, burning, and starving self.
Quote 17 - “People think you’re doing it for attention, you’re not doing it for that reason. I get to the stage when my head and all inside me is just buzzing and I’ve got to get a relief and that’s why I do it. Once I’ve done it three or four times on my arm it’s a relief. I’ve got to learn to live with the fact that I have got good things in my life and I am worthy of being here. There’s nobody more harder in this life on me than me.”

**Meta Theme 2: Issues around Mental Health Service**
1: *Accessibility*
Key to all those giving their stories were how they felt whilst trying to get help. Emerging from the narratives was the importance of being accepted, a welcoming and ‘friendly’ atmosphere. Responses revealed how the teams were perceived by the individuals often influenced by the impact of isolation caused by the illness.
Quote 18 - “Well, like I was saying before because of all the office space taking over there’s more staff here than patients, you know what I mean, that it’s known to be here for the service users not just for the service. I think you know, you get people, ok, are in the community you need a visit from the CPN who wouldn’t perhaps come
in for a drop-in time. Obviously you’ve got to have a lot of CPNs to do that but I think it’s not sort of friendly any more. It used to have a friendly feel. It just seems a bit more bureaucratic which sort of cancels out the friendliness doesn’t it? I think, I mean I am sure there are reasons why the drop-in facility was changed but I don’t know what the reasons were. I’m sure that could be abused very easily so maybe perhaps it wouldn’t help if that was sort of opened up again but I think it does seem more a sort of, you’re faced with more a feeling of bureaucracy than friendliness. I think what I said before, it’s like, you know, it’s not so much here for the service users as for perpetuating the service. So do they put clients, patients first or the bureaucracy, I don’t know. It’s that sort of thing that could improve if that were possible.”

Quote 19 - “Well I’m having the information and I think knowing I’ve got OCD and reading and the help the CPN has given me on it and the staff here, being understood more and to be able to ask questions if you want to and not being looked at as if you’re an oddity as if you’ve got Christmas tree or something growing out of your head. Being treated normally is something I think – I know if it wasn’t for the staff here, that there’s somebody there for you to ask. I know they’re not here at the weekend and all that and they can’t be your best friend, because you can’t ring them up can you and say blah blah, but I think it is a big help and if I have got something that’s really bothering me. You’ve got somewhere to come to. Well really it’s become a bit like me family here rather than me own family because they don’t understand or they don’t want to know about it, I don’t know what it is but you’re so alone in it all aren’t you.”

2: The Community Mental Health Team Duty System

Issues raised here were the need for people who know you/your history and the need for connection with a person who values you as an individual, and is not perceived to be judging you.

Quote 20 - “I have phone numbers to ring up … like the Samaritans but it’s very difficult talking to a stranger on the phone sometimes and you get, like I’ve gone through various things with you and this is what you have to do when you’re on the telephone. There’s nobody at the other end who knows your case history and when you’re feeling low, it’s very difficult.”
Quote 21 - “I know there’s always a duty officer on, I know that, because I’ve actually come down pleading for help and things like that but I always feel guilty that I’m taking up somebody’s time and some people can respond positively to you but you do pick up sometimes that, they look, you can sort of, thinking it’s time to go home, you know, it’s a job, they’re paid to do it and you don’t feel that contact.”

Quote 22 - “How do you manage on weekends? … I haven’t – I just get by – I ring my parents which is the way because, it’s difficult explaining your story all the time to people – I’ve been in to see the duty worker a few times and whilst that is really nice I don’t get, I get comfort from it. They aren’t able to offer practical advice as such because they don’t know my case and you can’t talk to them in half an hour all about your in depth problems but they sort of, they are quite often a mother to me in a way and that is just, I go home and feel oh everything’s ok, it’s reassurance I suppose.”

3: Accredited Accommodation Scheme (Acc Acc) - Respite
The Accredited Accommodation Scheme is facilitated within the Community Mental Health Team for individuals not requiring specialist 24-hour care, as an alternative to admission based on ordinary existing housing stock within our area, owned by responsible, nurturing individuals who act in a fostering capacity for relatively short periods. In this respect, the scheme resembles the family-based crisis home approach developed in Denver in the 1970s (Brook, 1980). This alternative to hospital was welcomed by three people interviewed who had accessed the scheme. A further two had heard of it and were waiting to use it.

Quote 23 - “I am signed up for the AccAcc service which I think would be a very good halfway, well that’s what it is, a halfway house between hospital and home, somewhere you can go where somebody is there which you don’t have any of the pressures of being in hospital.”

Quote 24 - “I suppose that a few years back it was then suggested that then rather than use hospital as time-out suggested that I take part in any project that was going on - with the landlady scheme which meant staying for anything up to five days who had been through a training programme and for me that seems to have worked really well and I still use the scheme even now on a regular basis.”
4: People within and how treated by - Administrators, Advocates, CPNs, GPs, OTs, Police, Psychiatrists, Psychologists, Social Workers, Support Workers

Connection was the most important need, and when people felt able to connect with those who were placed to help them, this fact alone played a significant part in people reclaiming an identity, a sense of value. This was the largest component throughout all the themes. Regardless of professional designation it was how people were treated that mattered in every narrative.

Quote 25 - “You can’t put it into words can you but I do trust the staff here. A, C, F, they’re all very good with me and I just feel that I have got somewhere and somebody.”

Quote 26 - “I will be going somewhere with ... But you know things like that mean a lot to me isn’t it. Like I said to her, you know if I came here today and you said no we’re not going on the trip, it meant so much to me anyway, because you asked me in the first place isn’t it. So things like that I think with the CPNs mean a lot to people. There again she’s the type of person who’s on the same wavelength ... And then I think that’s an important thing to have with them isn’t it.”

Quote 27 - “She didn’t force me but she gently persuaded me and in respect I did it for her for a long time until I could do it for myself and so I personally feel that if there was any criticism of the system I could come up with, it is that, that they don’t have the support workers now because I really miss that and she was just absolutely fantastic. You couldn’t put a price on how valuable she was to me.”

5: Care Plan/Assessment/CPA

Care Plans or the Care Programme Approach was mentioned by three individuals which may have reflected the lack of knowledge regards them or the lack of their significance to the people interviewed.

Quote 28 - “… but I constantly worry about this you know and that’s a worry but like they do a care plan here and I’ve got to follow that. They do risk assessments but I really didn’t know what that was about and I didn’t like the questions they asked me.”

Quote 29 - “Yes, what is the illness, like on my care plan it says signs of relapse and all this kind of thing well how do I know, how does anybody know?”
6: Community Mental Health Team (CMHT)

Certain aspects of great value to individuals had not been recognised by the CMHT or indeed by the service. One aspect was regards what is now considered outdated; a drop in-somewhere to feel accepted which is what people required before they could move on. The emphasis within the system of moving people on failed to recognise the importance of acceptance and hence was perceived as rejection of the self with people questioning, moving people on to where? Knowledge of the person was thus valued, rather than anonymity in larger towns which was frequently mentioned.

Quote 30 - “I think it's the fact that you're a person first and a patient second and I think here there's always been a good working team and I think also, like when you come here, I mean not so much in recent years but when I was here a lot, when they had drop-ins and that it was like you knew all the CPNs, you didn't just, not just the one you saw but there was more of a sort of corporate feeling. I think also it creates, there have been times in the past where I just sort of lost it for whatever reason and I've come here and it's felt sort of safe, you know and I can be reassured it's only temporary, I'll be alright in a couple of days so I think there was that feeling but that was mainly when they had the drop-in which don't happen now so I imagine it's not so easy to feel that if I was to be in that position again.”

Quote 31 - “Well there's nothing really because I know I matter. I mean they're very good, they're very good here. I mean I don't think they'll be like it in a big area. I suppose in a place like ... or something where there's loads and loads of people – because here I know most of the nurses, you know and I know if I had a problem I could just ring them up. So there's no problem, I wouldn't change anything, not around this area anyway.”

7: Treatments - Cognitive Behavioural Therapy (CBT), Counselling, Electroconvulsive Therapy (ECT), Medications

We were surprised that six of the 31 participants had had ECT. They all spoke of its longer term effects and also a lack of real understanding into why it was selected as a treatment of choice.

Quote 32 - “I was told it was the only thing left to try. I was told they'd tried everything else it was the last option so when that didn't work as well, being told that and it was
very confusing because, you know they say you only lose your short-term memory but my friends say that if they saw me, if I was with my brother or something during it I maybe wouldn’t recognize them and these people I’d known for a long time.”

Two people referred to CBT by name; however several more spoke of challenging thoughts and self talk which may indicate a similar approach. Although goal directed/outcome measured and evidence based strategies are being pushed by the service, individuals felt they needed far longer input in order to address very long standing issues that did not necessarily have a resolution or clear recovery point.

Quote 33 - “Other provision that I’ve had has been good but for me in my sort of issues I guess CBT was a good thing and I got a few sessions of that, cognitive behavioural therapy. Because I like rules and things and that’s about rules and about sticking to a pattern and sort of going through things logically which I like. It seems a short-term treatment though so I had some help with that and then they sort of say off you go and then if you relapse there’s no actual help to get you back. I don’t know, people say how can we help and I don’t really know is the answer. I know what doesn’t work but that’s not much good.”

Quote 34 – “I suppose it’s like a self-realisation and that’s what they’ve done here for me. They’re still helping me see that by challenging my thoughts that puts me in that black place as you could call it and saying to yourself well no you don’t have to think like that or well yeah that happens to everybody else that just doesn’t happen to you.”

Half of all narratives undertaken however spoke about the effects of medication. These were discussed in far greater detail, with exact dosages and what years people were prescribed them; possible interactions were mentioned but several appeared to accept the side effects without challenge.

Quote 35 - “The only way it affects me is when I have the Depixol it knocks me for six. I mean it makes me really ill, it makes me so tired and I have to go to bed. The day I have it, sometimes I have to go to bed in the afternoon and then the next day I’m, like this is my good week now, last week was my bad week when I had my injection. Next week will be the bad week, I won’t be really able to do much.”
Several mentioned the amount of different drugs tried but no one mentioned any other treatment modalities that were tried with such persistence.

Quote 36 - “And he put me on some tablets but I’ve had a lot of different tablets but the symptoms just got worse. I just didn’t … exist … I just feel dead inside.”

Quote 37 - “I’d go every week to see them and then these tablets, antidepressants don’t work. Well try these then. So you go to Boots and you’re having like six months worth. So you’d go back. Now I haven’t felt anything that’s changed – oh well try these then I ended up with a carrier bag full.”

8: Discharge/Follow Up

People felt they were followed up but did not feel it was sufficient in time.

Quote 38 - “Yes, I had somebody come in once a week to see me from the CMHT and that was helpful. I could have done with a bit more help really coming out of hospital but that’s all they could spare like was the one day a week. It was only about an hour really altogether you know.”

Others who felt due to illness they did not make contact welcomed a more assertive outreach approach.

Quote 39 - “It needs to be, basically, if you don’t go to make an appointment and you drop out of the system, well it needs to be the opposite where vulnerable are more likely to drop out of the system, they are the ones who need to be chased up.”

9: Gender Choice

Five different narratives spoke of gender choice.

Quote 40 - “He suggested it and I had a woman at first and it was nothing to do with her, it wasn’t her fault, it was the fact that all my life I’ve had problems with women. It was women I had the problem with and we just didn’t connect properly.”

Describing the impact of not having this choice:

Quote 41 – “I’m in supported housing and there’s the support workers there are men and they’re very practical and if I’m struggling and I need to go and get my shopping, I suppose I can go and do it on my own but if I’m struggling they will take me and bring me back, but there’s nobody to just call and take me for a coffee and talk about
girl things and make me forget all the anxiety and you know just, well the afternoon’s
gone by, I’ve not been in the flat I’ve been outside. Like Support Worker (female)
took me to … to Evans’ to get clothes that would fit me as nobody … clothes didn’t fit
me anymore. Things like that, that Support Worker would have taken me, you know,
when I’m ready, swimming and things and she said that she would have been able to
find a private pool somewhere so that I wouldn’t feel – it’s things like that you know
and it’s not there anymore.”

10: Groups/Courses
The importance of groups were recognised particularly as a way of connecting with
others although was not for everyone.
Quote 42 - “I didn’t enjoy it and I’ve never, I always sort of hated being sort of put in
groups and moved around as a group and I was very rebellious as a young woman,
teenager, whatever so it just didn’t wash well with me.”

The need to have rolling groups regards therapeutic interventions was mentioned by
three people in order to remind oneself of new strategies learnt.
Quote 43 - “So the anxiety management, I mean you can repeat that to me as many
times as you want but it’s always helpful because I forget where my thinking patterns
go and no matter what I did they keep bloody going back so that’s quite invaluable to
me but I constantly need reminding that that’s something that happened and this is
how I would change it.”

11: Home Visits
The importance of home visits were recognised particularly on discharge from
hospital and referred to by individuals themselves as a cheaper alternative to
hospital but also for other reasons.
Quote 44 - “the only problem I had apart from feeling tired was the medication, it
affects my balance and when I’ve had the medication I’m walking and people might
think I’m drunk. That is one reason why I didn’t particularly like having to come here
to get them. I mean I did do as I was told and come here to get the medication
because I know I’ve got to be on the medication because I know if I’m not on the
medication the psychosis will come back. I’m intelligent enough to know I can’t be on
the medication but it does affect my balance.”
12: Hospital

Again as with medication, 50% of the sample spoke candidly about inpatient psychiatric admission to hospital - 12 experiences were recounted as positive and 23 as negative. Both positives and negatives reflected staffing and/or staff attitudes. Admissions were from one event to up to nine for one individual.

Quote 45 - “The staff were really good but they were just under pressure all the time, everything was ‘in a minute, in a minute’. You know, if you want to go to the laundry give me five minutes and you’d be sitting around waiting. On ward round, on three occasions I didn’t even have a member of staff from the ward in with me because they were so short staffed so you feel you know you’re just another number. But sometimes I talked, sometimes I close up, I don’t want to talk, I just block it all out.”

An issue arose around identity and the feelings of depersonalization in hospital.

Quote 46 - “I know it’s very difficult when you’re in hospital but you know I think you can lose quite a bit of your respect there. Like they count your clothes and they go through things and everything and check if you’ve got things with you, you know, all that kind of thing and they ask you personal questions, it’s all very, it’s hard really.”

What was key from the narratives was the lack of clarity regards what hospital was trying to achieve as it was seen as respite from life for some and perceived as safety by staff but not a safe place to be by the individuals who spoke about it.

Quote 47 - “Even when I left the hospital I didn’t feel as though anything had actually worked because I still felt the same way after coming home so I decided to move and again dropped out of the system for a while.”

13: Mental Health Act

Seven of the people spoke about being sectioned under the Mental Health Act. Most referred to the length of stay which they felt was indicated by the Act but several acknowledged at the time they were not aware of how ill they were. No-one gave a clear understanding of the Act but appeared resigned to its usage.

Quote 48 - “I was forced in several times by Section 3 which wasn’t very helpful for me – I didn’t understand the situation because I was Welsh and slightly deaf and I misunderstood and lot of things but I had a helper in the end and he’s managed to keep me out of hospital for about three years now like – and that was.”
14: NHS System

The next two comments speak for themselves - the need for there to be space to grow for those working within the system rather than micro management and stifling goals and objectives. Similarly for there to be less talking and more action so that people can measure the value of their own input by the changes they see, not the number of reports.

Quote 49 - “Like, and I know I can see where they’re coming from, because it can be really frustrating being on the professional side because you’ve got the restraints and I mean, you’ve got the Health and Safety and all those other things that are in there for the system but sometimes, that’s the complaint. I haven’t got it with here, I’ve got it with the system itself because we’re too wrapped up in – it’s just gone out of my head – you have to do Incident Reports for virtually everything these days. Like I say, you can get into that stage of giving yourself over completely and being positive perhaps to a certain extent by the system but that isn’t good for you. You’ve got to, because of the system where they do closet you, like I say the incident reports and all the rest of it, it can stifle that creativity of the person and this is what I think needs to happen in the system is that freedom to let people have that bit of – when I say creativity I’m not just talking about photography or art or writing, but that freedom to let that person grow a bit otherwise that plant will wither. You’ve got to kind of let it grow and that sometimes I can get frustrated by. But there again I suppose when I was at work, I mean, you know, when I worked for the NHS we weren’t supposed to hold hands with the clients and stuff like that but I used to, sod it, you know. I mean you know it’s about people.”

Quote 50 - “I’m involved with the National Autistic Society and I regularly, every couple of months I go down to Cardiff to meetings of the Welsh Assembly Government. The last meeting which was only a few weeks ago we had … and the Children’s Commissioner for Wales, I’ve forgotten his name off the top of my head. We have … I, … , a good number of AMs come and what I’ve found is I’ve been going years now and what I’ve found is they’re very good at having strategic policies. We’ll have a campaign, or we’ll all do this we’ll all do that and you no soon start on one thing, and you have government funding, then you’re on to the next thing but nobody’s checking that the other one is actually materialized at user level.”
15: Out of Hours Provision
10 people, a third spoke of the need for out of hours provision. This again linked to people’s sense of isolation.
Quote 51 - “But I know that’s all they can do isn’t it that’s the job and that’s the work but like I say I do get that feeling of real loneliness at times. I live on my own and it was that thought thing at night, like I say, it was worse at night when I mean the main thing that seems to help me at night was the television because it stimulates visually as well as mentally kind of thing. You can get help at varying degrees but that can numb that thinking you know. It’s when you’re in bed and your mind’s just going like mad and all these thoughts are coming into your head and that’s been really difficult to cope with.”

All 10 people felt the need for a service that already knew them rather than the anonymity experienced by the use of out of hours GP services or call lines.
Quote 52 - “it’s not good enough I don’t think. They’ve got no way of knowing what’s wrong with you and if you’ve still got the voices and you can’t speak you’ve got no way of telling them you know. You need someone who knows you, whose been dealing with you on a regular basis and knows all your history. Like the CMHT you know so if that was open at weekends it would be a great help for people like me.”

16: Placement-funding
What was recognised here was the discrediting of self that occurs within the system as people are effectively “turned down.”
Quote 53 - “They asked me a lot of questions, I filled in all the questionnaires and everything and I thought well, yes, I’ll go there and I was trying to get funding but I couldn’t get funding and they turned me down.”

17: Voluntary Provision
The breadth of support and activities were recounted as positive and for one person helped them not to withdraw. It revealed the need to work closely with such agencies to address the characteristics required of our services - those that need to be maintained when changes occur.
Quote 54 - “I try to go to … every day even if it’s only for an hour just to say I am out and not closing myself away because this is part of my care plan, otherwise I will just close myself up and just withdraw away from society again.”

18: Waiting Lists/Delays
Waiting lists referred to in three narratives related to psychology and specialist eating disorders counselling.
Quote 55 - “Like I say, you know things have sort of been there at the right time. I’ve had the right help at the right time. Like I say my only problem has been the waiting list, the waiting lists don’t conform to when you’re at the right time do they.”

Meta Theme 3: Social/Contextual
Mental distress must be considered in the context of a person’s life experience i.e. within social, historical and environmental frameworks, it became clear from how the people emerged from their narratives that you cannot understand that person without listening to their story.

1: Childhood
Sometimes by giving the narrative and particularly in relation to their childhood/upbringing people were able to make their own connections with the problems they have. Connections that can be elicited just by reading the narratives has immense value also for any “professional” involved, without even having to ask specifically so much is revealed.
Quote 56 - “I was not allowed out. I was not allowed to do the normal things teenagers are allowed to do and even when I went away to college I think what was the final nail in the coffin, was the really I couldn’t cope with the freedom I had and so I put my own restrictions through food into my life if you like. I’m pretty sure my mother was as much to blame as my father but my father didn’t want to know. The first time I was hospitalized he once came to see me. He never ever came again and all he said was that it was an utter disgrace that I was in a psychiatric hospital and I said “But Dad nobody knows, only you.”

Quote 57 - “When I was first ill when I was 17 they were offered counseling and they accepted and had a couple of sessions and then they decided it wasn’t working. My
parents decided they didn’t want it any longer. They’re not really, gosh how to sum up my parents, they’re lovely wonderful people but they are not comfortable talking about emotions. They cope, they get on with life and everything is ordered and sorted and if you don’t understand it you just put it over there sort of thing. I remember my Dad saying ‘I don’t want to be talking about my feelings with this complete stranger’ so he couldn’t really and they still can’t face. I saw my parents this morning, they live locally, I see them a lot and they’re wonderful and are very good with practical help. Invaluable. They come round and if I’m really low they’ll do my shopping for me or things like that and that’s wonderful. They now give me a hug, albeit a kind of awkward hug but that’s really nice. I’ve got a couple of friends who I talk to, not really about deep emotional stuff. I tend to just keep that to myself and talk to (CPN) about it really. Friends, I haven’t really got many of, more acquaintances, I find it difficult being close.”

2: Debt/Money
This ranged from the effect of illness resulting in excess spending and debts to vulnerability due to illness, social circumstances as related to loss of employment, relationship breakdown and the need for specialist input in relation to maintaining tenancies.

3: Discrimination/Stigma/Labels
Nearly 30 years after the Mental Health Act the stigma attached to sickness of the mind has not been overcome. Entrenched prejudice and shame continue to surround individuals. In an NHS survey in 2011 - 16% of respondents believed that one of the main causes of mental illness was lack of self-discipline and willpower and around a half of respondents (48%) in 2011 said that mental health-related stigma and discrimination has not changed in the past year.

12 different narratives mentioned different levels of discrimination and the negative effect of labels. “Words like a chisel of a carver can create what never existed before rather than simply describe what already exists. As a man speaks, not only is the thing which he is declaring coming into existence, but also the man himself” (Martin Heidegger cited in Walker, 2006, p 71).
Quote 58 - “I didn’t know who she was, can’t remember her name but she told me I’d be on injections for the rest of my life and I walked out and I was crying, I was gutted because I couldn’t believe it. I was so upset and I so wanted to be a nurse and then I wanted to be a midwife, that’s what I wanted to do. It’s not like I’m stupid I could have done it. But you can’t be a nurse if you’ve got schizophrenia you just can’t do it and they wouldn’t have it.”

What was reflected on was whether pathologizing deficit based vocabulary is useful in helping people improve their quality of life. One thing that gets communicated is a cluster of symptoms under the heading diagnosis. Unfortunately what also gets communicated is the hierarchical role relationship as well as the pathologizing and deficit carried context. Labelling it appears has disconnected both professional and client from humanity.

Referring to A&E Dept: “I could have been taken seriously at the hospital. I could have been treated with respect and dignity.” Quote 59.

Through to close friends: “Then one of my friends found out something about me and he just didn’t want as much to do with me. I’d say hello but he’s not the same sort of friend he used to be and that hurt you know. I thought the one person I could rely on as a friend sort of thing and he didn’t - that hurt – and that point I again was going to kill myself.” Quote 60.

And in detail: “I’ll tell you what does stick in mind is that in this day and age mental health is always betrayed in the media and on the television and newspapers is always sensationalized right it’s always somebody knows someone or killed someone and they always make out people with mental health are completely potty and people with mental health problems that I’ve worked with before now right, they never ever show anyone who does normal things, they go shopping, who do the tea, who does the washing, does the ironing, does normal things, day to day life that everybody else does. They never ever portray anything like that on the television and if they do interview anyone with mental health problems they’re always completely over the top. That does annoy me because there must be millions of people that are like me that just get on with their daily life, they don’t cause any problems to anyone,
the only one they’re ever harmed in their entire lives is themselves and, but no one
speaks up for anyone who does normal things and that annoys me because news
it’s always oh they’ve knifed someone, they’ve done this, they’ve done that and then
it gives everybody with mental health problems such a bad name, and bad press and
that annoys me and in this day and age I think it’s ridiculous because in America
everyone’s a therapist, everyone sees a psychiatrist. If you’re not seeing a
psychiatrist in America there’s something wrong with you.” Quote 61.

4: Family
17 separate narratives spoke at length about the effect of family on them and vice
versa. They featured significantly in those persons who were suffering from an eating
disorder or obsessional compulsive disorders.

Themes relating to the family issues revealed needs in regards to others within the
family whether they were perceived to have a carer role or were just dealing with the
incomprehension of the change in their family member and lack of knowledge
regards the diagnosis and what this meant for them. This lack of understanding was
referred to in:
Quote 62 — “I imagine it would have been useful for my mother and my father if
they’d had someone to talk to them about the illness cause my mother got some
information about schizophrenia from the National Schizophrenic Society or
whatever and she got all this information and she read it all but she didn’t actually,
she never had anyone to talk to her, to explain things to her, she never had any of
that.”

Some were very poignant and speak for themselves in giving a clear picture of
where a person is now.
Quote 63 - “I came out and my dad came to see me and he was talking to me and I
said well you know I’ve just come out of hospital and I said well I know it’s kind of
you come and everything but I said it’s hard you know. But they did come and see
me in hospital but they don’t have nothing to do with me now. You know, it’s me that
makes all the contact and when I do it’s difficult. So just recently, I know I’m going off
the subject but I’m from a big family and my one brother had a bad traumatic thing
happen to him when he was growing up and I found that difficult. It was just before I
was in hospital and we never talked about it. He’s working and everything, he’s got a daughter and everything but he doesn’t talk to me and he’s the one I cared about and everything and he’s turned his back on me so you know I find it difficult so the family’s just ripped apart really, family are important and I live on my own now.”

5: Home/Housing
Eight narratives referred to the importance of housing, a home on their mental health. This covered varying aspects such as:
Quote 64 - “After S left the new people took over but it was never the same after S left so I put in for a flat. The hardest thing I’ve ever done is to move out of that environment where everything was done for you and you get institutionalized and then having to survive on your own.”

Quote 65 - “It was in a really bad area where there’s always cars getting burnt and pinched and always the police there and stuff like that and I literally hated it from the day I put my foot in there I just, I couldn’t make it my home so I just buried myself in the bottle which was my best friend till like last July.”

6: Isolation
This was referred to as being an aspect of chronic mental health problems - both self isolating as protection but also isolation from friends - it was often coupled in the narratives with the loneliness that predominated.
Quote 66 - “No I just didn’t feel anything, I didn’t have any emotion at all. I didn’t interact with the children; I didn’t want to know anybody. I just enclosed within myself. I didn’t want to go out, didn’t answer the phone, just couldn’t talk to people at all. I just isolated – and I live in isolation I just totally cut myself off.”

Quote 67 - “I’d be kind of alienated if you know what I mean. It’s like is he alright is he not alright kind of thing is what they’re. I’m there trying to act, be normal, try to talk to them and try and get on with my life and it’s like blah blah blah. It’s like you ok kind of thing. It’s kind of well annoying, rather depressing sometimes. The friends don’t know how to treat you after you’ve just been into hospital.”
7: Relationships
The importance of relationships hindering or helping a person to recover featured highly. Some aspects were down to basic human need.
Quote 68 - “I mean, hugs, they mean such a lot and it was just nice to hug. I mean, I don’t know whether, obviously you’ve experienced mental health, but you tend to build up a barrier as well and keep people away and that’s what I’ve done. I mean at first it was really difficult giving yourself to somebody and you got this brick wall up there and I think that’s what hurt me more than anything because you drop that brick wall down and let somebody into your life and then it kind of finished and that’s quite hurtful and that didn’t help like I say. That just put the tin hat on all the other stresses that I got in my life and just pushed me over really.”

8: Spirituality
Again those who mentioned spirituality in their narratives spoke of needing a connection.
Quote 69 - “Because I’m a Christian as well, because of my faith, I get a lot of prayer and things from church and so you know I pray to myself as well so I feel like I’ve like a healing in my mind.”

9: Work
With unemployment increasing, the negative effect of job loss on mental health has assumed a sharp relevance. Losing work has been linked to depressive symptoms, heavy alcohol use and even long-term psychological damage. But research suggests that loss of income explains only part of this pain. The rest has something to do with the deep connection people forge between themselves and their work. We want to feel like what we’re accomplishing has meaning to the world.
Quote 70 - “I mean I don’t think I could face going back to the job I was in. I’m still technically employed by them I know it’d be even worse now to go back so I’ve kind of realized that, well my doctor did say to me, it’d probably kill me if I went back there and I do think I need to get away from that and try and – I mean I used to work for myself so I’m hoping that perhaps I can work for myself again and I’ve got some control over it a bit more and I can, because my life isn’t in that order of coping 9.00 – 5.00., I mean working for myself I perhaps will probably be working more than that but it’s kind of different when you work for yourself. You haven’t got that control of
somebody manipulating you and stuff you know. So that’s what my plans are at the moment just to hopefully you know do something like that.”

Meta Theme 4: Central Needs/Being

1: Acceptance and Belonging

Quote 71 - “Yes. I’ve got a good CPN now but they’ve all been good but they treat you like, you might feel like you’ve got the world on your shoulders and you come through the door, just stepping in there and seeing a face really is just part of it. It’s like there’s no pressure on you I don’t think whereas in some places there is a lot of pressure on you.”

See many other examples e.g. Quote 19, 26, 30.

2: Connection - being listened to, being with others, importance of being/helping others with MH experiences, therapeutic relationship, touch

85 quotes referred to being listened to (22 of 31 interviews). What was revealed was the frustration of people not talking their language, not hearing narrative research led by people who have experienced mental distress crossed this barrier and allowed for common understanding and; “when you are understood you are at home. Understanding nourishes belonging. When you feel really understood you feel free to release yourself into the trust and shelter of the other person” (O’Donoghue, 1998).

Quote 72 - “I think that’s quite valuable as well because it is, you do isolate yourself, you don’t understand it and so, I mean I do now but I didn’t at the time and its soul destroying isn’t it, you just don’t know what’s happening. It’s terrifying and to be able to then talk to somebody and them say, I know because you think you’re the only person in the world and you, I think that’s why you don’t speak out because you think well whose going to understand that. But I think, yes, some people and meeting people that understand.”

Quote 73 - “I mean I could feel this morning that at any point I could have phoned and said I wasn’t coming and it’s still very much like that. I think it’s fantastic that you can (Researcher) … I’m really passionate that I can, yes.”
Quote 74 - “You can’t talk about it unless it’s to somebody professional or somebody like you that’s had the same experiences. Joe Bloggs on the street, or even a friend, doesn’t understand it.”

Quote 75 - “I’m quite happy with what I’ve done today.”

3: Choice

Many people appeared to accept what was told/given in terms of services or attitude revealing lower expectations overall or lack of knowledge regards rights and accepting of their own worthiness to request alternatives with a corresponding wish not to criticise services. This ranged from simple choices such as when in hospital:

Quote 76 – “I think I’d like, the tea came out of a machine. I’d like to make a proper pot of tea you know because the machine tea was alright but comparing the tea you make yourself it was much better what you made yourself than what was out of the machine. It was free out of the machine and that but it didn’t touch the cup of tea you could make you know, or coffee.”

To choices within the services:

Quote 77 - “I think what I could have done with is not a psychiatrist but a one to one, you know, counselor or even a CPN. Somebody with training but yet not in a sort of authoritative position because I’d just rebel.”

4: Communication

The importance of this overlaps with so many of the themes. Within the narratives people spoke about things they stated they had not done so before which emphasises the importance of peer support. People identified how communication with them reflected how they perceived themselves, whether they mattered. The need to be contacted, the need for clear information in order to prevent further isolation from a system that is supposed to be helping and even a suggestion of utilising computers to reduce that isolation.

Quote 78 - “I just think they should be more aware of messages, passing messages on because it might be menial to them but to people who suffer with depression it’s a big thing and you know they must understand that what seems trivial to them when
someone needs to talk then it is a different matter. Just to open up and talk is not an easy thing to do for people.”

Quote 79 - “Well the medication was supposed to be for; well somebody said it was OCD, you know obsessional compulsive disorder then somebody else said it was anxiety/depression. I mean I’ve questioned it, some people have, only recently I’ve been told that it’s psycho not schizophrenia but something like that you know. But I don’t know, it’s just a big, I don’t know.”

Quote 80 - “We did discuss communication really, how often people aren’t advised about what’s available and can’t access it because of that. It did just cross my mind that with computers, I mean I’m a total L plate person but maybe we ought to be able to use that technology a bit more for disseminating information and be able to use the people with the skills.”

5: Coping Strategies
Comments around coping strategies ranged from exercise on prescription, activities, art, writing, cognitive strategies and being able to share the experiences with someone able to listen and be objective but supportive.

6: Continuity
The importance of continuity was referred to in six separate narratives and a further three revealed the difficulties whereby changes to workers was actioned without clear communication. Most referred to the issues around their mental health as a reason for the very fragile nature of trust within a relationship that necessitated continuity. A reason people are reluctant to seek help.
Quote 81 - “Unfortunately the one who I had been seeing regularly was going to leave and go somewhere else so I went to somebody else and they left or got, then they left and it was another one and I didn’t find that very easy, you know, I really didn’t because you do have quite a strong bond with the CPN you’re seeing regularly and for it to suddenly change it can throw you.”

Quote 82 - “Honest to god what would happen when he goes I don’t know because this is the problem with the counselors, it’s like I have told him more than I’ve told
anybody, now if he moved on somewhere else, I had the same problem when I had a drinks counselor, I had this bloke that I got used to telling everything and then he moved and I had someone else and you’ve got to start all over again. That part I find hard.”

7: Loneliness/Isolation
People spoke of the isolation created by the nature of the illness, stigma and need for withdrawal to protect themselves (as identified by Charmaz (1983) “restricted lives”).

Quote 83 - “I don’t see my neighbours because they’re at work all day. I look after their parcels and the letters and it’s just thank you, you know and run up the stairs by me and that’s them gone until tomorrow morning when I hear them running back down again and unless a parcel comes I don’t even speak to them you know.”

Quote 84 - “I just didn’t feel anything; I didn’t have any emotion at all. I didn’t interact with the children; I didn’t want to know anybody. I just enclosed within myself. I didn’t want to go out, didn’t answer the phone and just couldn’t talk to people at all. I just isolated – and I live in isolation I just totally cut myself off.”

Quote 85 - “It was the shock of exactly what I had lost and I have missed somebody putting their arms around me, talking to me, you know, everything’s going to be alright. Somebody who can make me laugh … I’ve never known what loneliness was. I think loneliness is a killer, I really think it’s a killer, you know. It’s frightening.”

8: Loss
Loss was obviously coupled with loneliness but it encompassed such a breadth of loss—from lifestyle, jobs, relationships to self esteem and ultimately peoples identity as described as the whole self.

Quote 86 - “When my marriage broke up then that is when it all hit me. At the time I coped and put on a smile and I thought everything was alright and when I realized that when he left I just had the two kids that’s when I had time to sit and it hit me like a ton of crap, it really did. Everything came back that I didn’t want to think about any more.”
Quote 87 - “There was nobody I totally, what’s the word ... isolated myself. I lost a lot of things during that time, I lost, I loved people and I’d always been, I worked and always had lots of friends and just people around me and I lost all those things, I lost the ability to communicate, I lost everything. I think, I don’t know, right now I see it all in a different way, I see it all as really positive because nobody could say to me now, nobody could say to me oh I’ve lost ten pound, and I’d think you don’t know what it is to really lose. When you lose your whole self that’s when you’ve lost everything and I suppose it makes me quite thankful now.”

9: Recovery - things that helped

Recovery starts with listening to people, a process of discovery for both the listener and the listened to. Narratives can be utilised as a conduit for this resilience to emerge. Mental distress is seen within the narratives as a human experience which should not be used to define an individual. They reveal the difficulty of not having a time frame for mental illness and trying a combination of solutions, the importance of a multi-faceted approach. Organisations/professionals are there as guides but this clearly shows they do not own the recovery process. However they were welcomed by individuals in order to provide feedback on progress and recognition of the individual’s recovery- in order to establish a creditable definition of self.

34 sound bites or coded sections emerged around recovery which included 11 different narratives.

Quote 88 - “It's problems isn't it, it's not like a broken leg you know, perhaps in three months time you could be alright and it's quite frustrating because I suppose I am quite an independent person anyway and I'm quite logical so the mere fact that it's taking a long time you know, and I set these goals for myself which are unattainable so I’m learning that just take it in stages and stuff like that really but I mean I’ve just recently started exercise on prescription which I’ve found really helpful and I have lost a bit of weight through that and I’m starting a welding course. I’m doing one or two little bits and pieces you know. But, it's like a combination of things ... I mean I do like doing things. I’m doing a welding course because it's something I’ve always wanted to do since I was a kid, just to have a go at it. I mean it's really frustrating but it’s taken my mind off things a bit and I’m getting there and I’m doing it. I mean the first week I was really panicking, panic attacks and everything but as it's gone on
they’re diminishing. It’s like going to the gym, I was getting panic attacks but now I’ve been to the gym before I come here. I’ve been going for fourteen weeks now and I’m, enjoying it so I know you’ve got to chip away and build up and try and get some semblance of life back together.”

People were then able to recognize their own recovery:
Quote 89 - “Whereas I look at everything now, no matter how small it is as an achievement you know. Whether I had to go into town on a market day, it was busy and I did a job. I had to go to the bank which would probably be busy and I’ve gone in and I’ve had to do it, some bills had to be paid that day whereas in the past I would have run away from it all and relied on other people to do it for me. Or if the phone rang I’d leave it for somebody else to pick up or could you deal with this for me. I’d give permission and hand it over because I couldn’t deal with it but now I tend to have gone to doing things for myself more.

What was significant was the amount of people who identified attending the narrative as a marker in their recovery process.
Quote 90 - “I’m actually living in supported housing now which has got me this far, I’ve come here today so I’m on the way there. I have dealt with all the abuse issues.”

Quote 91 - “They started getting me do things I haven’t done in a long time … How’s that been? (Researcher). It’s hard, it’s still very hard and I do get a little bit apprehensive. Like four months ago I wouldn’t be able to sit here and do this for instance. So I’m aware of the things I can achieve in my life whereas before I might be thinking well I didn’t do much really, I’ve done nothing.”

An important part of recovery was taking control.
Quote 92 - “I’ve had this illness over twenty odd years so I know all the signs and symptoms of the illness. I know there are so many stupid people out there that will be on the medication but because they feel better they stop taking it and then they’ll get ill again but because I know the illness so well I can monitor it, I know what’s going on. I mean I don’t let it get to the stage where it gets out of control at all. The only way it got out of control, well it wasn’t schizophrenia that got out of control, when I had depression with *****, that wasn’t schizophrenia or the psychosis,
whatever you want to call it, that was the depression but I don’t let it get, if I feel ill and I think I need extra medication I will ring up and tell them.”

Sometimes with help:
Quote 93 - “It’s coming along, like I said before, months ago I wouldn’t have been able to do a lot. It’s like you say it’s like a self-realisation of yourself and your own behaviour and things that you’re actually doing and how to challenge those things that you are doing you know, in a positive way that you wouldn’t know anyway not unless somebody tells you how to. Sometimes you’re thinking you can’t – so somebody says what if you did so and so. You know, it’s that somebody who can give you that balanced view about it which I’ve never had really.”

Utilising metaphor people spoke of recovery as a new life or “a clean start”:
Quote 94 - “Since I got rid of the drink has – I’ve had to learn – it was like being in a coma for fifteen years if you want to know the truth and I’ve woke up because I’ve had to learn to deal with everything. Like if something happened to my life and I can’t deal with it instead of cutting my arms or thinking about taking a bottle of tablets or I’m going to go out and buy a bottle of vodka I’ve had to learn, I feel like a kid again. It’s a new life.”

Quote 95 - “My ex husband kicked all my teeth out at the front and I had all the roots left in at the top so they had to take, I went around like that for fifteen years, I couldn’t pluck up the courage to go to the dentist and have it done and I’ve been and had all them out in the last four weeks and I’m having new ones put in and it’s another part of the past I can bear now because every day I get up I look at it and it reminds me of the crap me and my son went with – cause my life has always been filled with violence.”

Quote 96 - “I got my senses jelipsis Had my teeth fixed and had my eyes tested. I got the glasses at home and jelipsis It’s all falling into place.”

A number of the narratives referred to the “illness” or “breakdown” as being a turning point, reflecting back on the experience as changing them for the better:
Quote 97 - “It’s made me a stronger person and to have more empathy for people with mental health you know and people in general because I work at ******* if I get a customer who I say hello and they don’t answer, at first I used to think crikey, you’re in a bit of a bad mood or whatever but now I sort of empathise with them because I think you don’t know what’s going on inside their heads you know, they’ve probably had a really rotten day or something and the last they want is someone checkout so you know what I mean so I just think, let go just deal with them the quickest way you can and just be polite really and do it that way. You don’t know what’s going on inside their lives so you know; show a bit of empathy really.”

The number of people who spoke about what they wanted to achieve, the tenacity they showed in trying to get things, whether it was a job, a particular therapy, walking to the shops or getting a future.

Quote 98 - “I mean I was telling the CPN, I rang up the Open University and I’m thinking about doing a law degree. I’m enquiring about it anyway. I don’t think it will happen … I was told by a social worker I know that I could get it for free because I’ve done the first year A level law and I could do it so I thought I’d do that. I mean I know I’m 45 and I’m late doing it but it’s just something to do and if I get, I could be a Legal Executive, I could do the law degree.”

**DISCUSSION**

Central to the above emerging themes and to the whole of this research process are the need for Connectivity, Being Heard and Being Valued within relationships whether they be with families, friends or services.

Relationships and involvement that reduce the impact of “restricted lives” and “discrediting of self” which are significant aspects of chronic mental illness have emerged within this study as the key factors that promote peoples’ self worth and ultimately potential for recovery or transformation. They were equally valued from both the service user perspective and the service user involvement perspective.

Similarly individuals, both those as researchers and those who came to give their narrative referred to the need to give something back and to help others in the process. Reciprocal imbalance seems to have a potential to cause mental distress
as well as both dependency and indebtedness, leading to a decrease in an individual's self worth or ability to cope with life challenges (Dunbar et al., 1998). This basic human need of reciprocity is frequently not acknowledged as a driver for involvement but we have identified that by considering it as a need in both involvement activities and therapeutic input individual and service outcomes are more likely to promote recovery.

The aim should be to raise awareness of caregivers and/or other persons in an individual's life to acknowledge the importance of creating or maintaining reciprocal balanced relationships and to avoid bringing a person into an over benefited position with respect to the helper, as much as possible. The concept of two equal individuals working together seems helpful in enabling service users to take responsibility for problems and choices and building self-confidence, trust and self-respect. This research indicates this can similarly occur within involvement activities. The level of inclusiveness achieved seems to encourage service users to feel valued and encourages personal growth.

This study allowed service users not just to come forward and give their narratives unrestricted but for the researchers to transform their identities in the process over a four year period in which all six remained committed to the process. It demonstrated that it can be achieved within the statutory organization if valuing conditions such as those identified by the researchers’ exist. It demonstrated a mechanism for redefining identities, increasing socialization experiences and regaining agency. This transformation process capitalized on the words of Frière (1993, pp.xii-xxii) with regards “the potential of women and men to know, to value, to establish limits, to choose, to imagine, to feel, to create, to decide, to formulate an action and direct it toward a goal, to refine and evaluate that action in order to humanize the world, reshaping or re-creating”.

The human desire and capacity for participation and self-determination is often suppressed by illness, labels, traumatic experiences, limited choices and deprivation as identified in our narratives but as Frike (1983) stated “it cannot be destroyed”. This very point came through in the feedback from every participant and researcher.
Through the process of involvement critical consciousness develops, leading to further action through which people cease to see their situation as a “dense, enveloping reality or a blind alley” and instead as “an historical reality susceptible of transformation” (Friere, 1972, p.58) This transformative power as described by Friere is central to this research.

“We have moved from being service users, to being researchers, a positive identity, which has motivated us all, yes we are useful, we have a purpose, we are being valued for helping to compile, an incredible piece of work, for many of us, confidence has returned, passion and purpose too, as well as an overwhelming feeling of pride, to be part of such an incredible project. For us, being part of a team, sharing, supporting, discovering and importantly, laughing together, has been incredibly affirming. (Researcher 4)

Similarly within this mental health project, experiential learning has provided the potential to make a significant impact on how involvement is operationalised. By learning in great detail about how the process was experienced by the researchers in addition to the narratives themselves we are in a better position to consider how at the deepest level, we share much with a person whose personal circumstances may initially seem separate to our own. The potential for an understanding of shared humanity (Warnock, 1987). If the workers own journey of collaboration and implementation starts from this belief in people; a belief in sharing and learning from one another it may create the environment conducive for people using the mental health services to both want and benefit from working alongside them.

“Yes, service structures, medication, practical help and meaningful occupation are all part of the recovery package, but the central theme for most of us is our lack of confidence and self esteem and for some of us our lack of and sense of identity at all. Listening, really listening to someone is a way of helping them to feel, perhaps for the first time in their lives, they have value just as human beings. And until you know that you do have value, you have not got any tools with which to build your own recovery, however helpful professionals are.” (Researcher 1)
The quality of the relationship and the establishment of a person-centred approach seem crucial in enabling the service to meet its aims. The relationships between workers and service users is characterised by equality, mutual respect and trust. The research project has offered a valuing yet challenging level of involvement which has been instrumental in enabling commitment over a period of four years and being part of individual's personal recovery. They have developed hope, and confidence in their own abilities. This further emphasises the time required to fully develop and embed user involvement within an organisation.

CRITICAL EVALUATION

Fundamental to a qualitative approach, is that the subjectivity of the researcher is acknowledged and consequently their role in constructing the narrative of any themes and report (Banister et al., 1994). The lead researcher on this project was in the role of manager of the adult mental health services locally and was mindful of the issues of power and control. The conceptualisation of power is important within the service user movement and more specifically to this project.

If power is treated as a commodity that can either be won or lost (Ghaye, 2000; Barnes and Bowl, 2001) it suggests that professionals must surrender some of their own power and pass it on to service users (Gillepsie, 2000). This notion that power is a finite quantity can impede the accomplishment of real empowerment. However If power is seen as something that may be generated within individuals through knowledge and learning, by increasing self esteem and by achieving goals through the sharing of power, then the very process of service user involvement and collaboration in regards to research projects such as this can become the vehicles that bring together Government paper rhetoric and lived experience of mental illness and services.

Within phenomenological research the establishment of a good level of rapport and empathy has been highlighted as critical to gaining depth of information, particularly where investigating issues where the participant has a strong personal stake. The value of also being or having been a service user would not in itself create this, therefore in addition to much exploration on rapport and listening, researchers were matched with those giving their story in as much as was possible with the information
available. Confidentiality and anonymity was stressed to participants, but some may have felt slightly inhibited in their responses, as all participants were still using the service and largely had good relationships with the workers. The researcher was mindful of this potential issue during the interviews and spent time making the participants feel comfortable, stressing the anonymity of their responses and noted that they were able to critically reflect on the service.

Reliability was maximised by ensuring that codes and themes were developed systematically and based on the words of the service users. The researchers re-read transcripts to check codes and interrogate the relevance of the themes developed across the interviews. They were then copied to the MAXQDA computer analysis system in order to utilise the data as a group quickly and clearly. In this way a hands on approach was maintained and the criticism of computer assisted analysis for reducing qualitative analysis to a mechanical and technical activity (Polit and Hungler, 1995) was therefore addressed directly in the time taken by the group on each narrative prior to its usage.

To enhance confidence in the reliability of the themes, having six researchers involved allowed for an inter-rater reliability check of codes. This was very important to the group as the aim they had agreed at the outset was that they would be faithful to what the participants have said, wishing to make clear any omissions and obvious interpretations that were made, such recognition becoming a group process whereby one member would point this out to another when it occurred. The ethical issue was raised by the researchers themselves regards misrepresenting, distorting or deleting findings which have been provided in good faith by participants. It was acknowledged that this part of the report did involve some interpretation and conjecture in deciding what to select and how to express and order it, but its main role was to describe rather than explain. Furthermore, triangulation of method could have been used to explore whether similar themes emerged from focus groups or quantitative evaluations. The findings can be reported robustly, and our preference here was also to include direct quotes - both ‘sound bites’ and more extensive quotes from participants to illustrate points. It was felt by all researchers that these gave a far clearer illustration of the themes and the reality of how these were experienced.
Greater reliability can be placed on the data gathered in an interview over that gathered by a list of self-completion questions in a survey. Although a possible criticism of this approach is a lack of rigour due to careless interview techniques and the introduction of bias. In this research the narratives were guided to avoid leading questions and the introduction of bias. A working awareness of bias is imperative in all interview research. Transcriptions were checked for context and content accuracy before analysis began. These precautions and the fact that conclusions drawn are grounded in actual data helps minimise the risk of bias. This is an iterative process that required a great deal of time and patience.

It could also be useful to gain feedback on the identified themes from the participants, to provide another level of triangulation however following the mapping and coding we made a group decision not to return to the individuals who gave their narratives for verification as this was both inconsistent with the descriptive Husserlian method (Husserl, 1913) and also in discussing Patterson and Zderad’s (1976) work agreed that descriptions of experiences given at that time were no longer pre-reflective. They are instead meta-reflective, that is, focused on what was said about the experiences, rather than describing the experiences as they came to presence.

This research aimed to enable the voices of the most disabled users, the 'silent majority' to be heard and the key factor in achieving this lay in the many different strategies sought to reach out to people however remaining largely reliant on workers encouraging and supporting involvement from the outset.

The research offers insight into the outcomes and processes of the project for the participants at this time, and although not necessarily generalisable across statutory mental health services, it does offer wider perspectives in which to inform service planning and delivery. It remains important for further research to evaluate the perspective from a wider sample of service users.
FUTURE RESEARCH
This research has highlighted a number of perceived benefits of utilising the narrative for both change within the individual and service, as well as some of the processes and factors which underpin this collaborative approach. It has highlighted an effective and valuing method in which to engage with those whose views are rarely accessed in any other involvement activity.

Future research should aim to measure the benefits of narrative within the Care Programme Approach/Mental Health Measure (2010) and recovery models in order that they become fully integrated and meaningful to the service user involved. Peer support has been noted to be a particularly powerful component of efforts to implement recovery focused services (Mowbray et al., 1997) and there is a growing evidence base showing peer support services have the potential to reduce hospitalisation and demand for other mental health services. Further research into how models of involvement such as this could be utilised within a peer support service is needed. A recent King's Fund report on mental health productivity (Naylor and Bell, 2010) found that, while further evidence was needed of its cost-effectiveness, peer support could both improve outcomes and reduce costs.

This research, like previous research, highlighted a possible need to further embed the model within services, and this will be important to explore in interviews, focus groups and evaluations with staff and stakeholders. A focus group with the service users would also be useful to explore the perceived validity of some of the themes and discussion points in this research and to explore ways to manage some of the challenges of the service user involvement.

RECOMMENDATIONS
There are plenty of ways of finding out what people think of a service other than using a questionnaire. This research demonstrates that the use of creative consultation techniques which can help people express their thoughts and opinions in a more interesting and meaningful way, reaching and valuing those voices not previously heard while still providing valuable outcomes that can be used to develop services. It recommends:
1) Utilising the narrative within the assessment process and Care Programme Approach.

2) Utilising the narrative within educational programmes for both staff and service users that promote the recovery principles. Additionally within induction programmes for new members of staff and within clinical supervision.

3) Utilising the narrative to address issues of safety, quality, engagement and complaints and more appropriate and cost effective use of healthcare resources - forming the basis of root cause analysis/critical incident learning.

4) Utilising this process of collaborative research to make service user involvement integral to the systems and to support the development of peer support/recovery workers to further enable the sharing, reciprocity and connection sought.

These 4 recommendations are explained by highlighting their value:

1) **Value of the Narrative as Assessment**

   Acknowledging the ‘humanness’ as opposed to the label of ‘service user’ provides a necessary starting point for appreciating their right and capacity to be involved in actively shaping and determining the outcomes for services and themselves as individuals. Narrative approaches separate the person from the problem and provide a robust, coherent, ethically inspiring and engaging way of helping people use their own agency to steer their lives. This research recommends giving the opportunity for hearing the narrative early on in a person’s experience of the service as a first step in the service user recovery process. Being heard as indicted in the narratives reduced the potential for disillusionment of the service whereby one knockback or discrediting event can prevent further engagement. By using a semi structured interview, the tools of recovery are placed firmly in the hands of the narrator themselves. Having the narrative audio taped with the permission of the individual provides a genuine record of what the person has experienced and can be utilised within a Care Programme Approach in order that it genuinely reflects what the person has experienced, their thoughts, values, strengths etc. The time spent listening without interpretation early on can have savings in the long run.
2) Narrative Research as an Educative Process
Narratives are a far more powerful and effective medium in which to feedback and learn from both poor and exemplary care as identified by service users. As they refer directly to local practice and engage the emotional as well as practical components they are more likely to bring about behavioural change in care. They can also be utilised by the person as a measure of recovery or reflection and have an educative component for both service user and provider; use in teaching and reflective practice within clinical supervision and peer support meetings and Care Programme Approach reviews for service users.

3) Participatory Research as a Quality Agenda Item
Part of improving responses to mental health difficulties is a journey into demystifying and consciousness raising about peoples’ experiences and what it's like to feel socially excluded and discredited. User involvement and collaboration therefore have a crucial role to play in this process. 12 separate narratives revealed great detail about their experience of depression and bi-polar disorder. Such detail is not given in the corresponding clinical notes or assessments, and hence cannot be utilised to assist in any outcome measures. These narratives in their entirety personalise people’s care. It reframes the identity of the person entering the service and those providing it and improves the communication between them; improved communication that affects outcomes in safety, quality, engagement, complaints and more appropriate and cost-effective use of healthcare resources. Root cause/critical incident analysis can be enhanced by the detail revealed within narratives without the person having to be involved in a formal review process. A local issue for example, was that the narratives reveal specifically the need for specialist abuse counselling and psychological therapies which allow such stories to be heard and alternative futures realised. The results of not receiving timely counselling after suffering the trauma of abuse was evident in the narratives and revealed costly longer term morbidity .

4) Value of the Process
As this participatory research has demonstrated, if done well it can be an evolutionary and developmental process, as individuals develop skills of inquiry. It
can be emancipatory not just by leading to new practical knowledge but to new abilities to create knowledge. That is not just producing knowledge and action directly useful to a group of people, but participation that can also empower them at a second and deeper level to see that they are capable of constructing and using their own knowledge. Thus participation is also a process of consciousness raising and thus an educative imperative to encourage new and validatory self-concepts. The research or projects in regards to involving the very people who use the services should not just be conceived as a means to an end but an end itself where the process is valued irrespective of any tangible outcomes. The reclamation and exercise of the user voice is integral to taking back and occupying valued social roles which have been lost through illness, discrimination or both. It is important that as many service users from as wide a range of backgrounds and social groups as possible are able to take part in the service user engagement programme and that they are properly supported to do this. As demonstrated, people who take part in service user engagement can gain valuable skills and experience, which can help them in their own recovery and that of the organisation. By incorporating a training element within service user involvement programmes you can not only help to change services but also change the lives of people who take part in the engagement work. It is important that any involvement is arranged flexibly to meet the needs of the people who attend them: It is also important that the people attending these groups are able to see the changes that they are making to local services and that they know they are being listened to and taken seriously (see Quote 50 - “nobody’s checking...”).

5) **Value of Embedding Service User Involvement**

Studies of this type of sustained involvement can lead to different ways of being together, as well as providing important guidance and inspiration for practice. Only a fundamental change of the very culture of the system will ensure that the changes made in policy, training and research will lead to genuine recovery of both individual and service. Involvement that attends to the human need for connection, creditable definitions of self and reciprocity will enable that transformation in order to continue to promote recovery orientated practice and enable it to become embedded in practice. This type of study emphasises the value of peer support which is in line with the government's emphasis on patient and user empowerment, as set out in its
NHS White Paper (Department of Health, 2010) in regards equity and excellence, and its vision for adult social care. On 1st November 2011, the Welsh Minister for Health and Social Services launched a 5 year vision – *Together for Health*. This states that the priorities and perspectives of the service user must be fully considered in designing services. Thus necessitating it outlines the development of mechanisms that actively involve service users of all ages, together with their families and carers, in monitoring the quality and efficacy of services. This research demonstrates how these aspirations can be achieved in practice. The study therefore recommends that action plans from each of the Narratives impact on the provision of services locally. These provide issues and solutions to future service provision and would demonstrate the commitment to act upon what was so courageously shared.

This report and the corresponding summary report written by the six service user researchers will be circulated to Betsi Cadwaladr University Health Board, Powys Teaching Health Board and Powys Agency for Mental Health and will be verbally presented by the research group to staff within all mental health services locally and nationally, and most importantly to the service users whom without their involvement none of this rich experiential learning would have been possible.
REFERENCES


Mental Health Foundation (1997) *Knowing Our Own Minds*. London: Mental Health Foundation.


**APPENDICES**

Appendix 1: Information sheet

Appendix 2: Interview Prompt Guide

Appendix 3: Consent form

Appendix 4: A section of coded transcript

Appendix 5: Codes

Appendix 6: Themes and Meta-themes

Appendix 7: Factors for Valuing and Valuable Involvement
Appendix 1: Information sheet

PARTICIPANT INFORMATION SHEET

INvolving service users in developing mental health services in Montgomeryshire

You are being invited to take part in a research project, which we are doing as part of a local initiative to improve the services to you.

Before you decide, it is important for you to understand why the project is being carried out and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the Research?

We wish to offer training, support and supervision to people who have used the mental health services to interview other service users who are currently receiving input from the North Powys Community Mental Health teams. The purpose of the work is to hear service user accounts of their experience, in their own words, by telling their story.

We refer to these stories as ‘discovery interviews’. This is then read out to the research team and issues relating to service improvement are identified. This has been found to be a very useful way in helping health care professionals understand patients and carers needs and identify areas to improve the service.

Why have I been chosen?

You have been chosen as you are currently receiving Mental Health Care in this locality. We hope to be interviewing approximately thirty service users in the next few months as a part of this project.

Do I have to take part?

You do not have to take part if you do not wish to do so. If you do decide to take part you will be asked to sign a form giving your agreement to take part in the research. If you decide to take part you are still free to withdraw at any time and without giving a reason. This includes
your right to stop part way through the interview. A decision to withdraw at any time, or a
decision not to take part, will not affect the standard of care you receive.

Please do not reply to us if you have made, or are planning to make, a complaint about local
Mental Health Care Services. We will be interviewing patients who have made a complaint,
but only after the complaint process has been completed. The interview will be audio-taped.

What do I have to do?

If you are interested in taking part, return the reply slip attached to the letter or contact André
Hutchinson. You will then be contacted a few days later to arrange a date and place
convenient to you for an interview. Any questions you may have can be discussed with
André.

At the interview, you will be asked to discuss your experiences of living with a mental health
condition. A trained interviewer who themselves has experienced a mental health condition
and received a service will ask you what has happened to you, right from the time when you
first thought that you might have difficulties. The interview will be taped on an audio tape. It
is important that you tell this in your own words, as if you were telling the interviewer your
story. The interview will take place in your local CMHT centre so that you may have access
to additional support if required. Each interview should take no more than one hour and we
will tailor it to the amount of time you are able to give.

What happens to the information I give at the interview?

The interview will be tape recorded so that the interviewer can listen to you without the need
to take notes. Following the interview the story is typed up from the tape.

Your personal details, any names of people or places mentioned will remain confidential, as
they will not be included in the written story. The story is then read out to the research team.

We have found that listening to these stories helps health care professionals to understand
patients and carers needs and to make improvements to Mental Health Services. The written
information will be stored securely and only authorised staff will have access to the
information.

We will ask your consent in order to seek permission to potentially use direct quotations from
the story you have given. No quotations will identify names/places which might inadvertently
identify you.

If something is heard that suggests unacceptable or unsafe practice, the interviewer will be
required to report this matter locally. In the unlikely situation of this happening, the
interviewer will discuss this with you and will explain what will happen. This is designed to
safeguard patients.

What happens to the tape recording of the interview?

Some of the tapes will be used to help us to train interviewers and maintain high standards
during the Project. The people listening to the tapes for this research will be subject to NHS
confidentiality policies.
The tape will be kept in accordance with our policies in a locked cabinet in a Powys Local Health Board Office and retained for 5 years. They will then be destroyed by the lead researcher.

**What will happen to the results of the Research Project?**

Local Mental Health Care providers aim to use the stories to help them improve their care and services. The results will be published in a newsletter, which will be made available to you.

**Who is organising and funding the survey?**

The Powys Local Health Board provides support to the research team and ensures it is monitored and follows ethical procedures. Powys Agency for Mental Health are also supporting this project by means of both practical support and funding.

**Who has approved the survey?**

This survey study has undergone a rigorous process and has been approved by an NHS Research Ethics Committee, who are authorised to give approval to patient research studies.

**Contact for further information**

André Hutchinson, Bsc (hons)
Manager, Adult Mental Health services
North Powys
01938 558969/01686 617300

Thank you for reading this information leaflet and considering taking part.
Appendix 2: Interview Prompt Guide

Suggested prompts:

• Can you tell me when you were first aware that you were experiencing difficulties?
  • And how has that affected you now? (To bring person back!)
  • How did you go about seeking help?
  • Are you able to tell me about what happened?

• How did you feel (about this..That)?
• What do you remember most at this time?
• What was it about......that you remember?
• How do you feel you were treated?

• Do you think anything could/should have been done differently?
• What effect did it have on you/your family/friends etc?
• What or who do you think helped?
• What or who do you think was unhelpful?
• Was there anything that surprised/ shocked/ worried/ pleased you?
• Can you tell me more about ... (that?)?
• Can we come back to...................?
• Is there anything else you would want to tell me about....
• If things could be exactly right for you from the Mental Health Service, how would they have to change?

• What would you change about the Mental Health Service for it to say back to you...You matter?

Appendix 3: Consent form:

SERVICE USER CONSENT FORM

INVolVING SERVICE USERS IN DEVELOPING MENTAL HEALTH SERVICES IN MONTGOMERYSHIRE

Your local health services are working to improve services for patients with mental health difficulties.

As part of this programme, we wish to hear from service users about their experiences - about how you felt, the things that happened to you and your family and the things that are most important to you. This will involve you telling your story to a person trained in interviewing skills who has also experienced mental health difficulties and received a service locally. This will be tape recorded and is what we refer to as a discovery interview. It would take approximately one hour.

The interview will be undertaken within a Powys Local Health Board building and there will be support offered to you before or/and after the interview.

Full details are contained in the Patient Information Sheet – ‘INVolVING SERVICE USERS IN DEVELOPING MENTAL HEALTH SERVICES IN MONTGOMERYSHIRE’

Anything you tell us will be treated anonymously - your name will not be passed on to anyone else and any records we keep of our discussions will not have your name recorded on them. We may use direct quotations from your story in order to highlight aspects of care/issues that will inform MH care providers. These will not include any names of people or places which may inadvertently identify you.

The experiences that you describe will be important for three reasons: -

1. To help us learn about what is important to service users.

2. To help us improve the service to service users and carers

3. To involve service users in the research process so that it enables people to speak freely about the experience they have had.
We would like to emphasise that you don’t have to take part in this programme, it is entirely voluntary.

Should you decide to take part, you are free to stop at any time (including whilst having the interview) without giving a reason. If you do decide not to take part or withdraw from the process your care, now or at any time in the future, will NOT be adversely affected in any way.

For our records - to show that you understand the work we are doing and to show if you are happy to take part - please complete the following:

Have you read the Research Information Sheet?  
YES/NO

Have you had the opportunity to ask questions and discuss the research?  
YES/NO

Have you received satisfactory answers to all your questions?  
YES/NO

I hereby consent to participation in this research on the understanding that I can withdraw at any time and that my current and future care and treatment will not be affected.

I understand that all the information gained will be confidential and that information which is taped will be stored securely for 5 years and then destroyed by the lead researcher.

I wish to take part in a discovery interview

Signed: .................................................................
I can confirm that I have explained to the service user the purpose and nature of the research.

Signed..............................................................................................................................

Designation......................................................................................................................

Date....................................................................................................................................

If you have any concerns regards giving consent or require additional information please do not hesitate to contact:-

André Hutchinson, Bsc (hons)
Manager, Adult Mental Health Services
Appendix 4: Copy of an Excerpt of coded Transcript

(Interviewee) Yes. I think that’s quite important really. Like I say, you know things have sort of been there at the right time. I’ve had the right help at the right time. Like I say my only problem has been the waiting list, the waiting lists don’t conform to when you’re at the right time do they (laughter).

It can be quite frustrating because you know it’s…..

(Interviewer) When you couldn’t get out of the house, what about your shopping?

My partner did everything for me.

Are you with somebody now?

No.

So you didn’t have to face –

I didn’t have to. He did everything and apart from he did the shopping and he even took care of my money really, everything. He had my bank card. I didn’t have money or anything, I just, he made sure I had cigarettes and he did the shopping and I didn’t need anything else because I didn’t move from the sofa. It’s an awful experience when even now I go up and down at a very erratic rate. I can’t gauge one day to the next. I mean I could feel this morning that at any point I could have phoned and said I wasn’t coming and it’s still very much like that.

I think it’s fantastic that you can

I’m really passionate that I can, yes.

(Long pause)

If you could have perfection from the mental health service, what would you have liked

Take it all away (laughter).

Let’s stick slightly to reality
Well, the waiting list... the part where I got stuck because they were redoing everything, you can’t really do anything about that. Nothing really... The support workers. I find that, I mean cause that was invaluable to me and would still be now if.....

If it was available?
Yes

So what did you feel you got from the support worker?
I remember going out with her one day to do shopping or she took me to acupuncture, which I found absolutely amazing, and I got into the car and you know that feeling that you’ve forgotten something and we got where we were going and she said you’re very quiet today are you ok, and I said I’ve forgotten something and I don’t know what it is and I’d had a sort of panic attack coming out of the house and it was really sort of wow-you know and it was so slow and so subtle that she helped me with it you know and I wouldn’t have moved from my partner because I stayed at my partners and it was wrong for me. I wouldn’t have moved on without that support and help. I really think that that’s a big mistake.

So what do you think she could be doing for you now?
Now, oh Like I say I’m in supported housing and there’s, the support workers there are men and they’re very practical and if I’m struggling and I need to go and get my shopping, I suppose I can go and do it on my own but if I’m struggling they will take me and bring me back, but there’s nobody to just call and take me for a coffee and talk about girl things and make me forget all the anxiety and you know just, well the afternoon’s gone by, I’ve not been in the flat I’ve been outside. Like **** took me to Evans’ to get clothes that would fit me as nobody.... clothes didn’t fit me anymore. Things like that, that **** would have taken me, you know, when I’m ready, swimming and things and she said that she would have been able to find a private pool somewhere so that I wouldn’t feel – it’s things like that you know and it’s not there anymore. If I had a relapse then she would have come................

Accessibility
Anxiety ¬Panic attacks
Being Listened to ¬Attending Narrative Giving
Experiences of MH Problem¬ Agoraphobia ¬Restricted Lives
Gender Choice/Issues
Lack of service
Support Workers
Appendix 5:

Codes

Code System [976]

Abuse [22] ¬ Alcohol abuse - Sexual abuse/rape - Bullying

Accessibility [21] ¬ Duty System

Accredited Accommodation Scheme [8]

Administrators [6]

Advocate [1]

Agoraphobia [2]

Alcohol issues [5]

Anxiety [2] ¬ Panic attacks

Aspergers/Autism [1]

Being Listened to [25] ¬ Attending Narrative Giving [27]

-Being with others [12] - Importance of others in same position/understanding [18]

Care Plan/CPA/assessments [5]

Causation-Persons understanding [7]

CBT [2]

Childhood [17]

Choice [5]

CMHT [19]

Communication [16]

Complaints [3]

Connections [4]

Coping Strategies [4]

Counselling [1]

CPN [28]

Debt/money [6]

Declined Help [1]


Different Perspectives [16] ¬ Understanding/Awareness [15]


Disengagement follow up [1]

Drugs [2]

Duty System [4]

Eating Disorders [21]

ECT [10]

Exercise/activity [5]

Experiences of MH Problem [29]


Feeling stuck [4]

Gender Choice/Issues [5]

GPs [14]

Groups/Courses [9]

Home Visits [6]

Home/Housing  [12] ~ Importance of Housing Support [1]

Hospital  [17] ~ Institutionalisation-Good [12]-Bad [23]

Labels [7]

Lack of Continuity [7] ~ Lack of continuity but also importance of... Lack of Understanding [20]


Lack of service [1]


Mental Health Act [9] ~ Sectioning

Needing Support [1]

NHS System [8]

O.T [5]

Obsessive Compulsive Disorder [4]

Out of Hours [11] ~

Personality Disorder [1]

Placement-funding [1]

Police [1]

Post traumatic stress disorder [1]

Post-natal depression [8]


Psychologist [6]

Recognition-Relief [2]

Relationship-issues & importance [8]

Respite [2]


Service User Support [3]

Social Worker Input [5]

Spirituality [4]

Stress [2]

Support Workers [10]

The Place [8] ~ How it appears/ambience etc


Things that helped [31]

Touch [2]

Transport Issues [1]

Trust [14]

Voluntary Provision [12]

Waiting Lists/Delays [9]

Work [13]
Appendix 6: Example of Single Theme & Meta Themes from Service User Narratives

**Social/Contextual**

**Childhood**
“My parents were very loving but they didn’t really know how to be loving so there wasn’t much affection and it was all quite serious, well very serious at home geared towards achievement and doing your best and that sort of thing. Not much comedy, everything was serious. We watched programmes on the television for educations sake all that sort of thing really.”

1 of 18 coded segments

**Debt/Money**
“Well I told my C.P.N... I’ve got these credits cards... a lot of money, scared of losing being ripped off and in the end I was ripped off so we cut them all up and we went to Citizens Advice Bureau,... worked for me they took me on their books. So we got it all sorted out. I got a year planner at home, put all my pay days, you know little stickers, income support days, DLA days, I got it all worked out and I know how much I can take out of the bank now ... without worrying...”

1 of 22 coded segments

**Discrimination/Labels/Stigma**
“I could have been taken seriously at the hospital. I could have been treated with respect and dignity.”

“I was so upset and I so wanted to be a nurse and then I wanted to be a midwife, that’s what I wanted to do. It’s not like I’m stupid I could have done it. But you can’t be a nurse if you’ve got schizophrenia you just can’t do it and they wouldn’t have it.”

2 of 22 coded segments

**Family**
“I know I sort of talk about it. I never see them, you know. It’s always me that has to make the effort but they’re all going away this week, they’re going on holiday abroad and it’s like (pause) they just get on with their lives really. I suppose in a way I’m not, I’ve stopped.

1 of 21 coded segments

**Home/Housing**
“It was in a really bad area where there’s always cars getting burnt and pinched and always the police there and stuff like that and I literally hated it from the day I put my foot in there I just, I couldn’t make it my home so I just buried myself in the bottle which was my best friend till like last July.

1 of 14 coded segments
Appendix 6:
Example of One Theme & Meta Themes from Service User Narrative

**Social/Contextual**

**Spirituality**
“Because I’m a Christian as well, because of my faith, I get a lot of prayer and things from church and so you know I pray to myself as well so I feel like I’ve like a healing in my mind.”

“I was involved with the church and that gave me something that gave me something I suppose to aim for.”

2 of 4 coded segments

**Work**
“Only factory – monotonous stuff – but gets you out and a pay cheque at the end ...I would like to do some voluntary work at some point, soon I think even if it is only a couple of hours a week.”

“I couldn’t concentrate, I couldn’t hold down work or anything like that you know so I had to give up work.”

2 of 14 coded segments

**Isolation/Loneliness**
“No I just didn’t feel anything; I didn’t have any emotion at all. I didn’t interact with the children; I didn’t want to know anybody. I just enclosed within myself. I didn’t want to go out, didn’t answer the phone, just couldn’t talk to people at all. I just isolated – and I live in isolation I just totally cut myself off.”

“Then one of my friends found out something about me and he just didn’t want as much to do with me. I’d say hello but he’s not the same sort of friend he used to be and that hurt you know. I thought the one person I could rely on as a friend sort of thing and he didn’t - that hurt – and that point I again was going to kill myself.”

2 of 11 coded segments

**Relationships**
I mean, hugs, they mean such a lot and it was just nice to hug. I mean, I don’t know whether, obviously you’ve experienced mental health, but you tend to build up a barrier as well and keep people away and that’s what I’ve done. I mean at first it was really difficult giving yourself to somebody and you got this brick wall up there and I think that’s what hurt me more than anything because you drop that brick wall down and let somebody into your life and then it kind of finished and that’s quite hurtful and that didn’t help like I say. That just put the tin hat on all the other stresses that I got in my life and just pushed me over really.

1 of 10 coded segments
Appendix 7: FACTORS FOR SUCCESSFUL INVOLVEMENT

Throughout this 4 year process we have identified key factors which need to underpin any type of service user involvement if it is to be meaningful and go beyond a tick box agenda.

- **Individuals need to feel valued**
  The following areas need to be considered:
  - A welcoming physical environment
  - An opportunity to contribute
  - A choice of whether to be involved and how much
  - Acceptance of personal difference in all its manifestations
  - Support Systems- A knowledge that both professional and peer groups exist and are easy to access.
  - Integrity and shared values- An understanding and a belief in the purpose of the involvement ‘activity’. A person within that activity that can act as a mentor who has values and vision that matches yours.

- **Challenging**
  Involvement needs to be a positive challenge. This means:-
  - It is challenging enough to take me out of my comfort zone
  - It needs to demonstrate respect and not be patronising. The belief that because we are service users we can do everything is patronising...We cannot – to believe that everything will be possible solely because of our lived experience is flawed thinking. It has the potential to put people in failure situations whereby recovery is hindered by unrealistic expectations that further damage the self. Honesty and integrity are required at all stages of involvement in order to build a realistic appraisal of self. And its ok NOT to do things too!
  - No use being romantic about involvement when really being involved is hard work

- **Genuine Equality**
  - Being involved means needing to acknowledge and not deny the power issues that naturally arise
and work with them openly and honestly.
- Equality is about having all the information and knowing what is expected of you so you can make choices.
- In order to feel equal you need to feel safe. This requires training/networks that value and supports and does not discredit or patronise you.

• **Fun**
  It has to be enjoyable in order for the commitment to be sustained otherwise it becomes a duty and it no longer has a benefit for that individual.
  - There needs to be an opportunity for shared humour...whatever the involvement entails.
  - And there needs to be biscuits!!!!!!! ...N.B The small things matter!!!