

# rethink



## Getting back into the world

Reflections on lived experiences of recovery

**Rethink recovery series: volume 2**

## Contents

<b>Summary</b>	<b>3</b>
<b>Introduction</b>	<b>5</b>
<b>Study design and methods</b>	<b>7</b>
Methodology	7
Research design	7
Recruitment of involvement researchers	7
Training of involvement researchers	7
Recruitment of research participants	8
Interview process	8
Analysis	9
<b>Participant profiles</b>	<b>11</b>
Involvement researchers	11
Research participants	11
Matching involvement researchers and participants	13
<b>Findings</b>	<b>15</b>
Contextual recovery themes	15
Basic and material needs	15
Stigma and isolation	16
Relationships	17
Receiving support	20
Treatments	21
Summary of contextual themes	26
<b>Personal recovery themes</b>	<b>27</b>
Identity and self-awareness	27
Taking responsibility	29
Self-management and resilience	31
Having a purpose and belonging	35
Spirituality and cultural wisdom	36
Summary of personal themes	39
<b>Recovery mediators: bringing the contextual and personal together</b>	<b>40</b>
Acceptance	41
Locus of power and control	42
Dependence, independence and interdependence	44
Summary of recovery mediators	44
<b>Conclusions</b>	<b>46</b>
<b>References</b>	<b>47</b>
<b>Appendix A: Interview schedule</b>	<b>48</b>

## Foreword

This report is part of Rethink's programme of work on recovery and focuses on the experiences and perspectives of people facing the challenge of recovering from mental illness. It involved an innovative model whereby Rethink's research team worked in partnership with seven people with personal experience of mental health problems and treatment who interviewed 48 people with similar experiences across England. AstraZeneca has provided a sponsorship grant towards this independent programme.

Rethink are proud to produce this report which summarises what we found. The study focuses on the person with mental illness in their daily life to understand recovery. It looks at how individuals are equally dependent on personal resources as well as opportunities and supports available in their environment to navigate their own 'recovery journey'. The report describes how recovery may look like and be possible for people who experience persistent or recurring mental health problems. We hope that the findings may be useful to people with mental health problems as well as those in supportive roles, reminding everyone involved in mental health of the opportunities as well as obstacles that can be provided or reduced to assist the work on recovery.

This project has been hugely important for the Rethink research team. It has been a very enjoyable, stimulating, challenging and rewarding experience working in partnership with service users to produce this report. We hope others also find it useful.

### Paul Jenkins

Chief Executive, Rethink  
October 2009





## Summary

This research report from a study involving in-depth interviews with 48 people describes what made mental health recovery possible given particular circumstances and conditions.

As part of the Rethink research team seven involvement researchers, who had personal experience of mental illness and psychiatric treatment, have led the interviews and the write-up of findings. The research process involved seven stages allowing integration between data analysis and personal experiences prioritised through collective agreement:

1. Group construction of themes and structure for the interview guide
2. Reflexive exchanges through dialogue about experiences during interviews
3. Involvement researchers writing post-interview personal reflexive notes
4. Thematic analysis of interviews drawing on the reflexive notes
5. Group construction of analytic framework identifying key themes
6. Involvement researchers identifying data for themes and including personal reflections
7. Group validation and edit of collated write-up of themes

The 48 study participants were recruited from across England. Participants represented age groups from 18 to above 65 years and there was a balanced gender representation. The significant majority described themselves as White British. The participants all had substantive experience of mental health problems and treatment, and 64% reported they had had a diagnosis of severe mental illness.

The analysis identified ten key themes of importance in shaping the individual recovery journey. These could be broadly grouped in themes describing issues in the context or external environment, and themes that were of a personal nature.

### Contextual recovery themes:

**1. Basic and material needs:** Recovery crucially depends on issues such as secure accommodation, financial freedom and certainty, and basic human rights and being a citizen.

**2. Stigma and isolation:** Prevailing societal perceptions and attitudes impact on the person in recovery. Stigma blocks recovery and leads to a low mood and isolation.

**3. Relationships:** Positive relationships where the person feels supported and encouraged are essential to give the person the confidence to move

forward. The challenge for people in recovery is to distance themselves from negative relationships, while building and nurturing supportive relationships.

**4. Receiving support:** It is essential to engage with people to receive support when unwell. Mental health professionals are required to take a human approach. Mutual and informal support networks can play a critical role in maintaining recovery.

**5. Treatments:** Psychiatric hospital was described as a negative experience, although some felt that it had been necessary at the time. Medication was by most considered an essential part of their treatment, but one that should not stand alone: the right type/dosage and personal choice were highlighted. Talking therapies were described as an important part of the treatment package.

### Personal recovery themes:

**6. Identity and self-awareness:** Recovery involves experiencing a greater sense of self and confidence in one's own identity. This involves issues such as understanding the illness and developing relationships and social roles to support personal growth.

**7. Taking responsibility:** Participants described the importance of themselves taking an active role to engage in recovery. This can be frightening, and it is important to have personal incentives and adequate support in the process.

**8. Self-management and resilience:** It is important to develop knowledge of personal illness triggers and to learn from others – coping strategies can be very individual. Living through longer periods of wellness builds resilience and confidence in recovery.

**9. Having a purpose and belonging:** Being part of something bigger and being recognised by others is essential. Too much pressure can have a negative effect – important to find roles and challenges that are appropriate given individual circumstances.

**10. Spirituality and cultural wisdom:** For some, feeling close to God or using spiritual techniques could be a source of comfort and help put the mind

at rest. Finding the right level of involvement with spiritual issues is important, but rarely professionals offer support in spiritual matters.

Further data analysis identified three recovery mediators highlighting ways in which contextual and personal factors work together, and the importance of the actual situation for and resources available to the person. The recovery mediators describe the dilemmas and challenges of daily living that meet the person in recovery, presenting a range of options as to how contextual factors and personal preferences may be combined to suit the individual situation.

**a. Acceptance:** It is crucial that the person feels accepted by others and finds a way to accept themselves and their condition in order to progress towards recovery.

**b. Locus of power and control:** Mental illness often leaves the person feeling deprived of any sense of having control over their own lives. Recovery involves (re)gaining this, often by starting small through developing self-management techniques.

**c. Dependence, independence, and interdependence:** Often people with mental illness feel dependent on others and on treatments. Finding a balance between regaining independence and recognising interdependency is essential to recovery.

Recovery is neither something done to the person nor something that can be achieved by the person in isolation. It is about how the person relates to their environment and the role and opportunities that the environment allows for the person. Recovery happens in the space in-between person and context: personal relationships, physical space and other economic, social and cultural factors.

This project has afforded the team time to work together on understanding the 48 narratives. The interactions between participants have been crucial in shaping this project which used an innovative methodology to explore recovery. We hope the material presented here will be useful to other researchers. It has certainly been an important project for us at Rethink.

## Introduction

This report presents findings from a study examining how people find ways to better live with persistent or recurring mental health problems. The perspective is based within an emerging research and theoretical literature around the concept of 'recovery'. The study and this report has been produced in collaboration with seven people with personal experience of mental illness and psychiatric treatment.

Recovery from mental illness has attracted increasing attention since the publication of personal (service user, patient, consumer, client or survivor) accounts in the 1980s (e.g. Anonymous 1989; Deegan 1988). The concept challenges the view on psychiatric diagnoses such as schizophrenia as necessarily chronic and degenerative illnesses (Bentall 2003; Boyle 1990). Instead, there is now a more optimistic attitude (Lieberman et al. 2008), supported by antipsychotic medication (Mossman and Lehrer 2000) and improved therapy and support (Larsen 2007; Slade 2009).

Recovery research has taken two overall directions: 1) illumination of personal experiences of and views on the course of recovery from mental illness and 2) the identification of prevalence and course of recovery as described by specific clinical outcome measures. The latter line of research has established that recovery from severe mental illness, such as schizophrenia, does happen either completely (15-26%) or in part (50-75%) for the majority of people diagnosed (Jablensky 2009; see also: Harding et al. 1987; Whitehorn et al. 1998). Cross-national research suggests that the recovery outcome is likely to be significantly influenced by the social and cultural environment (Isaac et al. 2007; WHO 1979).

The clinical outcome research is supported by research documenting and systematising the experiences and perceptions of the people who are recovering from mental illness. But the research on people's experience of recovery also challenges medical notions of recovery as meaning simply cured or free of symptoms and/or medication (Diamond 2006; Whitwell 1999). It has been described as the difference between notions of 'personal recovery' and 'clinical recovery' (Slade

2009). They are different in that it is possible to experience personal recovery while still having recurring psychiatric symptoms, such as hearing voices. For this reason, some prefer the notion of 'being in recovery' with emphasis on the process and ongoing work, over the static idea of 'having recovered'. Personal recovery from mental illness describes the way in which a person is living and dealing with their mental health problems without being overwhelmed and dominated by these.

The Scottish Recovery Network provided a rich research portfolio documenting the many different ways in which people may experience recovery from mental illness (Brown and Kandirikirira 2007). Although this individual variability is widely recognised (Lieberman et al. 2008), empirical research based on people's own accounts has sought to describe recovery as a journey involving specified components and stages. A review (Andresen et al. 2003) identified four key component processes of recovery:

- Finding and maintaining hope
- The re-establishment of a positive identity
- Finding meaning in life
- Taking responsibility for one's life

The same team of researchers (Andresen et al 2006) also looked at studies examining phases in the recovery process which suggested five stages:

- **Moratorium:** A time of withdrawal characterised by a profound sense of loss and hopelessness.
- **Awareness:** Realisation that all is not lost, and that a fulfilling life is possible.
- **Preparation:** Taking stock of strengths and weaknesses regarding recovery, and starting to work on developing recovery skills.
- **Rebuilding:** Actively working towards a positive identity, setting meaningful goals and taking control of one's life.
- **Growth:** Living a full and meaningful life, characterised by self management of the illness, resilience and a positive sense of self.



This existing evidence on the process of recovery describes it as ‘an individual journey’ with an emphasis on self-management skills. However, the role of social, cultural, therapeutic and psychiatric factors and interventions to either aid or hinder this journey and skills development process are less well documented. Research designed to further critically investigate these links and interrelationships is essential in order to identify the role of contextual factors and avoid ‘recovery’ merely becoming a fancy catchphrase to gloss over a fundamentally unchanged or reduced provision of mental health services (Hopper 2007, Johnson 2004).

The study reported on here is placed in the tradition of ‘personal recovery’ research, and we put a positive emphasis on how things may work for people in different circumstances (rather than what doesn’t work!). Actively drawing on people’s lived experience of mental illness throughout various stages of the study we have sought to make visible the particular contexts and circumstances that

people felt as either enabling or hindering their recovery journeys. As such, the report and the findings are presented from the perspective of people themselves, supplementing publications on recovery written primarily for mental health professionals (e.g. Slade 2009).

Recovery can only be driven by the person themselves. It is not something that can be ‘done to’ anyone. We hope that the findings will be relevant for people who feel overwhelmed by mental health problems and are struggling to believe that recovery can be possible for them. The findings may provide inspiration and encouragement to make best use of individual circumstances and opportunities to work towards personal goals. Equally, we hope that people in supportive and caring roles will find the report useful by presenting the challenges and dilemmas people living with mental illness face when embarking on a recovery journey, and the important roles they take in supporting this – allowing people to get back into the world.

# Study design and methods

## Methodology

The study uses qualitative research principles of participation and investigative exploration to gain in-depth understanding. An innovative aspect was the way in which the study sought to optimise the contribution that reflexivity could make to understanding mental health recovery, by drawing on lived experiences. Taking a partnership approach to service user involvement (Trivedi and Wykes 2002), the central resource for the project was seven involvement researchers, who had personal experience of mental illness and psychiatric treatment. Rather than merely 'collecting' individual narratives and analytically mapping these to identify recurring themes, communalities and differences, the study instead engaged the research team in reflecting on what made recovery possible or impossible given particular circumstances and conditions.

This approach was encouraged through sharing experiences and commenting on particular circumstances for change – seeking to get beyond a mere description of particular events to an understanding of what actually happened. In contrast to reflection, reflexivity is not only concerned with 'thinking about', but also describes the impact this has on people and the direction the change may take (Giddens 1991; Riach 2009).

## Research design

The study involved 48 in-depth interviews with people with personal experience of mental illness, conducted and analysed by a team of seven researchers who also had personal experience of mental illness and were trained and supported by the Rethink Research Department.

## Recruitment of involvement researchers

Essential requirements when recruiting were that the applicant should have personal experience of mental illness and mental health treatment. Experience of and interest in research were considered desirable, and ability to work as part of a team was considered essential. Variation was sought in terms of gender. Participants were sought to be spread across England to allow close proximity to carry out local interviews. A total of seven people were recruited,

and all seven have remained involved throughout the research and write-up process.

Involvement researchers were paid per hour based on the current starting rate for a research officer in Rethink. Our approach recognised the importance of appropriate financial reward for involvement work (Hamilton 2009). Paid hours for specific tasks were always clearly presented in advance to ensure that involvement researchers were aware of the level of input expected and the limit to which they would be financially rewarded for their contribution. If individuals spent additional hours on a task it was considered a voluntary contribution.

## Training of involvement researchers

The research team took part in a six-day training programme led by an experienced mental health survivor training and research consultant (Alison Faulkner) and supported by two Rethink researchers (Sarah Ajayi and John Larsen). The first four days of the training programme (run over two weeks) included: introduction to the research project, discussion of the research topic and development of an interview schedule, interview skills and reflexive practice, and clarifying support needs and supervision. The course was delivered through a combination of tutorials and practical and role-play exercises. Social activities following the training were arranged to encourage bonding within the team.

During training, the team revised an earlier draft interview guide developed by a group of four people with personal experience of mental illness (two of whom were also part of the team of seven). The interview guide was refined through discussions about personal experiences of mental illness and ideas around recovery. It was constructed in a way to explore participants' experiences and perspectives, moving from open to more focused questioning. In particular, we were mindful to avoid starting by simply asking 'how do you understand recovery?', which would have limited the data to an examination of the particular word. To generate data and insight grounded in people's lived experiences we instead first explored aspects of people's lives relevant to living with mental health problems.

The interview guide contained these key sections (see details in Appendix A):

- Perception of self in relation to mental health
- Turning points
- Important people
- Helpful and unhelpful things
- Ideas of recovery
- Representations of recovery
- Personal gains and achievements
- Recommendation to others
- Reflection on the interview itself

Additional two days of training included role play practice interviews, group discussions and practical preparation in advance of the interviews taking place.

Ethical approval for the study was secured via the NHS National Research Ethics Service (NRES).

### Recruitment of research participants

The study sought to include a range of different experiences of and perspectives on mental health recovery across England, while applying a predominantly opportunistic sampling strategy. A study information leaflet was distributed through mental health charity networks advertising for participants. The involvement researchers were also active in promoting the study through their local and personal networks. Particular attention was given to recruit participants across different English regions. It was also sought to achieve representation of people of different ethnic background – although attempts at targeted recruitment through BME groups did not generate much interest.

Prospective participants contacted via telephone the Rethink researcher (SA) who provided information about the research and what taking part would involve. The conversation established whether the participant had direct experience of mental health problems and had used medication as part of a treatment package for mental illness, seeking to include people with a range of psychiatric diagnoses and experience of a range of treatment options.

No other specific inclusion criteria were used. If interested in taking part, prospective participants were sent an information and application pack. On occasion this was followed by further conversations to clarify information on or provide reassurance about the interview setting. Prior to the interview all participants returned a signed consent form and a questionnaire for basic sociodemographic and mental health experience profiling.

### Interview process

The practical arrangement of the interview was organised by the Rethink researcher (SA), who also ensured that the researcher was not personally acquainted with the participant (in which case another involvement researcher would be assigned to conduct the interview). Interviews were hosted within Rethink services or the Rethink Head Office, or occasionally an external mental health organisation. A local Rethink worker or other mental health support worker was available on-site to support both the involvement researcher and the participant. In addition, a Rethink researcher was available via mobile. The first one or two interviews were conducted by involvement researchers in pairs for peer support. As confidence rose and techniques became proficient, researchers conducted one-to-one interviews alone, with the support from the designated support worker available outside the interview room, but in close proximity.

To start the interview the researcher explained the project information sheet, and written consent was obtained (again) to make sure that people did not feel under obligation to participate and that they were still willing to take part. Interviews lasted between 1 and 2 hours, and some took place over two sessions, allowing for a short break if that was felt needed by the researcher or participant. Researchers were sensitive to the need for the interview to be comfortable for the interviewee as well as the interviewer. The interview guide covered themes of a sensitive nature, some of which could be uncomfortable to address for some people, so care and consideration was given to providing a supportive environment to participants.

After the interview the researcher recorded key points from the interview and their reflections on how the information shared by the participants might relate to their personal experiences and views. Some involvement researchers also kept more extensive personal diaries from the beginning of the study, where they reflected on their wider experiences of taking part in the study.

### Analysis

Data analysis principles of exploration and interpretation were used to actively engage with participants' experiences and insights. Analytical generalisations arose from reflexive insight, challenged and validated through group discussions and critical interrogation of the data. This reflexive co-construction of knowledge applied a radical approach to recognise richness in the subjectivity of lived experience. Validity was sought in critical examination from peers through dialogue and facilitated discussions.

Interviews were transcribed externally, and after being checked against the audio-recording for accuracy by a Rethink researcher (SA) they were sent to the involvement researchers. Each involvement researcher did a thematic analysis on the interviews they had themselves conducted. In identifying themes they were referring to their post-interview notes on key points as well as their personal reflexive notes. Initial guidance on doing thematic analysis was provided and experiences with applying this approach were shared during a team workshop day to address any queries or uncertainties. Revised analysis guidance notes were produced following this.

Having completed all data collection and thematic analysis the research team took part in a 2-day residential workshop where involvement researchers presented the analytic themes. All themes were written on individual Post-it notes that were stuck on a wall and arranged in overarching themes.



During this process extensive discussion ensured that the most relevant categories were applied and that no substantial themes were missed. The discussion also identified different categories of themes. The team was then split in two and each group discussed a category of themes and how the interviews they conducted provided data examples of key issues within each, providing a plan for writing up data. A Rethink researcher (JAL and SA) facilitated each of the groups.

After the workshop involvement researchers continued examining their individual interview transcripts to identify quotes relating to themes within the general category and they wrote short texts explaining the analytic point addressed by each quote. Where relevant their own personal experiences and reflections were added to either further substantiate or challenge particular points identified. These analytic texts were sent to a Rethink researcher (SA) who collated the material with quotes from all the researchers in a joint document, structured under thematic headings.

The collated joint analysis document was sent to all researchers in advance of a second 2-day residential workshop. Researchers made notes on how points raised by other researchers were either contradicted or substantively elaborated by the interviews they had conducted or their personal experiences, backed up by specific examples and quotes. During the 2-day workshop the researchers went into the two groups established on the previous workshop to work through, edit and elaborate the write-up of individual themes, facilitated by Rethink researchers. To provide a critical distance and increase the co-construction and validity of findings the groups exchanged themes, so that they worked on themes they had themselves not been involved in drafting initially. After a joint discussion of mediator themes, which cross-cut and combined the ten key themes, these were equally written up by the two working groups.

The resulting findings section was subsequently reviewed by a Rethink researcher (JAL) for language and structure, and a draft was circulated via email to the research team to incorporate comments and corrections before finalising. Feedback received on preliminary findings from three conference and seminar presentations to audiences of academics and service user researchers assisted developing the clarity of presentation.

In overview, the reflexive process involved seven stages each allowing a higher level of analytic synthesis and integration between personal experiences and themes prioritised through collective agreement:

1. Group construction of themes and structure for the interview guide
2. Reflexive exchanges through dialogue about experiences during interviews
3. Involvement researchers writing post-interview personal reflexive notes
4. Thematic analysis of interviews drawing on the reflexive notes
5. Group construction of analytic framework identifying key themes
6. Involvement researchers identifying data for themes and including personal reflections
7. Group validation and edit of collated write-up of themes

## Participant profiles

### Involvement researchers

Seven people with personal experience of mental illness were recruited to take part in the study as involvement researchers. Two of these had been part of a team of four who were recruited in the summer of 2007. The other five were recruited in the spring of 2008. Within the team, some people had prior research experience, as both participants and researchers, others had experience of coordinating and leading self-help groups, working in supportive ways with other mental health service users.

The involvement researchers had extensive experience of mental health problems and receiving support and treatment for these. It was between 11 and 31 years since they had received their first psychiatric diagnosis, and they had received a range of different diagnoses, as indicated in figure 1. As is

commonly the case, for a number of people these diagnoses had been revised and changed over the years as the person's circumstances and conditions fluctuated – which explains why there are more diagnoses than people.

In addition to these formal psychiatric diagnoses, as indicated by the 'other' category, involvement researchers identified a number of additional diagnoses that they at different points in time felt most accurately described their conditions. These were: addiction, mood disorder and self harm.

### Research participants

An opportunity sample of 48 people with experience of mental illness took part in the study as interview participants. As shown in table 2, the group was diverse in most respects except regarding ethnicity,

**Table 1: Demographic overview of involvement researchers**

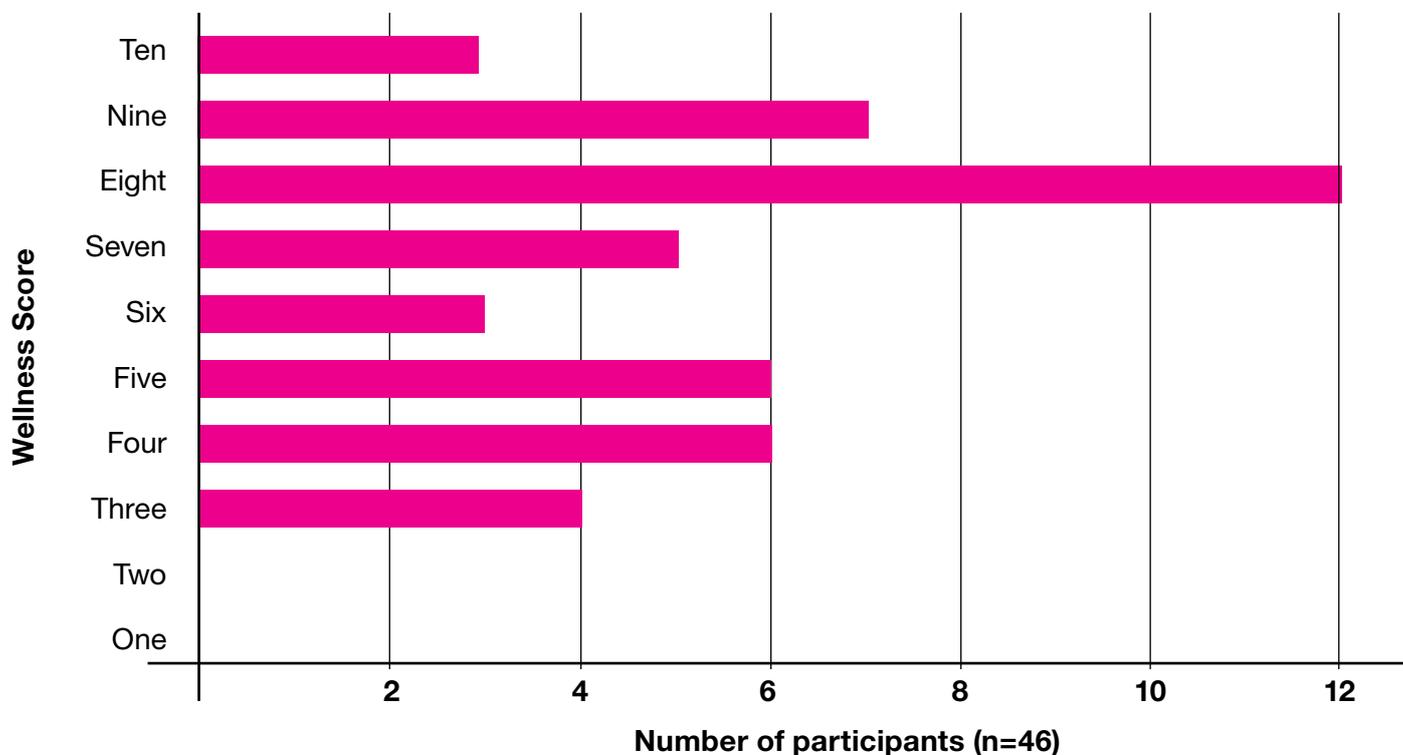
Involvement researcher	Gender	Age group at recruitment	Ethnicity
A	Female	55-64	White British
B	Male	25-34	White British
C	Male	45-54	White British
D	Female	25-34	White British
E	Female	45-54	White British
F	Female	35-44	White British
G	Male	45-54	White British

**Figure 1: Involvement researchers' mental health diagnoses**



Table 2: Profile of participants (n=48)

		Number of participants	Percentage of Participants
<b>Gender (n=48)</b>	Female	26	54%
	Male	22	46%
<b>Age group (n=48)</b>	18-24:	3	6%
	25-34:	6	13%
	35-44:	11	23%
	45-54:	16	33%
	55-64:	9	19%
	65-74:	3	6%
<b>Ethnicity (n=48)</b>	African	1	2%
	Asian	1	2%
	Black British / Caribbean	1	2%
	White British	43	90%
	White Other	2	4%
<b>Region (n=48)</b>	London	12	25%
	South East	5	10%
	South West	15	32%
	Eastern	4	8%
	North West	12	25%
<b>Diagnosis (n=47)</b>	Bi-polar	20	43%
	Depression	17	36%
	Anxiety	17	36%
	Schizophrenia	10	21%
	Schizo-Affective	5	11%
	Eating Disorder	7	15%
	Personality Disorder	7	15%
	Dual diagnosis	1	2%
	Other	6	13%
<b>Ever had a diagnosis of SMI (severe mental illness)? (n=47)</b>	Yes	30	64%
	No	17	36%
<b>Ever used medication to manage mental illness? (n=47)</b>	Yes	45	96%
	No	2	4%
<b>Lives alone (n=47)</b>	Yes	20	43%
	No	27	57%
<b>Marital status (n=45)</b>	Married	11	24%
	Widowed	3	7%
	Separated	2	4%
	Divorced	4	9%
	Cohabiting	5	11%
	Single	20	44%

**Figure 2: Participant self-rating of wellness (n=46)**

as only 5 (10%) were not White British. Participants were drawn from across different regions in England representing a good geographical spread. Just over a third came from the South West region, and a quarter were drawn from London and the North West region.

Participants had a wide variation in experience of mental illness. Similar to the involvement researchers, several people reported the experience of multiple conditions and changing diagnoses on their personal journeys. The most frequently reported mental health diagnosis was bipolar, followed by anxiety, depression and schizophrenia. The person with highest number of diagnoses reported six different types.

Prior to the interview, participants were asked to self-rate their wellness on a scale from 1 to 10 (1 being unwell and 10 representing very well). Most people rated themselves as feeling well (mean score: 6.8, median score: 7). As illustrated in figure 2 one in four (n=12) participants self-rated as 8, three people rated themselves as 10 and four self-rated as 3, which was the lowest rating.

### Matching involvement researchers and participants

Central to our interpretive and reflexive methodology was the active engagement of involvement researchers with the research participants, sharing and challenging experiences and perceptions. The interviews were constructed as a forum for people to talk about their experiences openly and in their own way as well as 'giving something back', which was frequently mentioned by participants during interviews. Each researcher carried out between 6 and 9 interviews with people who had a range of personal and mental health experiences – see tables 3 and 4.

Variation in experience allowed increased opportunity for learning from others' experiences and critical reflection on how mental health recovery was shaped given particular individual circumstances and contexts.

**Table 3: Participant profiles as matched against involvement researchers**

	Interviews conducted	Gender of participant	Ethnicity of participant	Age range (years)	Regions covered
<b>Researcher A</b>	7	Female: 5 Male: 2	White British: 5 African: 1 Anglo-Irish: 1	35 - 64	South West: 4 London: 1 South East: 1 East: 1
<b>Researcher B</b>	6	Female: 1 Male: 5	White British: 5 White European: 1	25 - 64	South West: 6
<b>Researcher C</b>	7	Female: 4 Male: 3	Black British: 1 White British: 6	25 - 54	London: 2 North West: 1 East: 3 South West: 1
<b>Researcher D</b>	6	Female: 3 Male: 3	White British: 6	35 - 64	South East: 1 London: 5
<b>Researcher E</b>	7	Female: 3 Male: 4	White British: 7	18 - 54	South East: 2 South West: 5
<b>Researcher F</b>	9	Female: 5 Male: 4	White British: 8 British Jewish: 1	18 - 74	North West: 9
<b>Researcher G</b>	6	Female: 5 Male: 1	White British: 4 Asian: 2	25 - 64	London: 4 North West: 1 South East: 1

**Table 4: Participant diagnoses as matched against involvement researchers**

Diagnosis of participants	Involvement researchers						
	A	B	C	D	E	F	G
<b>Anxiety</b>	3	3	1	2	1	3	4
<b>ADHD</b>	-	-	-	-	1	-	-
<b>Bipolar</b>	5	2	3	2	2	5	1
<b>Depression</b>	3	2	1	2	1	3	5
<b>Eating disorder</b>	2	-	1	2	1	1	-
<b>Personality disorder</b>	2	-	-	2	2	-	1
<b>Schizoaffective disorder</b>	1	1	1	-	-	-	2
<b>Schizophrenia</b>	1	4	1	1	2	-	1
<b>Dual diagnosis</b>	1	-	-	-	-	-	-
<b>Other</b>	-	-	-	1	2	1	1

## Findings

Ten key themes emerged from the data, describing different areas of the person's situation and life orientation impacting on individuals' experiences of mental health recovery. They could be loosely grouped in two clusters: those that primarily concerned the situation or context for the person and those that were of a more personal nature.

### Contextual themes:

1. Basic and material needs
2. Stigma and isolation
3. Relationships
4. Receiving support
5. Treatments

### Personal themes:

6. Identity and self-awareness
7. Taking responsibility
8. Self-management and resilience
9. Having a purpose and belonging
10. Spirituality and cultural wisdom

The ten themes were written up in a collaborative effort involving all the researchers during workshops based on data examples provided by the involvement researchers. Rather than simply seeking an answer to the question 'what is recovery?' the study details how individuals have found ways to overcome or live with their mental health problems, drawing on contextual and personal resources.

## Contextual recovery themes

The five contextual recovery themes are presented by drawing on quotes from the interviews and analytic reflexive notes from involvement researchers to illustrate their importance in respect to mental health recovery. Each quote is referenced by providing a bracket with the interview identifier and the line numbers in transcript. At the end of the section there is a summary of key issues emerging from each of the five themes.

### Basic and material needs

Having a place to live and secure finances are both basic to recovery. Getting these issues sorted out were vital in the recovery journey for some participants who had experienced homelessness and rough sleeping. For some, the first step was being offered supported housing. However, this was sometimes problematic because other people's behaviour might interfere with their own recovery; for example, noise, money being stolen, or feeling physically vulnerable.

I cannot over stress the importance of giving people somewhere to live that is their own; where they are free from harassment from other people they're living with and from staff. (RGS04, 156-160)

One man mentioned how having his own space is a sanctuary for him:

I'm quite sensitive to different things. I like being around people, getting out and doing things. But I also find it really helpful to be able to just sit somewhere quiet – to be in my own space; a space where I can just wind down from things and process stuff. (TB02, 316-337)

Secure accommodation provides a basic sense of feeling comfortable and secure, but also a feeling of control and being in charge of your own life, as illustrated in this extract from an interview between the interviewee (I) and the researcher (R):

I: Definitely finding accommodation, secure accommodation. The place I was in before I had problems with neighbours, the heating system broke down – no hot water. And finding the flat, you know, my own space – dry and comfortable, has made a difference.

R: Why do you think having your own space has changed things for you?

I: For me this is about control. When you have your own place you are in charge – you pay the bills and manage your spare time within your own environment. (RAS01, 633-633)

Several participants described how having good quality, secure accommodation was helpful to their recovery, and often were felt to have a direct impact on their mental health problems.

I'm happy having my own place with a bedroom, living room. ... All my psychotic symptoms dissipated totally when I got my place, and have never come back. (RGS04, 147-152)

Having your own space and being able to decide who enters through the front door gives independence and some control over who to engage with. One woman, who had previously shared supported housing, described how having her own front door enabled her to choose her social contacts, rather than having to mix with people who might be physically threatening, or detrimental to her mental health in other ways:

I quite like having my own space. I decide who I let in, who I don't let in. (RGS04, 128-129)

Money is another basic need. Getting the benefits you are entitled to and having a safe place to keep money helps people to take control of their life. Getting such practical things sorted out is crucial to enable people to embark on the road to recovery. For one participant the mental health worker had been helpful in achieving this:

Getting practical things sorted... [that was] help that I really needed. Once you get it together on a practical level, then everything else sort of falls into place a little bit more (RGS04, 645-649).

Participants stressed how their recovery was supported by basic human needs and rights, such as being a parent and being able to take care of their children:

My little boy... him being at home, him being happy and healthy... that proves to me that I'm in recovery, I can look after him, I can bring him up, I can have him at home with me. (RAS01, 947-959)

## Stigma and isolation

Several research participants felt that their mental health issues had brought with them a social stigma, arising from views generally held in society and people's fears of mental illness. Sometimes they were aware of others rejecting them directly; often they developed an internal sense of shame. One person who was diagnosed with schizophrenia felt it came with very negative connotations.

I'm sure there are people who really have a different view of you once they've heard that word [mental illness]. They just see you in a different light. (TB03, 1255-1283)

Consequently, feelings of isolation were a major problem for many people, leaving them feeling stranded on the margins of society.

I don't have much of a social life... I get quite down sometimes. Loneliness and stuff, I suppose... It would be good to have closer friends, you know, people to just hang around with and go places. I usually go to places on my own. (TB05, 39-41, 529-533)

One person stated:

I'm not very good at friends. (RAS05, 547)

When loneliness becomes habitual – for example during depression – a deeper sense of isolation may occur. Participants referred to the difficulties in establishing the small daily contacts that most people would take for granted. One talked of people 'living in boxes'. She explained:

We're losing the ability to communicate with other people and it brings isolation... it was the year before I attempted suicide... I was really kind of clinging onto the edge of the world. (RAS02, 942-948)

This profound sense of isolation, linked with the stigma attached to mental illness, and often linked to the breakdown of significant relationships with family or friends, has a different quality to loneliness or just being alone. For some, isolation can mean being totally cut off from human contact and this can in itself have further impact on someone's mental health. One participant linked this isolation to suicidal feelings, commenting:

My life wasn't worth living and I think before that I was often quite isolated. (RAS02, 193-197)

Such isolation, linked with mental illness, can hold people back from joining with groups or in activities that might be helpful to sustaining them or contributing to their recovery. Some people, when they are mentally unwell, feel such a sense of disconnection that they are unable to reach out to other people. One man, normally friendly and sociable, experienced depression as causing a radical change in his behaviour.

*When you're depressed, [at] my worst, I felt totally alone. You know, there's nobody... and disconnected from people. (AH05, 946)*

However, he recognised that being on his own isn't good for him, and causes isolation. One researcher (A) had similar feelings when she was ill. She felt cut off from others, as though she was in a glass bubble, mentally 'in her own world'. The stigma and fear that lead other people to ostracise those with mental health issues can contribute to a vicious cycle of isolation. Some people talked of deliberately cutting themselves off from others as a coping strategy.



The strategy of isolation can be a way of not having to relate to others when symptoms are very severe, and therefore not allowing the possibility of being rejected.

*I think one of the biggest things that has helped me is [that] I isolated myself for maybe a year in the house. I watched TV, but I didn't go out into society much... to try to make sense of what had actually happened to me. (TB04, 577-583)*

In the face of loneliness and isolation, building relationships with others is an important aspect of moving towards recovery. While isolation was spoken of as both a symptom and an effect of illness, gaining a sense of belonging to society or a community was mentioned by many of the interviewees as an aspect of recovery. A participant described how they over time had changed coping strategy from one of isolation to getting out among people.

*As soon as the voices started getting hard, I would isolate... and just really try and keep away from everyone. Now what I tend to do is, if they are getting worse, I try and get around people. (PJB03, 500-507)*

Seemingly small things can help lift isolation. This participant talked about how chatting to a neighbour or friend made a real difference to her daily mental health – just having a little human contact.

*The neighbours are nice, they come in for a cup of tea, sit outside in the garden. The last place I was in I was so isolated, no-one ever knocked on the door, no neighbours. (TB03, 130-139)*

## Relationships

Relationships play a complex role in the context of recovery from mental illness. Many research participants explained how relationships could be both helpful and unhelpful, in various circumstances, at various stages of recovery and with various people. Relationships are very important during recovery, but raise issues which are also linked to isolation, stigma and feelings of belonging. When a person develops a severe mental illness, even the most caring of families can feel frightened and unable to cope. Relatives and friends can feel left out of the discussions by professionals, because of confidentiality. They often don't know how they

can help and this can lead to them becoming stressed themselves. Some family members can be actively unhelpful by stigmatising or being very unsupportive, which can lead people to withdraw from the family network. One participant said this of her mother:

She can be very upsetting actually... you can talk about things but she doesn't really understand. She reacts in a way that's not so helpful and she suffers from depression herself... I mean, apart from speaking to her on the phone once a week, there's not much support, but then perhaps I don't really want it at my age. (TB03, 426)

Other participants felt that the family was trying to be supportive, but in a way that started to tip the balance of power and control of what they felt should remain their personal choices.

My parents were quite helpful from a distance... they were helpful in the beginning but towards the illness they became a bit disruptive and overpowering. They wanted to control everything by thinking: 'you are our son and we want you to get better'. (TB04, 996-1006)

The same participant described how he was able to manage the relationship with his parents by keeping them at a comfortable distance to safeguard himself and maintain self control.

Yeah, we get on ok. We don't communicate a lot but that's my way of holding my own turf and keeping my own sort of space. Because they are parents, once you let them in, they can flood in and take their position as parents again. I've distanced myself to give me a bit of freedom. (TB04, 996-1020)

But for some, being able to share their experiences and concerns with the family remains a core component of their recovery, as this participant explained:

I also think that's part of recovery. [It] is actually being able to open up to family as well. I think family is one of the hardest things. (AH04, 1286)

One participant, who had been isolated from his family, described how he had learnt to get the best from his relationship with his family. He decided to tackle his isolation by spending the next few Christmases with his family.

I spent Christmas here on my own. That was one of the worst Christmases I've ever spent. ... So I said 'you know what I'm going to do? I'm going to go home every Christmas' and for 2004, 2005, 2006 I went home. And it made a difference. (RAS04, 1938-1947)

While this pragmatic attitude to getting the best from existing relationships certainly was helpful for this man, research participants generally described relationships where there is mutual understanding and empathy as most supportive of recovery. People with their own lived experience can offer help and support to others who are going through similar hard times. Friends who are also mental health service users can show empathy and understanding and give non-judgemental support, all of which are vitally important to people's recovery. People can reclaim hope, by observing others who are further along their recovery journeys.

I love talking to other people... I've really learnt from meeting people with different diagnoses that we're all the same. All that's different is what we do, and how extreme we get. But I finally understand the symptoms and that's all due to your life and your life experiences. (AH04, 1975)

This participant finds her service user friends mutually very supportive, but they would also be aware not to overload each other. This is an important point, as it is possible to get exhausted when someone is ill and very demanding with time. Nevertheless, the understanding and unconditional support given when the chips are down is invaluable, the feeling of not being judged or dismissed. Other participants described how friends could suffer from overload if asked to listen and be supportive too often. One person described a strategy for managing the amount of support he asked of individuals, by increasing the number of people he knows:

The more people I know, the more I can spread my support around, rather than overwhelm the one or two people I know. And that way it works better for me as well. (AH06, 3232)

But often the challenge experienced by people is not to increase the number of people they know, but to retain the friends they already have. One of the researchers (B) experienced that his old friends broke with him when they found out he had a mental

illness, and he felt that he had been completely ostracised. When people become unwell, the process of continuing or discontinuing relationships sets in motion and can greatly influence the process of recovery. Not all relationships are beneficial: some can exacerbate illness rather than facilitate and forge positive, helpful relationships. Often people lose friends as a result of becoming unwell: because they can be seen as a burden or a nuisance. This participant chose to break from friends as he associated personal difficulties with the people around him. He explained:

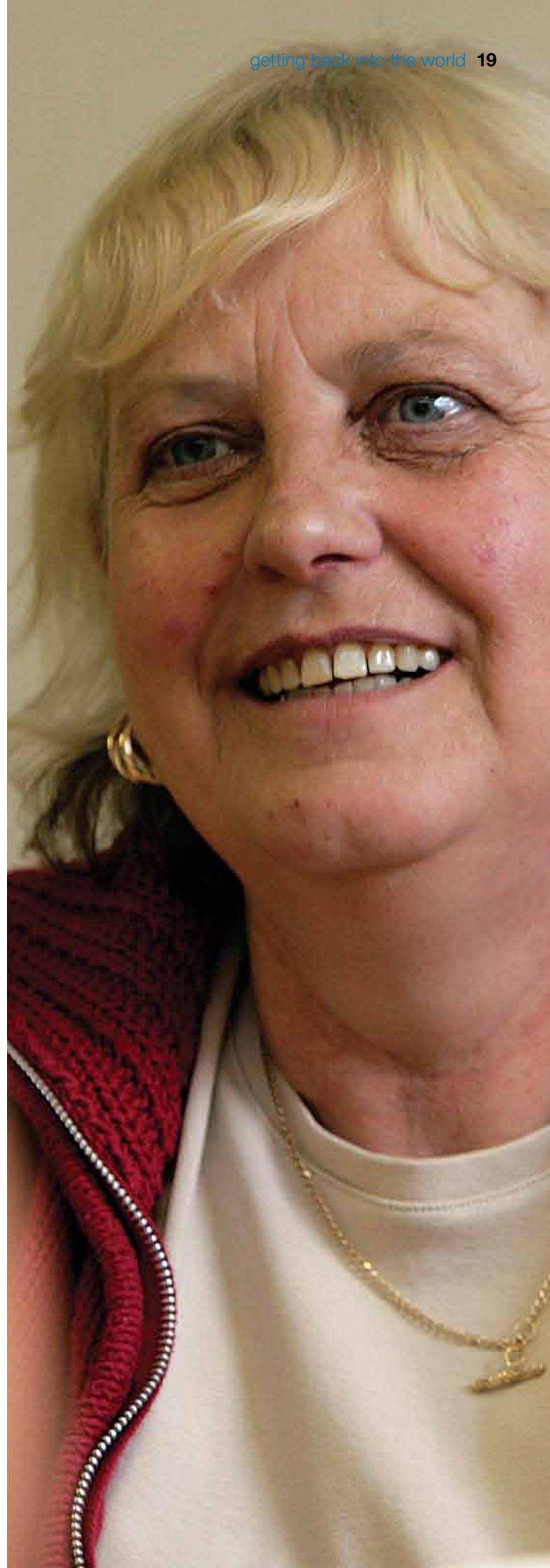
All my friends had imperfections really, and I felt like starting afresh. I just wanted to meet good people. A lot of my friends were nice people, but I just wanted to start meeting people that were really good. (TB04, 1073-1084)

Taking the decision to end a relationship and start again has been an important way forward for some people, but a step back for others. Whether the experience of continuity or discontinuity in relationships is helpful or not seems to depend on whether this is a personal choice or one that the person has no control over. One person talked of the role his friends played when he became unwell.

However much my friends had helped me, to some extent, they were actually holding me back. They were effectively... they'd got into the habit of treating me as ill, but expecting more from me despite that. (AH06, 553)

Making the break is not always about mental illness, but can be about establishing a sense of independence, which may also be related to taking responsibility for oneself. A few participants talked of needing to make a break from family. One person who did not have positive family support explained that for him, leaving home was a frightening step. However that step proved to be a vital turning point allowing him to progress, rather than remaining frozen in his past. He explained how breaking away from the family home had helped him start a new life mixing with others.

Changing... for the first time in my life... I did actually mix with people from all backgrounds... I was advised by a social worker to leave home. They said: 'its an oppressive atmosphere. You'll never do anything in life, you'll never mix socially, and your thinking will still be distorted'. (TB06, 550)



The most helpful relationships provide enduring practical and emotional support, also through difficult times. One person tried to explain the nature of such a relationship:

I think a lot of it is encouragement. It's just having some sort of deep friendship, some kind of relationship that you actually find positive. (TB03, 165-18, 276-282)

Drawing on his personal experiences, one of the researchers (B) emphasised the importance of this, and stated his belief that everybody needs at least one close relationship to remain mentally healthy in the long run. It is possible to be completely self-reliant and shut people totally out of your life, but eventually, loneliness sets in, and this can lead to further illness. The challenge is finding the right person – not an easy task – and to recognise the significance of interdependence.

### Receiving support

Receiving the right kind of support when unwell is crucial. The right support includes being listened to by caring and understanding professionals. Participants talked about appreciating professionals who treat them as individuals, tailoring their approach to each person's needs. Some have found it helpful to build supportive networks around them: a few close, reliable relationships. It is also vital that support can be accessed when needed, particularly during times of crisis.

People hope that their relationships with mental health professionals can be genuine and 'human'. Sometimes staff behave as if they are the only ones with knowledge and insight: they remain superior and detached. However, service users have a vast knowledge about themselves and their recovery journeys, and good professionals recognise and acknowledge this. Truly helpful relationships with professionals work best when there is a giving and sharing of power, knowledge and expertise. People who use services are fully aware when professionals are not really interested in them. Successful relationships with professionals are forged when the person is genuinely caring and considerate towards the service user; being prepared to go that extra mile and to work with the individual.

He [the psychiatrist] was lovely. I see so many over

the years... But this particular one, he really did care... And I think he looked upon us [his clients] as his friends (AH02, 773-4, 789-790)

The same participant commented on the importance of having continuity. A comfortable and trusting relationship had built up with their CPN (community psychiatric nurse), disagreements could be aired. The participant felt really supported by their CPN, whether the issues were emotional or practical.

[I've had the] same CPN for the last ten years, [he is] fantastic, is great. Available on call pretty much any day, any time. Wonderful! Will discuss things with me, will tell me off if he thinks I'm doing something wrong. I'll argue with him, we'll come to a compromise. (AH02, 1458)

It is of paramount importance that someone suffering from a mental illness feels they can talk openly about their experiences. The importance of being listened to was mentioned repeatedly throughout the interviews. One person spoke about the relief in talking to someone about the voices she was hearing.

It's nice to be able to talk about them [the voices] freely. And it takes away some of that fear. And it takes away some of their power. (PJB03, 461-465)

It is very important for people to be able to access instant support when they are unwell or in a crisis. This may be by phone; a conversation and advice can help enormously.

I can say the Samaritans have been there for me, more than once. ... I call the Samaritans my invisible friend. (RAS04, 767-772, 1293)

One participant talked about receiving support from a Rethink helpline to help cope with and manage symptoms. It was about having a reassuring conversation. The same person valued having an alternative support to her boyfriend, because she felt that going to him sometimes negatively affected their relationship.

I rang for support rather than going to [boyfriend's name] and throwing all of that at him which is more or less completely designed to ruin our relationship, because I've done that many times in the past... The change was about, instead of acting out, and having a massive tantrum ... I actually rang for support and I listened to what people had to say. (AH04, 1073)

When asked what they would recommend to others who are trying to recover, one participant suggested:

Set up a support network with family and friends and professionals. You've got to trust the professionals, even if you don't at first and you just pretend you've got to have them in a support network, you're going to need their help. (RAS01, 1121-1126)

Also another participant talked about building a support network to help him stay out of hospital.

I'm not going to go back to hospital. What I've actually tried to do is build a circle around myself... my daughter and half a dozen friends and I've talked to them a lot about what bipolar is, what the signs are, what to look out for, what to do so warning signs should be picked up and it should never get to that point. ...my daughter, I talk to her on the phone at least once every day... I've got a friend I talk to on the phone at least twice every day, often three times and I think he would pick it up... currently everybody knows. (RAS03, 1318-1344)

The importance of support is not only about receiving support, but also about supporting others: the exchange of giving and receiving support (see also the theme 'having a purpose'). For some, recovery involves both being helped and helping others.

I joined a bipolar support group and ended up helping run it, I have support groups online that I joined and I'm a member of MDF. (RAS01, 94-97)

Some find it helpful to engage in activities that bring people together and encourage social interaction. One participant talked about attending an art group and enjoying the opportunity to engage with others.

The art group, when I first went there no-one spoke, we just got on and I think that was because we [were] all so ill we couldn't interact with one another and then gradually we became quite chatty and through activity we talked. (RAS02, 951-967)

One researcher (B) had had a similar experience, when joining in with local walking and gardening activities for service users. To outsiders he appeared to be just joining an activity, but he found that this was often a less threatening environment in which to start talking and recovering.

## Treatments

Research participants talked about different types of treatments and their role in personal experiences of recovering from mental health problems. Three broad types most often discussed will be given some further attention in the following sections: hospital, medication and talking therapies.

### Hospital

When participants spoke about the time they spent in a psychiatric hospital it was mainly described as a negative experience. They talked about lack of privacy, having no independence and feeling ignored, with staff being too busy to talk and engage with them. Some mentioned not feeling safe.

When you're in hospital you do lose your independence. You lose your privacy. Often you're in a dormitory. You lose your freedom, because you're not allowed out quite often. (AH02, 2534)

When you're in hospital they sedate you, they abuse you physically, especially if you have a section and they take your rights away (RAS03, 409-415)

While the hospital experience generally was described as not particularly therapeutic, and one to be avoided, some participants felt that the experience of hospital represented a key stage in dealing with the problem. It was felt to be the start of treatment and this could be an immensely sobering experience. One participant explained that if it had not been for hospital he would have ended up in a worse situation. For some, hospital was a 'necessary evil' (RAS06, 818).

In some ways it took me out of a bad situation. I don't know where I would have ended up if I'd been left with what I was doing. (TB02, 950-1000)

One researcher (A) similarly felt that all her hospital admissions were entirely necessary even if she didn't realise it at the time. The hospital provided sanctuary and care when this is most needed. Also, some had found that certain aspects of the hospital experience were beneficial.

When I was in hospital I did quite a lot of art therapy and I got a place at that art school to do art (RAS07, 80-83)



Similarly, a researcher (E) found that art therapy enabled her to express and consider issues more beneficially than talking therapies. In general, participants' comments indicated that a lot could be done to make the whole ordeal of the hospital experience more therapeutic and less chaotic. High staff turnover was an important issue for some participants, particularly for those who had experienced several hospital admissions.

People [staff] who know you, they are able to offer more support, just because they know you and they know what makes you tick and what you're likely to be worrying about, and they know what sort of things in the past have helped. (AH02, 1332)

However, several participants felt that staff on hospital wards generally expressed an unhelpful attitude, and that staff were unavailable to talk to patients. One researcher (A) had observed how staff on a hospital ward were not actually engaging with the patients but seemed to be wandering around. Participants often described hospital staff as having a distant and indifferent attitude, and that there was lack of a real therapeutic, caring rapport.

[T]here was no real what I call bedside nursing. [Staff were] very cut off from you, very sort of domineering, very telling you what to do. Quite threatening in some ways... I feel as though they sort of 'break you in' when you first go into hospital and make sure you don't play up too much. (TB03, 787-815)

Aside from staff attitudes, participants generally found the physical environment of the hospital to be hindering rather than supporting their recovery.

When you're not well you need a therapeutic environment, and I would say that the in-hospitals really weren't. And when other people would come into hospital, say, my doctor told me to come in here to have a rest, well, they weren't able to get a rest. It was too noisy. It wasn't a restful place at all to me. (AH02, 2605)

Some found getting their basic needs met, such as getting enough sleep, was difficult. One interviewee talked about how staff checks during the night had been very disturbing.

They [staff] come round every hour and flash a light in you and I was going 'what?' I tried to hang myself the next morning. (RAS02, 407-409)

One researcher (C) had similar experiences of hospital. He remarked that staff seemed far more interested in following procedure rather than considering patients' needs - such as sleep!

### Medication

Medication played a significant role in participants' experiences of recovering from mental health problems. These experiences were both positive and negative, and medication was often an issue people felt very strongly about, touching upon a range of different areas of their lives. The general view was that medication should only be one among a range of treatments used to assist people to recover. Many expressed a sense of powerlessness and not having their concerns over medication taken sufficiently into account by mental health professionals.

Some research participants felt that the process of finding the right medication involved a lot of 'trial and error'. For one person, changing to an atypical anti-psychotic drug was a turning point. The change of medication allowed them to return to education.

After I had taken the [named drug] for about a year I then... you know [when I had conversations with] my CPN I decided that I would go to college. (RAS07, 378-381)

One participant realised how essential his medication was:

I came off the medication and was hallucinating. (RAS04, 241)

But it is not only about finding the right type of medication, also the right dosage for the right time. Some described feeling frustrated with their psychiatrist for not seeming to appreciate that people who have been manic, but are now stable, need to have their medication lowered to enable them to get on with their lives. One researcher (C) agreed with a participant that the GP's are usually far more understanding in this respect.

Yeah alright, I needed the high dose when I was severely manic, but once I came out of that episode I was just sleeping all the time. And I've got a five year old son that I was trying to get back. He'd gone to live with his dad when I went manic and I couldn't fight to get him home if I wasn't awake enough to fight, so my GP and my social worker

aided me in lowering the dose just by two point five milligram and we've now got it now to ten milligrams a day. (RAS01, 165-176)

Some participants talked about experiencing negative effects from being treated with the wrong medication as a result of misdiagnosis. One person had a hypomanic episode when treated with anti-depressants. This led to a diagnosis of bipolar rather than depression.

Thankfully it [the manic episode] then got me diagnosed as bipolar so I could be put on the correct treatment instead of anti-depressants which were sending me into hypomania, which nobody realised. (RAS01, 90)

Some talked about experiencing horrible side-effects to medication.

I had [named drug] fairly early on, oversedated me, it was horrible. ... That was absolutely awful. ... The only effect I noticed was this oversedation, just constantly falling asleep just sitting in the chair. (RAS03, 232-247)

Participants who had struggles with their medication explained how they sometimes feel that the negative side-effects outweigh the benefits. Some wish to access support from mental health services, but do not want to take medication.

The psychiatrist had discharged me in 1993 because I said 'I'm not going to take medication'. He didn't like that, so he discharged me. ... At that time it's the worst I've ever had medication side-effects of tiredness... I decided to come off it... it caused me to go to bed about six, six thirty, and then I'd sleep... I wouldn't surface unless they [my parents], you know, came to knock on my door, until about nine the next morning.... And I felt awful. I'd never felt awful on any medication. I decided I wasn't going to take it. (AH02, 566)

Some participants would have liked to receive better advice and support regarding what they could do themselves to avoid or minimise some common side-effects of medication. One participant felt strongly that he should have been advised to exercise regularly along with taking medication in order to counteract the weight gain medication can cause.

The weight gain was terrible, it was really bad... I do a lot of exercise now, I run 3 or 4 times a week just to get the weight off... I would have been a lot

happier if, when they put me on [medication] they also put me on some sort of exercise machine or physical support to counteract the weight gain. (TB03, 1464-1490)

Regular exercise can help maintain a healthy body and counteract the weight-gain side effects of neuroleptic medication. One researcher (B) had a similar experience that exercise can help to lift your mood and to gain more energy.

Some participants felt that they are not given enough support to come off medication. They had the impression that pharmaceutical companies and most of the health service are geared up to prescribing, but not to un-prescribing.

I think all drugs are corrupting, and the more people who are put on drugs, the more people are going to feel like they can't control themselves, and also they're going to feel committed to a system, an economy, which can produce these drugs, and feel that they can't cope without them. (RAS05, 1763-1779)

One researcher (C) had had a similar experience, he felt he was given medication and forgotten about, with no plans other than his own for reducing dependence. One woman talked about her desire to come off medication:

I take conventional medication. I hope one day to come off it but it is a necessary part at the moment, but when I try to get off it, I kind of lose perspective again. (AH04, 2193)

This experience resonated for one researcher (D) who had difficulty coming off medication. She experienced withdrawal problems when cutting down on medication rather than a return to old symptoms. Participants also said that using medication to treat mental health problems should not be the only way; there are alternatives such as talking therapies. One participant explained how he seeks to find a balance between different treatments.

I: I think that people can be helped, not everyone, but a high percentage can be helped to recover to either a little or a large degree, without resorting to meds...

R: Would you say that a combination of meds and other therapies is the way ahead?

I: Well, in an ideal world I'd say yes. I'm certain a percentage of people in extreme states are only going to respond best to meds. ... Medication definitely has a place. I think it's about balance. (TB02, 839-875)

Some described how there was a definite psychological element to their problems which they felt would respond better to talking therapies or counselling. One participant had been on many different medications, including depot injections and oral tablets over decades in the mental health system, but said what she really missed was being able to talk about her problems.

I find it [talking] very useful, yeah very useful. I mean that's the best way, communication and reading. ... you need it... to deal better with problems you need some kind of recourse to some support - apart from just medication. (TB03, 1723-1734)

### Talking therapies

Talking to other people, whether individually or in groups, was described by participants as helping them to develop a new perspective on their situation. One person who had not benefitted from traditional medical treatment commented:

I do find talking to people really helpful, you know discussing through group stuff that I've personally found helps to get a perspective on what I've gone through and what I'm going through. (TB02, 919)

Talking therapy groups can help equip people with new skills and ways of dealing with life's stresses. A researcher (E) had found that group therapy was more helpful than individual work, as it changed the dynamic from the 'well' person helping the 'ill' person to a group endeavour where group members could provide helpful insight as well as empathy to the different group members.

One participant gained a great deal from having psychotherapy and found it had changed her profoundly. Initially she had found it difficult, but stuck at it and found a breakthrough. Eventually, she was able to see where her behaviour was leading her and to take another direction. Although her family was very private, through her therapy, she had become more open. She described how good she felt she could confide in and get support from others who had had similar experiences:

I've just had some psychotherapy for three years, and I really feel that it has helped a lot and it's been quite a profound experience. ... It's almost like a festering wound, that hadn't been really healed over properly. So, by looking at it and talking about it and coming to terms with it is almost that ... the stuff has come out of the wound and it's being allowed to heal. A year-and-a-half of the psychotherapy I found it extremely difficult to cope, gruelling, and I really wondered if I was doing the right thing, but then... it just felt as though I had reached a turning point ... taking a different direction. ... I haven't really wanted to talk about it before to many people, I found it very hard to confide, and now, maybe with the psychotherapy, it's sort of helped [me] to be a bit more open. (AH07, 26, 622, 735)

CBT (cognitive behavioural therapy) had been experienced by several participants, but received mixed reactions. Some had found it useful, and one described how it had helped her to think about issues in a different and more positive way:

I have to try and challenge that and say to myself: 'well, what would another way of looking at that be?' (AH02, 190)

It was the first time she had had an opportunity to talk about hearing voices.

That [CBT] was a tremendous help. It was the first time anyone had really talked to me about voices and the content of them... I have read somewhere that people with schizophrenia really shouldn't be offered that type of help, but it jolly well helped me. ... He said, if he had read my notes, which he hadn't done before he started working with me, he probably wouldn't have done it. (AH02, 1523)

As a result of the CBT she has developed coping skills to manage her intrusive voices and forged a good relationship with the nurse. Through being able to challenge her voices, she is now able to live independently, which has meant a great deal to her. The nurse who worked with her at the CBT also gave her practical support, helping her to achieve things in her life. Most importantly, moving into a flat of her own. The nurse was also able to spot her potential as a trainer and encouraged her to work alongside him.

However, others had found the technical skills involved in using CBT difficult to understand and to apply in practice. In the experience of one researcher (A) CBT can feel a bit too 'technical' to master when one is feeling unwell. The very positive experience of using CBT described above could perhaps relate to it being part of a wider 'support package' provided by the nurse.

Although many people find talking therapy useful, it has traditionally only been available to few on the NHS, although the new NICE guidance for schizophrenia recommends wider use. But in the experience of participants, even in situations when talking therapies had been available in principle, there were often long waiting lists, which meant that the talking therapy may not have been helpful at the time it was actually available. One participant described how they had received counselling, but that it was too late. The problem he had with a relationship had developed further, and he felt that the counselling was no longer appropriate, or as helpful as it would have been earlier. Some people for whom talking therapies were unavailable on the NHS had sought alternatives or made up their own treatment packages.

I've done lots of things. I have in my twenties, I used to go to group therapy. Oh no, that started at about 18. Then I had individual therapist, psychiatrist. I've been in this... I've tried a lot of my own things, like... encounter groups, counselling, I've trained recently as a life coach. (AH05, 1443)

Some life skills courses can also be useful. For example assertiveness training, that may help to improve self esteem. One person's mental health problems stemmed from a stressful situation at work. His colleagues had been treating him badly and by doing an assertiveness course he had learnt a better way of interacting with others.

I've done the assertive course and it has been really, really helpful because they have helped me find my position in society... I used to be more passive, quite submissive. I've learned to become more assertive and confident... Being a bit more assertive gets you a more even place in society. (TB04, 1660-1692)

### Summary of contextual themes

**Basic and material needs:** Recovery crucially depends on the person having basic and material needs met. This involves a secure accommodation where it is possible to feel safe and ensure privacy; having some control over who to share the physical environment with. It is important to have financial freedom and certainty, being able to pay the bills. And basic human rights are important: for example, being recognised as a parent and taking on the responsibilities this involves.

**Stigma and isolation:** Participants described how they were struggling against negative perceptions and attitudes regarding mental illness, and the role these could have to block their recovery. This stigma contributes to a low mood and a feeling of isolation. And the feeling of isolation can become real when people shy away from meeting with others out of fear of being stigmatised. Participants emphasised the importance of fighting against this by finding opportunities to be meeting with others.

**Relationships:** Participants described relationships as having a crucial role in recovery; both as enablers and as blockers. Positive relationships where the person feels supported and encouraged were essential to give the person the confidence to move forward. Negative relationships were described as keeping people trapped. The challenge for people in recovery was

to distance themselves from negative relationships, while building and nurturing supportive relationships.

**Receiving support:** A significant issue for participants was engaging with people to receive support when unwell. This was particularly described as an issue in respect to contacts with mental health professionals. Participants appreciated that the professional took a human approach, took time to listen and genuinely cared. To stay well and deal with crises, participants described how they were building support networks of family and friends. Some highlighted the importance of not only receiving, but also giving support. A few mentioned their preference for informal social networks for support.

**Treatments:** The experience of admission to psychiatric hospital was described as a negative experience, although some felt that it had been necessary at the time and an important 'eye opener' that led them to recovery. A range of views were expressed regarding psychotropic medication, most considering it an essential part of their treatment that should not stand alone. Participants highlighted the importance of getting the right type and dosage, and that the person should have a say when determining this. Talking therapies were described as an important part of the treatment package, although participants had had different experiences with specific therapy types.



## Personal recovery themes

The following five themes describe dimensions of recovery that are of a more personal nature, concerning what the person can do, or how they approach or see aspects of their lives. It is however important to note that there is not an absolute division between the contextual themes described above and these personal themes. Often the different themes overlap or merge into each other through the lived realities of individual lives. Nonetheless, as analytic themes they do mark out issues that require particular attention when understanding participants' experiences of mental health recovery.

### Identity and self-awareness

The notion of identity is of crucial importance in respect to recovery. Participants talked about learning to accept themselves, to stop conforming to others' ideals and expectations and to just be themselves. The data suggest that this marks a crucial turning point in recovery.

I've been more willing to be myself and I think for a lot of time when I was young... especially in England you have this herd mentality, you know, 'everyone is like that, you should try and be like that', and so it's only been really in the last five or ten years ... that I've sort of said 'well that's daft... I'm going to be myself warts and all', and if people see these, for god's sake, does it really matter. ... part of the answer to that is just to say 'well, be yourself'. (PJB01, 1201-1210, 1224-1225)

The same participant recognised that society may affect a person's ability to be themselves. There may be external pressures to assume roles that are not comfortable for that person, or they may suppress aspects of their personality in order to be accepted by others. Becoming oneself may involve letting go of others' or society's ideals.

You've got to really work out what society has done... you've got to say 'sod it, chuck that'. I mean, you know... and the enjoyment is becoming yourself and then becoming your full measure. (PJB01, 1233-1239)

Similarly, a woman spoke of how moving from a rural area to a city enabled her to become a different sort of person, and establish an independent identity, which was very different from that of her family:

Being your own person and not being part of your family, you know, sort of rigmarole; making your own name; making your own mistakes; being responsible for your actions, I think it's very important; and having your own independence, basically. (RGS05, 1719-1751)

Change in identity can be a major challenge, but also a positive opportunity. One person felt his identity had been compromised when he spent time with the wrong people, who he called 'druggies'. He talked about becoming a bigger person as he recovered:

I've actually noticed like a new kind of person coming through... so like I'd seen like an improvement in myself ... like more somebody. Looking back on my life like seven or eight years ago there wasn't much, there wasn't much of me, much as a person, because like I had problems, I was a mess, drugs didn't agree with me and like I went down the wrong way... and I've seen a big improvement in my mental health, in me as a person as well. My mental stability and attitude like has increased so much (RGS02, 60-90)

To become this new person he spent less time with the 'wrong kind of people' and chose to take 'the good road' for his future:

I was a mess, I was like a nobody, I was like a nobody. I've been making something of myself for so many years, like I've just come so far: I've overcome staying off drugs. I had a drug problem, I got off drugs and sorted my life out, got down with the right people, instead of like associating with the wrong kind of people, people who I'd just do drugs with. I got out of that life and gone down the good road, the right road, instead of being on the wrong road. (RGS02, 116-128)

Some participants found their diagnosis very helpful in clarifying issues of identity. A woman explained that she was receiving mental health treatment, but had always presented to the doctor as depressed. However, when Prozac triggered 'a huge hypomanic episode' she was diagnosed with bipolar disorder. This was significant for her in that it fitted with what she knew about her behaviour, and it enabled her to recognise herself and to start to accept herself:

I: It was the most amazing and eye-opening thing to find out [the diagnosis]. It was, it was wonderful to know.

R: And the diagnosis fits you, does it? You accept it?

I: Absolutely. It was almost like textbook when they told me about it, when they explained what was going wrong. I'd had problems like this for years. It just, and I went home and I kind of researched it, and googled it and read everything I could, and it just seemed to make perfect sense. It felt like all of a sudden I could relate to and have some sympathy for the person I had been for the last 30-odd years, really. (RGS06, 117-138)

This recognition of what she felt was her true self was the start of her progress towards recovery. However, some feel that they cannot identify with their given diagnosis, or believe that they are misdiagnosed.

[Being diagnosed as] paranoid schizophrenic, that was unhelpful. They knew I had a mood component to my problem. I slipped under the net for them because I had long periods of wellness... it's only recently I've had the mood stabilising drugs that I've been on and they've really worked. (RAS07, 1061-1073)

One woman had originally been given a diagnosis of borderline personality disorder. She felt that because of this diagnosis, she had not been taken seriously. Getting the correct diagnosis also had implications for her treatment: once she got what she believed was the correct diagnosis of bipolar disorder and changed medication, she started to feel a lot better.

So I was quite frustrated by that and by the diagnosis. And I felt it meant that I wasn't treated, you know, I wasn't treated so seriously, when I was unwell ... I just find that diagnosis a very difficult one because it's then commenting on your personality, which is who you are, you know, it's like, it's very damning, I think. (JB06, 512-524)

Some people become so identified with their illness diagnosis that they find it difficult to let it go. They fear that without it they will not know who they are, or perhaps fear that they won't receive the support or care that having the illness has afforded them. Amongst the participants it appeared that more positive identification was expressed towards the diagnosis of bipolar, in contrast to schizophrenia and personality disorder. This may link to the public perceptions and values attached to specific mental health diagnoses. In this sense there is a close link to issues of stigma:

I think knowing that there's so much stigma was unhelpful and it would have been great to see so much campaigning being done years ago, to find people. I'd have felt more likely to, to come out and say 'I'm not feeling very well, actually, and I do all these mad things'. But I've kept it as a blanket of shame for a long time. (RGS06, 2557-65)

Common perceptions of mental illness can make it difficult for people to engage with their experiences and feelings:

I was terrified of it really, before. I think I was scared of being crazy or nutty, scared of the way I was acting. But now I'm not. Maybe that's changed me. I just accept that this is the way I am, and once you've accepted it, then you can work with it. (RGS06, 1819-1825)

Many feel there is a stigma attached to mental illness and it is not always something people wish to identify themselves with. One participant talked about the importance of her volunteering work where she spends time with people who don't know of her mental illness, and how this allows her to be 'normal', to assume her true identity, not that of her illness. On the other hand, participants also described how they found it helpful to meet other service users within the mental health system to share knowledge and experiences. The same participant who did the volunteering work spoke about learning from others who had had similar experiences to herself:

One of the most positive things about being in the system it's sort of picking up other people with sort of... with similar stuff, I guess. ... Several friends that I found within the system, normally who are a bit older than me and are just very wise and have been through similar things, have been very helpful. (PJB06, 107-111, 535-539)

Hence, the same person may apply identity strategies that are both 'normalising' and based on collective learning through peer support. It doesn't have to be either-or. A researcher (E) found that it was the experience of being with other people with whom she could identify in a bipolar support group that confirmed her own self-diagnosis. Previously doctors had been reluctant to agree with this diagnosis, as she had presented to them only when depressed. But the recognition of herself in others confirmed her identity as someone with bipolar

disorder and meant she could learn more about her illness and strategies for self-management. Later, her 'self-diagnosis' was confirmed by doctors. Another participant commented on how beneficial it was to be around people who had been unwell, but were now in recovery. He found it reassuring they were now 'normal'. Many find it valuable to have role models or mentors; people who can impart their knowledge or simply give hope by showing that recovery is possible.

People's experiences are roughly the same as [what] you know, or you can see that people have succeeded or are coping with stuff. (PJB01, 1319-1324)

For some interviewees the researchers were perceived as positive role models of people in recovery. Other types of role model were described as useful in strengthening a sense of identity and self-worth. One man had an actor as a role model that helped him to build confidence in difficult situations and gave him guidance on how to act.

### Taking responsibility

By taking responsibility for their mental illness participants described how they regain some control over their mental health, and that it can therefore initiate their recovery. One participant spoke about the different things that had contributed to his mental illness. He explained that society and other people played a role, but he also felt it was important to recognise his role and to take some personal responsibility for his mental health.

Try and understand... what is your role, and try and reduce the mess. (PJB01, 1370-1373)

He felt that, in order to recover, the person must want to help themselves. Part of recovery seems to be about making a decision to get better, actively wanting recovery.

The person has to be able and willing to help themselves (PJB01, 1410-1411)

Statements from other participants highlighted how it is important that the recovery process is gently nurtured and taken slowly. It may be frightening to let go of the role of being unwell. During illness personal responsibilities may be removed, or lost, so recovering may mean people have to take up old



responsibilities again, or assume new and unfamiliar roles. One interviewee talked about how other's expectations led her to hold herself back from recovery.

Oh, another thing in the recovery is it was frightening to let go of, and people would expect things of me. So it's been nurtured to allow that to happen. Because I know at one point I didn't want to do anything that made people think that I was recovered, because they'd expect something. Or they might expect too much from me. So you know, I held myself back as well, because recovery was too frightening. (PJB03, 643-654)

For some, taking responsibility may be accepting that they have a mental illness and need help. One interviewee talked about accepting she had a mental illness and that she needed to take medication. An important turning point was when she became aware of her situation; her mental health and her need for support.

[I have] accepted now, I, you know, did need medication, that I did have a mental illness, because

I just thought that they [mental health professionals] were all barking mad. (PJB03, 837-840)

Some participants talked about their need for ongoing support from medication and mental health professionals. One interviewee recognised the importance of keeping in touch with doctors and continuing to take medication even when feeling well. He also talked about taking responsibility for his mental health by avoiding things that made him unwell, such as partying. He recommended caution for people seeking recovery:

Not getting carried away with thinking you're well and keeping taking your medication, keeping in touch... Don't just think 'oh I'm well', 'I'm going to party' or whatever. You know, keep in touch with doctors. (PJB01, 1375-1377, 49-52)

A recurrent theme was how the sense of 'having something to lose' could be an important driver for taking responsibility. As explained by this participant with a criminal record, when describing what it is that keeps them out of prison:

[Before I felt like] 'prison isn't a deterrent for me'... most people would be fearful if they even got arrested, whereas I'd been through it before. Whereas now I've got like more to lose and it's like I wouldn't want to. (RGS07, 438-49)

Changing yourself also challenges a sense of personal pride in who you are:

Whatever skills you've got and whatever skills you learn, it still takes a while to change your behaviour. I think it's like your pride, isn't it? (RGS07, 759-765)

The data show that hitting rock bottom could aid someone's recovery, in that it enabled them to learn about themselves, and could force them to make decisions and take responsibility about how to improve their situation. What they learnt from the experience could help them move on, as one participant explained:

I would say that it's sometimes better that someone becomes desperately ill and recovers, than they're held in no man's land. Because once they go down there's always a chance that they'll clamber their way up. (JB02, 329-334).

Similarly, one of the researchers (F) found that no-man's land was about being in a place of not being so ill as to be desperate for help – and therefore not

needing to seek help. Hitting rock bottom forced her to make a decision – between committing suicide and seeking help. Many participants talked about how receiving support was extremely beneficial to their mental health, in particular, sharing problems with people who understood. However, one participant realised that he could come to rely on this support, and that this could make him dependent.

I can become dependent like a baby in four hours in a psychiatric setting. So that can do damage. So you have to be able to receive what is useful and to discard what is damaging. (JB02, 308-312)

However, getting support does not necessarily lead to dependence. Instead, it can help someone to become more independent, either by encouraging them to do things they once enjoyed or by giving them some control of their treatment. One participant explained how his wife had encouraged him to go to music events, while another described how her psychiatrist had let her have control over her treatment:

I liked the music, but I didn't particularly want to go and mix with the people that evening and I was quite stressed out. And my wife said to me at the time, she says: 'you know, you'll feel a different person once you get there,' and a bit of gentle persuasion and a bit more gentle persuasion, and, anyway, a friend rang me up and I decided to go. (JB04, 176-185)

I think my psychiatrist... he'd say, 'right, well, there's a range of things we could do; what would you prefer?' And he made me realise that I have responsibility over it, as well, rather than just [saying]: 'you should take this pill and everything will be all right.' (JB08, 176-185)

Taking responsibility also involves facing personal fears. For one participant this involved challenging his social anxiety:

I was afraid of meeting people. I said: 'if I'm afraid of people I will...' - there's a branch of medicine where you treat like with like, so if I was afraid of people, I will go out and meet people. So I joined a fell-walking club. (JB02, 99-103)

However, there needs to be an incentive for someone to face their fears. The same participant explained how his incentive for becoming a walk leader was to get a girl-friend.

Another turning point was I noticed that the girls picked the walk leaders as partners, so I bought myself a compass and became a walk leader. (JB02, 836-839).

Incentive alone may not be enough to motivate someone to face their fears though. If there is a risk involved in facing the fear, then the anticipated reward has to be sufficient to outweigh the risk.

I: Well, there's risk involved and people who are vulnerable don't like risk. If there's an incentive, if the incentive is greater than the risk people will make the first move. ...

R: So it's got to be a sort of really good incentive?

I: It has to be a good incentive. Otherwise they won't do it. Because there is a lot of risk involved. There's stark fear. Going outside your comfort zone – sounds like a very small thing, but it's massive.

R: So is that fear of failure or what?

I: Fear that no matter how low your existing self-esteem it will drop again. (JB02, 871-888)

Some need considerable encouragement to take on new challenges and responsibilities because they lack the self confidence to initiate these steps on their own. One participant found it helpful to have persistent but friendly support, although they originally found it challenging:

I was asked to escort this lady that was going to the computer class but she found it really difficult to get out... I thought: 'oh god, I can't do that. I know, I'll go to [named staff] and I'll go to [other named staff] and they'll sort of kick up a fuss and tell the tutor off.' And they just thought, 'oh, it's a very good idea.' [I thought:] 'No, it's not a good idea, it's a terrible idea.' Anyway, I supported her to get to the class and I felt so good that I... I didn't feel as I could support myself and it just made me feel that, you know, that I had something to offer. (PJB03, 82-115)

Taking responsibility for oneself crucially involves recognising one's responsibility to others, as discussed under the themes of relationships and self-management. One participant described how an awareness of the effects on her husband of her excessive spending money when manic had helped her take control. It was important for her to recognise that responsibility is mutual:

I: I feel more responsibility to him than I would have done before.

R: So that's, you're saying your relationship is important, it gives you a sort of sense of having to be responsible to somebody else, so...

I: Because I feel a sense of not wanting to disappoint somebody who works as hard as he does to try and keep things afloat. Well, I don't know. Maybe I'm just more aware of my behaviour and how, the effects it did have, and know now that I can, if I really, really work at it, alter some of how it affects us all. It doesn't always work, but it works nine times out of ten. That comes from him being so understanding, so then, and not judging me, so then it's easier to feel responsible for that person, because they're also feeling responsible for you. (RGS06, 2145-65)

For some, realising the impact that you are having on other people can be a highly significant turning point:

That was a very important turning point in my life to say that rather than blaming someone else for my problems, I would take responsibility myself and say look at the disadvantages my behaviour has caused my wife. (JB02, 380-396).

## Self-management and resilience

Self-management refers to organising one's life to maximise health and avoid unhealthy behaviours or triggers. It can be an important part of the recovery process. In order to self-manage, it is necessary to have good self-awareness of the mental illness, its triggers and the factors that aid recovery. Experiential learning is important. One participant had attended a psychoeducation course: she talked about how helpful it had been to learn about the triggers for bipolar disorder from others with the same condition. It also made her realise how individual the warning signs were for her condition.

But if you get a group of people all together and you can all see the commonality of, like, the symptoms but it might be that... I remember at some... one guy saying he starts listening to, like, any disco when he's getting high. And another guy saying: 'oh, I cook loads of pancakes'. (JB08, 323-330)

Once someone realises certain things or situations can trigger their illness, they are in a better position



to do something about it. However, sometimes people need an incentive to self-manage. The same participant with bipolar disorder described how she used to run with her mania, but starting a new job gave her an incentive to self-manage – to try to stop the mania from escalating.

Normally, when my mood starts getting high and I feel like the energy and the, you know, the urge to go out and party and whatnot, and I just go with it... But this time I thought: 'I can't have an episode now, I've just started a new job'. (JB08, 97-105).

Self-management is all about what people know about their own needs – whether this is listening to music or cooking pancakes – not what is decided on someone's behalf by mental health professionals. In contrast, there are situations where professionals undermine self-management potentials. For example, a woman who had found exercise to be very helpful was disappointed by a psychiatrist who advised against this, and did not take a more holistic view:

The next [psychiatrist] was very prescriptive in [saying that] 'we need to give you some mood stabilisers. You don't want to do too much exercise, because that will over-stimulate you, because you're bipolar, and you don't want to over-stimulate.' And I thought, 'what...?' So there was, that was

a really old-fashioned entrenched view of keeping bipolars down, I thought. Whereas the other doctor accepted that there was a good balance between exercise, nutrition and [inaudible]. ... I felt very squashed to hear it. Actually hearing it made me feel squashed. Which is very unhelpful as well. (RGS06, 2302-2337)

Participants described forms of self-management strategies that involve both gaining more control and direct influence over their own situation, and others that involve disengagement from unhealthy practices or situations. Knowing the diagnosis can be useful because it gives individuals an opportunity to find out about their condition and their difficulties, and how to deal with these. However, as discussed in the section on identity, the diagnosis is only helpful for the person if they feel that it accurately describes their difficulties. This woman talked about how the diagnosis makes her feel that she knows what she is dealing with:

Things have been easier to manage, because I'm, it's almost like someone telling you what's wrong with your knee, and that you need to do this, this and this in order to make that knee a little bit more easy to manage. It's as simple as that on some levels. Not, it doesn't always work that way, but it feels that I can, that I can manage it, because I know what I'm dealing with. It's not the bogey-man, it's not... It's just, I just know what I'm dealing with and I manage. Before I had no idea why I behaved how I did, what made me the way I was. (RGS06, 169-191)

A number of participants talked about the value of writing. One man described it as a cathartic process. He was able to unburden himself through writing and felt that this had been helpful.

I started to think: 'well I'll write a bit about what happened now' and... it turned out to be a good thing and whatever the content of what I was writing it seemed to get things out of me which was, I think, good. (PJB01, 99-106)

He had a good understanding of what he needed in order to stay well. When he talked about the medication he commented on his need to be in charge of that and to have autonomy – being and feeling in control of himself.

Well I'm still sort of fairly convinced that I happen to be eighty per cent chemical in terms of what I need

and what puts me right. For instance one night's sleep can often make a big difference... wanting and needing to be in charge of my medication and being able to go freely and not have other people interfere. (PJB01, 140-150)

The importance of having some control over your prescribed medication resonated with researchers (B, C). For one participant this 'self-medication' also involved illicit drugs. When she is manic, she uses cannabis to help her relax.

It, kind of, allows me to relax a bit more, because if you get racing thoughts, and whatnot, and you, cannabis can just, sort of, make you chill out a bit. (JB08, 525-530).

However, only one participant in the study found recreational drugs beneficial. Others found that using illicit drugs made their mental health problems worse.

I: I've had 17 years of addiction problems.

R: Illicit drugs?

I: Yeah, so that was alcohol and drugs. So that was tied in. I think it exasperates the mental problems but it wasn't the sole cause. There's more to it than just addiction. But having addressed the addiction to street drugs I find this helps. (TB02, 35-47)

And another participant with experience of using both illicit drugs and prescribed medication commented:

I think all drugs are corrupting. (RAS05, 1848).

Individuals can find it helpful to develop or relate to external forms that provide a structure and a 'prompt' to assist their self-management strategy. This can involve writing notes with tips and advice for yourself, and carrying these in your pocket – as one of the researchers does (C). One participant described admiring a film actor, whose example he uses to modify his own feelings and behaviour in difficult circumstances:

His focus is on what he's going to do, so like he doesn't let anything around him affect him, so I've tried to like apply that to myself... He doesn't get affected emotionally by what's going on, just thinks of what he's going to do, things like that. ... Like, I do have, like pictures [of the actor] in my wallet and I look at it in certain situations if I've got to be confident. (RGS07, 888-916)

A participant explained how he created a structure through organising the environment. Just being surrounded by a pleasant environment can really help to lift someone's mood. This person talked enthusiastically about how much she enjoyed the countryside.

My house is only about two miles from the forests and the fells, so I just love it. It's just wonderful, it's really lovely (JB01, 2009-2011).

Besides being surrounded by beautiful countryside, a pleasant home environment can also aid recovery. One participant realised how unhelpful it was to have an untidy home, and he then set out to tidy up his home with the aim of improving his mental health – the 'tidy environment, tidy mind' theory:

Just as if you're in disarray in your mind, your premises will all be in disarray as well but just do it the other way round. (JB02, 667-670)

He realised that it was necessary to start small:

A place to start is somewhere very small, perhaps a sock drawer, sort out your drawer, sort out under the sink, get that absolutely right. (JB02, 575-578)

Sorting one's life out can be a huge task. Therefore starting with small steps can help prevent people becoming overwhelmed. One of the researchers (F) could identify with this. She has noticed that she feels more depressed when her garden looks a mess. Doing a small amount of gardening each week helps keep the garden looking nice. However, if she does not do any gardening for a month or more (particularly in summer), then the resulting jungle can make her feel so overwhelmed that she feels unable to even do any work in the garden.

Where for some the motivation for self-management seems to come from the individual, others find it helpful to have roles or responsibilities that provide an external discipline. One described how her children helped her keep to a routine:

If I don't dress early, then I don't dress until ten minutes before my lot comes in from school, because I don't want to see, I don't want her to know that I haven't been able to manage that day. So I'm kind of very keen on pushing myself in that way. So having some level of routine is hugely important to live from day to day. (RGS06, 1396-1405)

Making appointments was another way of maintaining a useful routine, by introducing an external discipline:

Making appointments I would, making them so that I have to go, and my mind, deciding in my mind that I have to go to them, so then I'm going to have to do those things. So that's a very important part of recovery for me, to keep that. (RGS06, 1425-31)

Some participants explained how physically moving to another space can help, by creating distance and a greater feeling of control. But this does not work for everyone: another person found it helpful to stay in his flat and avoid being exposed to too many stresses, when feeling unwell. This relates to a wider strategy of disengagement. Participants talked about how much psychosis has played a part in their condition. This man had discovered a technique he uses to avoid full blown psychotic episodes:

And the other thing that has helped me is 'disengaging' from the psychotic behaviour or psychotic feelings. So, if I hear voices or see something strange, I don't engage in it. I think it's a conscious choice. You can either engage in it, which can get you in a spiral of elation or, if you want to keep an even keel, I don't engage in it. (TB04, 583-605)



By using a mental strategy to avoid psychosis this man had learned a vital 'wellness tool' he used as part of his self-management, thus regaining some control over his condition. One researcher (B) could recognise the importance of this, as he had always felt completely at the mercy of his psychotic symptoms.

The data suggested that recovery is closely linked with resilience, as elegantly phrased by one participant:

Recovery is longevity in wellness, simple as that. (RAS04, 1464)

Another interviewee commented on the need for an individual to know what helps to build their own resilience and to work on that. She talked about how experiencing numerous traumatic events can lead to illness because resilience is reduced further with each event. Building resilience seems to be connected with awareness of self and personal needs, and doing things that support oneself.

How is it that somebody can come through 2001 things and be ok, and somebody else with mental health issues are shattered. And a lot of that could [be] because they have had so many life situations... you know, if you get too many major life events happen in a short period, you know, it's too much. If the other person only had the one traumatic thing then resilience might be higher. So recovery and resilience go together...and it's looking at what makes you best resilience and building on that. (PJB03, 918-932)

Viewing others in a more objective light helped another participant build up resilience. He realised that some people were simply unkind and, as a result of this realisation, was less likely to put up with abuse.

I can see the relationship with my mum and dad more objectively. And I can also see other relationships objectively, in that, in that just because somebody treats you bad, it doesn't mean to say it's your fault that they treated you bad. It's just that they're probably not very nice people. (JB07, 480-488)

For one participant, her ability to set appropriate goals had been central to her recovery and has given her resilience as she was building a kind of momentum achieving things.

So my aim was first to get out of hospital and then it was to get my little boy back and then it was to stay stable a month, and then six months and now my aim is to get to twelve months. If I make that I'd love to say eighteen months. (RAS01, 227-232)

Having clear goals helps people to develop resilience. Having a clear and succinct definition of recovery helped some people to develop resilience and move towards recovery, as this participant explained:

The definition of recovery which I used is 'an individual journey towards a more valued life'. (RAS06, 1248)

Resilience also contributes to a stronger sense of self and personal pride:

I'm proud of the fact that I keep going, that I'm still alive. (RGS06, 2780-1)

### Having a purpose and belonging

Having a purpose and making a contribution to society is something that many participants mentioned as being helpful.

Recovery is about getting things together. Making something of yourself, sorting your life out, where you get back into the world. (RGS02, 1526-9)

One interviewee talked about how giving was much more important than receiving. He did not think people's mental health generally improved unless they showed altruistic behaviour:

So people are understanding, if you have the personal qualities, if you are able to milk your experience to the advantage of someone else. That's a way of giving. People generally don't improve unless they show this quality, altruistic behaviour which is to give. Giving is better than receiving. (JB02, 285-291).

Another participant talked about the importance of being occupied and being valued by others.

Being occupied. Having... having a, you know, some kind of self worth and feeling that you are valued by other people. This sounds as really big-headed that you need all of these things. But I found that crucial: me feeling valued. (PJB03, 487-493)

In this sense, having a purpose and belonging were closely connected for many participants. One participant spoke about enjoying volunteering at a conservation park. She valued having a place to go, somewhere she could belong. It was important to her that she could step away from her identity as someone with a mental illness and be accepted.

There is also something about meeting people, and again at this particular Park, they've had lots of people with mental health problems going there over the years... nobody knows who has and who hasn't got mental health problems. So... it's... a real place you can belong. A bit like a church or something, in a way. I really like having places. I think a lot of people with mental health problems aren't in relationships, including myself. And so I need to have places that I feel I belong; places I can go to; even borrowing other people's family or just... places like this Park or a church or something. (PJB06, 666-683)

But the importance of having a purpose could for others be less about belonging to a group and more about the benefit of having control and ownership of something. For one participant, working on her own project gave her a lot of joy. For her, the important thing was not only having a role and purpose but also having something that is hers, something that she has some control over, that she can work on and see progress and develop:

So that's where I am. It is just for me so much joy to have my own project. (PJB03, 146-147)

While having a purpose and being occupied was described as meaningful and fulfilling, it could also involve a sense of uncertainty and risk. One participant discussed her desire to work full-time but also her apprehension at taking on more stress. The hope of returning to, or taking on, full-time work was mentioned by other participants. The desire to work full-time may be about achieving potential or about earning money and being independent. It may also be connected with identity, the need to feel like an equal member of society, to fit in and belong.

I would like to feel as if I could work full time... I can't deal with stress... So yeah, it would be nice to actually extend that to full time and feeling able to cope. (PJB03, 750-766)

As also discussed under the theme of taking responsibility, some were concerned about taking on new challenges and how this might affect their mental health. Feeling incentivised and supported were emphasised as essential. While many participants said that, for them, getting work would be an indicator of their recovery, some were also conscious of a government agenda to get people 'back to work' and stressed that any entry into the world of work should be on their own terms:

[Thinking about] recovery. I think that's a funny word. That it might have started out with one meaning but now has something completely different that the government have given it. The government's recovery is 'everyone getting back to work'. (RGS06, 2612-29)

Participants expressed the desire to pass on the understanding and experience of their distress, either by training, working with or talking to others, so that the knowledge would not be wasted. They hope that mental health professionals can increase their understanding of mental distress and that services might be improved. One participant explained how helping psychiatrists to understand was an important motivation for her:

I personally think [that] people who suffer with the illnesses, you know the mental health illnesses, are generally actually more of an expert... Psychiatrists you know, you know, they're fine, they do, you know, they do pretty well at their job, but it's like because they don't necessary have the actual illness it's a bit hard for them to say what it's like, that's why they need us to sort of fill them in on what's going on. (RGS03, 2059-2109)

Many participants said that they find it helpful to be with others who have had similar experiences to them. It is about them feeling and being understood and not being judged. They speak of having empathy for each other:

It's meeting like-minded people, or people who know what it's like from others that matter to them. It's working with people like that too, that would help so living in a community, in a way, of likeminded people who know what it's all about and not being afraid to tell those who you hope you can trust and to be brave enough to say that 'well, if they didn't understand then so be it', rather than to be crushed by lack of understanding which is what happened to me for so many years. (AH01, 904)

One of the researchers (A) similarly feels a great desire to pass on 'insider' information about her mental health journey, so has taken on training others. One important motivation has been using bad experiences for the good; another is trying to help professionals understand the lives and experiences of service users. There is a widespread desire to influence service provision, although some service users do not feel their comments are trusted or taken seriously. It has in this researcher's experience been important to be working with one or two professionals who have appreciated the value of what she had to offer, and being willing to work together as equals. Similarly, a participant who had experienced discrimination felt the understanding and self-awareness she had gained through illness had given her an advantage, so she was no longer willing to see herself as excluded.

And I've learnt that it's not a bad thing to have a mental health problem, and that I'm not separate to the rest of society, no matter how much they might like to think we are. (RGS06, 2751-2755)

Another talked about feeling part of his local community. He described experiencing a sense of belonging and feeling integrated and accepted by people who were not necessarily like him; who perhaps did not have a mental illness. When asked to describe any achievements in his life, or anything he felt proud of, he answered:

I feel... just being able to be part of my community which is not necessarily full of people like me. (PJB01, 1258-1260)

### Spirituality and cultural wisdom

Spirituality is an important subject for many experiencing mental illness (Mental Health Foundation 2002). Some participants talked about very lucid spiritual experiences when they were unwell. For some there is a desire to explore these experiences, to acknowledge them and be able to talk about them, and for others it is important not to get too caught up in spirituality and to remain grounded and 'in control'. One participant talked about it being unhelpful to get too involved with spiritual or religious people or practices; he felt they could be damaging.

Spirituality, now I'd say it was good and positive for me, but in some early days a bit of spirituality can

just get connected up in the wrong side of things and push you too much slightly with your thoughts. So I think as long as you keep your feet on the ground and you don't get too up into the spiritual level I think it can [be positive]. But I think you've got to be careful. I'd say church, Christians, they've been damaging as well as helpful, but I think if you get on top of spirituality then it's going to work for you. (PJB01, 801-821)

One participant described how she used Buddhism to help manage her mental health. Practicing mindfulness allowed her to stay in the present rather than worrying about the future or getting stuck in the past; it also helped her to avoid panic attacks.

I had no idea how to get here in the bus and I began panicking on the bus. But I brought myself into the moment and I said, well, 'you're not there now, you're not doing that now, this is where you are now' (JB05, 80-85).

Another participant used to meditate alone in the cathedral when her husband was terminally ill, finding the stillness comforting.

I realised he wasn't going to get any better, and I just used to go and sit in the back of the cathedral and meditate, just by myself. (JB09, 1112-1116).

She had found a way to make selective use of the service so that it could play a positive part in her life.

I do go to church. I can't take communion since my husband died. I just get too emotional. But I do like to go to evensong in the cathedral, which is a lovely service... and they have this lovely little, lovely little choir boys... And the cathedral [inaudible] is absolutely magnificent. (JB09, 1094-1103)

A number of participants felt they would greatly benefit from having the spiritual aspect of their mental health experiences acknowledged and listened to by mental health professionals. One participant talked about her need to speak openly with professionals about her spiritual experiences. She also felt that current mental health services are lacking understanding in this area.

I also... think it's the one last taboo with mental health professionals; a lot of my psychotic stuff has been around religious stuff. I have found that a lot of people have not let me talk about it, because it's kind of like 'well, you could get psychotic if we start'... And I've actually been very lucky to find



some professionals that will let me talk about it and that will realise how important it is to me... I think people are getting much better at meeting needs in terms of diet, being given space to pray in and all that sort of thing, access to chaplains and stuff. But in terms of actually being able to talk to psychiatrists and professionals and it being considered as a normal part of life rather than part of your madness [there is still a way to go] (PJB06, 577-610)

Some participants talked about feeling the need to withhold their spiritual experiences because they think the experiences will be dismissed by professionals as a symptom of the illness; as part of the psychosis rather than a spiritual experience in its own right. One interviewee spoke about his apprehension in talking to his psychiatrist. He feared if he spoke about his spiritual experiences, his doctor would think he was psychotic and therefore insist he needed further treatment.

I: I probably would talk about it now, but at the time [when in hospital] I didn't really want to be in there for any longer; you want to get out as soon as possible. And personally I wanted to reduce my medication as soon as possible.

R: You thought by talking about it he might assume that you were unwell, rather than just considering or talking about it?

I: Yeah. He would have said 'you're psychotic, give him more medication until it goes away'. That is the impression I got. (TB04, 1215-1239)

Participants described the benefit they got from spirituality as providing an 'anchor' and point of focus that gave them comfort and a sense of direction. This was similar to the way in which some people described their use of cultural wisdom, often represented by proverbs that encapsulated important values or passed-down wisdom. For one of the researchers (C) this type of cultural wisdom had in some ways replaced his previous preoccupation with spirituality. Participants gave examples of the cultural wisdom they use, including these:

You put good into life, and good comes back to you (RGS02, 1153-1155)

Blossom where you are planted (RAS04, 592, 597, 1196)

Some participants used short catchy phrases like these as a reminder of important lessons life has taught, and help them focus on taking a positive and constructive approach to life. For example, one man used the phrase 'blossom where you are planted' as a reminder for himself that he should work on making the best out of his current situation with its possibilities and limitations. He had learnt from experience that focusing all his energy, dreams and aspirations towards goals which were very difficult to reach could make him distressed and unwell.

While such cultural wisdom or proverbs providing values and guidance for action can be immensely helpful, it is important to point out that they may not always be so. One researcher (C) explained that as a boy he had been taught that 'milk is good for you'. Convinced of the validity of this powerful culturally endorsed phrase, he made special efforts to drink milk daily. Only later he found out that he has intolerance to milk, and that avoiding milk in the diet significantly improved his general wellbeing.

That such proverbs are passed down as cultural wisdom and generally recognised in society increases their social availability, and possibly also the sense in which they represent a widely accepted and proven truth. This can both be their strength, but at times also a potential problem, as illustrated by the example of 'milk is good for you'. But our data suggest that individuals may also construct their own individual wisdom in catchy phrases, for example:

Drug addiction, that's the best thing I've ever left. Best thing I've ever left. (RGS02, 1326 – 27)

It doesn't do you any good to feel resentful about things. (RAS07, 517)

Whether taken from the cultural repertoire or developed by the person themselves, a person may find strength in proverbs or sayings that support their personal recovery.



## Summary of personal themes

**Identity and self-awareness:** Experiencing a greater sense of self and confidence in own identity was described as a crucial aspect of recovery. For some this involved developing a greater sense of independence and at times challenging existing or developing new relationships to support personal growth. Diagnosis played an important role for some by giving them a better understanding of their illness, but it was crucial that they felt they could identify with the given diagnosis, which was more rarely the case with schizophrenia compared to bipolar disorder. Participants spoke about the importance of having positive role models and being with others who could confirm a positive social role.

**Taking responsibility:** Participants described the importance of themselves taking an active role to engage in recovery. This means putting yourself outside the personal comfort zone, and that can be a very frightening thing to do. Some explained how they in this process could feel a need to hold themselves back, as they feared being met with too high expectations and facing the risk of failing. It is essential that the person feels that there is an incentive which makes it worth the risk. Recognising their responsibility for and impact on others could be an important incentive to engage in recovery. Equally important is that the process is supported and happening at a pace to allow it moving forward in a way that feels safe and sustainable.

**Self-management and resilience:** Knowledge of personal illness triggers and developing strategies that work for the person are crucial aids in the recovery process. Some participants found it very helpful to meet with others who have experience of mental illness to learn from each other and also understand how coping strategies can be very individual. For some it involves introducing daily routines, for others organising their physical environment, and others find it helpful to bake pancakes when starting to feel unwell. There is no one-size-fits-all. Being able to live through longer periods of wellness was described as important in building resilience and confidence in recovery.



**Having a purpose and belonging:** Being part of something bigger and being recognised for making a contribution to others or the community was described as having a key role in recovery. For some this simply meant 'being valued' and others described how they took on volunteering or occupational roles. But some warned that there could be too much pressure on 'getting back to work' and that it was important to find roles and challenges that are appropriate to the person given individual circumstances. Being together with like-minded people who understand their situation was important in developing a positive sense of belonging.

**Spirituality and cultural wisdom:** Some participants felt that spirituality played a significant role in their recovery. Feeling close to God or using spiritual techniques could be a source of comfort and help put the mind at rest. Some described the role spirituality had played in their mental health problems and pointed out the importance for them of finding the right level of involvement with spiritual issues – allowing them to be 'in control'. Complaints were raised over the general lack of skill amongst mental health staff to engage in conversations about spirituality. Some participants used cultural wisdom or catchy phrases in ways very similar to spiritual techniques.

## Recovery mediators: bringing the contextual and personal together

During the collaborative analysis workshops the research team identified recurring issues in the accounts of recovery, within and alongside the ten themes described above. These chimed with the experiences of the involvement researchers who had undertaken the interviews. Each of the three issues identified appeared as a refrain as people described their experiences of recovery – as issues which affected them at different times in different ways, but had to be grappled with if progress towards recovery was to be sustained.

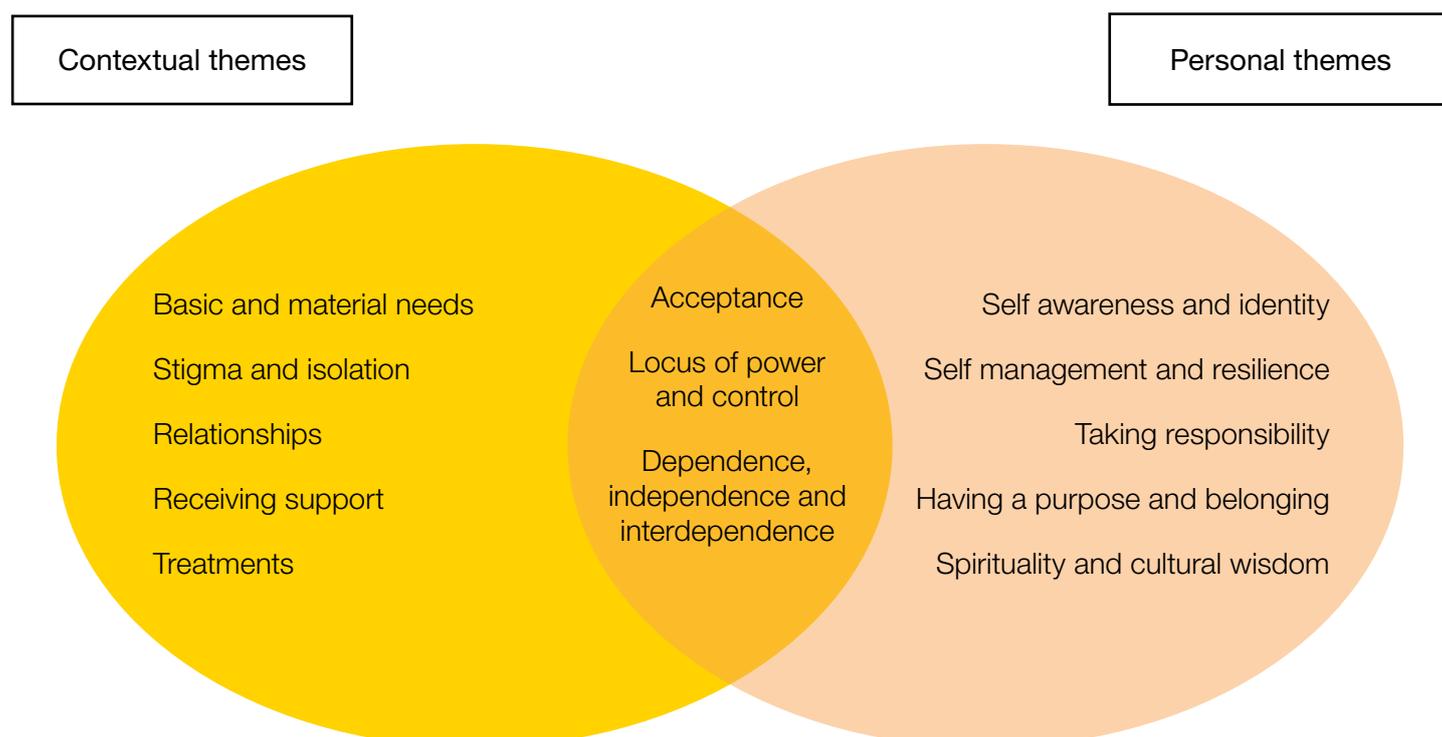
By cross-cutting the ten analytic themes they were involved in shaping the ways in which contextual and personal factors combine in individual recovery journeys (as illustrated in figure 3). Because of this mediating role we call them recovery mediators.

They are:

- a) Acceptance
- b) Locus of power and control
- c) Dependence, independence and interdependence

In agreement with other research (Brown and Kandirikira 2007; Davidson 2003), our findings and the discussions under the ten themes above show that there is no ‘one way’ to recovery. For this reason, the mediators do not in themselves indicate a concrete ‘road’ or specific ‘solution’ to recovery. The mediators articulate crucial dilemmas and challenges of living (or existential challenges) for the person in recovery, presenting a range of options as to how contextual factors and personal preferences may be combined to suit the individual situation. The recovery mediators provide generalised analytic concepts to consider these challenges and dilemmas, while remaining grounded in the variability and fluctuation of individual circumstances. The concepts are in this sense non-essentialist and

**Figure 3: Recovery mediators of contextual and personal themes**



provide a frame for change and ongoing negotiation. Like people's circumstances are in flux, ways in which contextual and personal factors combine to define individual pathways of recovery are equally so. The recovery mediators tell us about the type of issues people are dealing with in making recovery a reality.

This section presents the three mediators, and discusses how each play a role across the ten analytic themes in supporting mental health recovery. Key points from each are summarised in the end.

## Acceptance

The notion of acceptance was interpreted in various ways by participants: acceptance of self and acceptance of your situation or illness. When people became ill and afterwards, being accepted rather than rejected by others helped people come to terms with what had happened. However, participants also talked about accepting their own illness, and the consequences of that in changing lifestyle, attitude and expectations, and as a precursor to recovery.

*I was terrified of it really, before. I think I was scared of being crazy or nutty, scared of the way I was acting. But now I'm not. Maybe that's changed me. I just accept that this is the way I am, and once you've accepted it, then you can work with it. (RGS06, 1819-1825)*

Accepting experiences and what has happened, including during episodes of acute mental illness, is crucial to wellbeing and a sense of self (Larsen 2005, Wisdom et al 2008). For example, accepting the mental illness or the need to take medication or engage with other types of treatment and support. It can be very hard to accept a psychiatric diagnosis, because of the way society views mental illness. The person fears how this will affect their life: Is it in ruin? It may be easier to deny it. To be denying may be a defence mechanism – a way of coping without having to question oneself and self awareness. A person can be reluctant to face the difficulties that could have triggered the mental health crisis.

People may be pushed to acceptance when they feel that there is nowhere else to go, as discussed under the theme of taking responsibility as 'hitting rock

bottom'. As symptoms get worse, and behaviour changes, the person is more likely to notice that something is 'not right' with themselves, particularly as others may increasingly react and make comments.

Acceptance relates to belief, how one sees reality: a personal reality. By denying a mental health condition people may feel more free to be who they want to be. In this sense acceptance and denial are linked to identity. The fundamental question is how one feels able to accept oneself. Unless people accept their illness they are unlikely to go for treatment. Each individual's understanding of what has caused their situation/ experiences/ illness will make them more likely to accept particular interventions or treatments. For example, if people consider it has a psychological cause, then they are likely to be more accepting of talking therapy, whereas they are more likely to accept medication if they think the cause of the illness is biomedical.

In the early stages of mental illness it may be that the person is not aware of what they are doing or that they have a mental health problem. Accepting there is a problem can be aided by other people, and the quality of relationships is important in that process. People will listen more to and take advice from others who they feel are caring, someone trustworthy, and are less likely to take on information from people who do not demonstrate that they genuinely care.

Having a diagnosis confirmed and accepting it can be a way to secure benefits, treatment and support. Equally, the acceptance of a mental health problem by friends and family may be necessary if they are going to be called on for support in difficult situations. However, for the person it can be difficult to accept receiving support, especially if the person is anyway fighting to gain and retain control and independence. Hence, the issue of acceptance often involves strong contradictions for the person.

Feeling accepted and valued by God can be essential for some people, and it may be felt to be therapeutic and calming. However, many professionals find it difficult to accept that a person may find comfort and help in spirituality. Not

having this aspect of personal faith recognised by significant others can in itself be felt as a rejection and denial of the self.

The question of acceptance relates to stigma. It is about being accepted by others, including family and friends. Feeling accepted is closely linked to belonging, while not feeling accepted leads to feelings of rejection and isolation. Acceptance of a person's mental health condition can be harder for close relations than for friends. This may be because they are more involved and feel more responsible. Or perhaps they feel at fault. It may also be that they think the mental illness will reflect badly on them – that the stigma 'rubs off' – and they feel ashamed and anxious of others' condemnation. It can be easier to feel fully accepted by other people who have had similar experiences of mental health problems. Such sharing of experience can provide crucial help when people feel most vulnerable and lonely. However, this need to feel accepted can drive people to socialise mainly with other people who use mental health services, cutting themselves off from mainstream society.

*It's meeting like-minded people, or people who know what it's like from others that matter to them. It's working with people like that too, that would help. So living in a community, in a way, of likeminded people who know what it's all about and not being afraid to tell those who you hope you can trust and to be brave enough to say that 'well, if they didn't understand then so be it', rather than to be crushed by lack of understanding which is what happened to me for so many years. (AH01, 904)*

Sometimes other people cannot accept the illness or the difficulties experienced by the person, and therefore seem to reject the person completely. This feeling of not being accepted adds to the difficulty of having a purpose and a role in society as well as a mental health problem. This has an important impact on self-confidence and wellbeing. Being accepted and being part of a bigger picture gives a sense of purpose and a feeling that it is possible to contribute to society, both of which combat a sense of emptiness.

## Locus of power and control

The issue of power, and where it is located, resonated throughout the data, cross-cutting and binding together the ten analytic themes in a number of ways. The system of mental health services can be felt to be immensely powerful and disempowering to people who are using it. Becoming ill often equates to a sense of losing control of one's whole life; and control must be reclaimed for recovery to be effective and long-lasting. The notion of power relates closely to that of control: having control and the power this gives, or being powerful and able to gain control. In our data the two concepts are inseparable and complementary, which is why we speak of 'power and control', but apply each depending on the context.

Perhaps most significantly, mental health recovery relates to the degree to which people experience having control over their own lives: being able to determine one's own destination, or being controlled by others. Often, participants described how they felt having no control and power, and they had to work hard to gain this. When meeting with mental health professionals people had often felt that it was the staff who had all the power and were in control of making decisions about treatment. In these situations participants felt they were not given real choice.

*I can become dependent like a baby in four hours in a psychiatric setting. So that can do damage. So you have to be able to receive what is useful and to discard what is damaging. (JB02, 308-312)*

Being in charge of personal medication could be a way to gain a greater sense of control. However, the medication can in itself be perceived as being 'in control'. People can feel controlled by their medication, and feel a loss of their own power and sense of self – 'it's medication that is making you well' – and recovery does not then originate from the individual. This can contribute to a sense of being powerless. Hence, an understanding of the illness or condition and strategies for self-management play an important role in engaging on a journey of recovery.

The question of the locus of power is equally of importance in respect to non-professionals such as family and friends. There were examples within the data of people speaking of their families making them ill and having the power to exclude them. This may be a consequence of having been unwell: close family and friends as a consequence start to perceive the 'ill person' with less credibility. For some, gaining some sense of distance from the family could be a way to regain a sense of being in control. Developing relationships where power and control were felt to be in balance were helpful steps towards recovery. Participants described how being with other mental health service users could contribute to a sense of empowerment – ensuring that personal experiences and views are validated and valued.

Mental health stigma from wider society can be extremely disempowering, and experienced as a control mechanism. It permeates how people see each other, and informs how people are going to behave by removing opportunities and choices within society (e.g. work and training). If people are excluded from society they lose power and control. People can also lose and disempower themselves by internalising the social stigma of mental illness. They

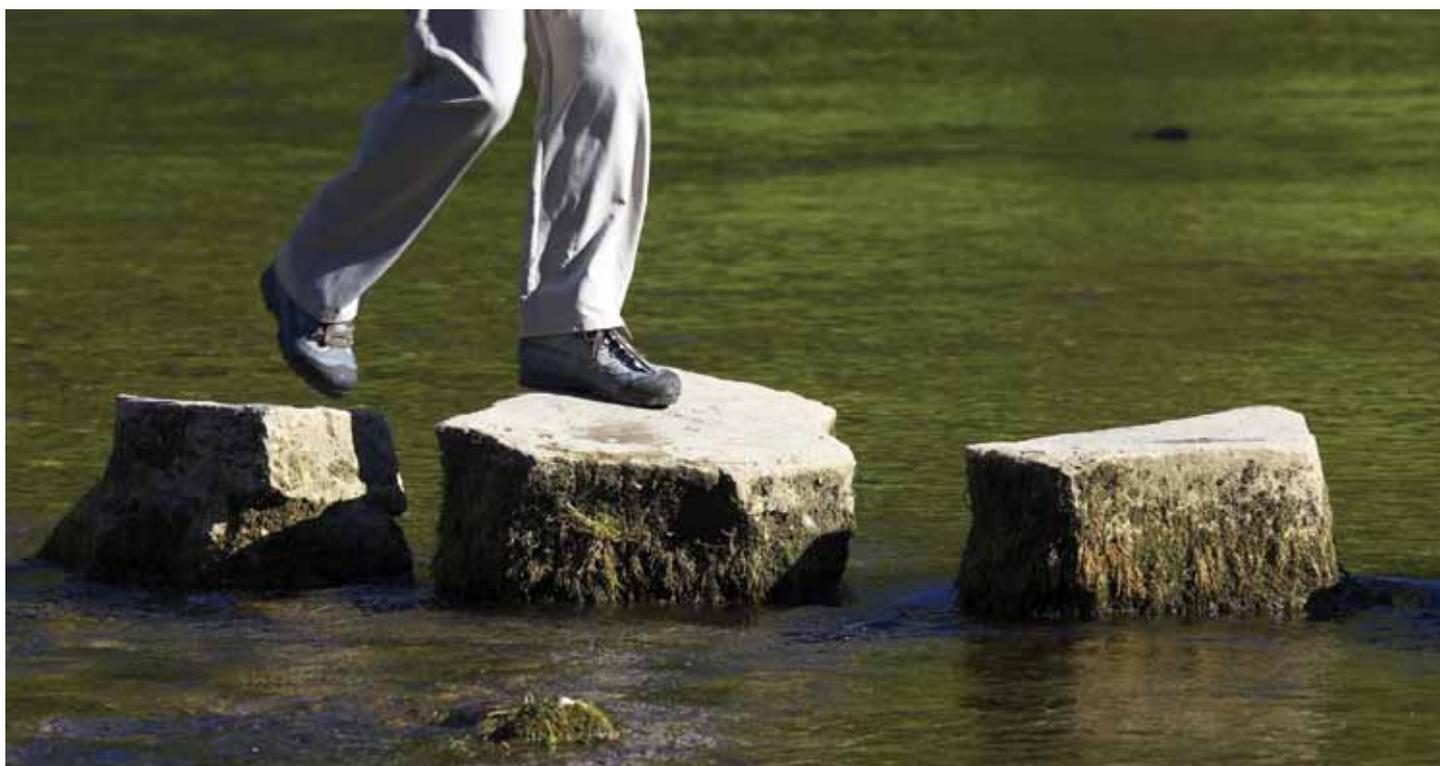
may feel that getting a job or a partner is beyond their grasp.

Control also has a very concrete and material expression. For those relying on the state for financial support there is a real sense in which the state, and the officials who represent it, hold the financial power and control. They retain the ultimate right to make demands on people's lives and actions. Access to appropriate housing was another material expression of power. Participants stressed the importance of being able to control their own space, by being able to close their front door, and deciding who to let in.

*I quite like having my own space. I decide who I let in, who I don't let in. (RGS04, 128-129)*

Being disempowered may lead to people feeling less than human. Mental health recovery is fundamentally about reclaiming a personal identity and developing a renewed sense of self. This links with taking responsibility for the situation and relocating a feeling of personal power rather than feeling that power and control lie elsewhere, outside the self.

*Recovery is about getting things together. Making something of yourself, sorting your life out, where you get back into the world. (RGS02, 1526-9)*



Having a purpose and being able to give back are important ways to feel empowered and valuable. Some participants talked about the comfort in feeling close to the power of God. Others developed self-management strategies that gave them a greater sense of being in control in their everyday lives, and when faced with crisis.

### Dependence, independence and interdependence

The triple notion of dependence, independence and interdependence as a mediator of mental health recovery highlights the crucial role of relationships as emphasised in our data. When ill, people often find themselves in a position of enforced dependency. Recovery encompasses a move towards a balanced combination of dependence, independence and interdependence, varying according to the specific situation or relationship.

People described how they have felt dependent on mental health services, and that it had been necessary for them to break this dependency – both mentally and actually – through actions like taking responsibility and finding ways to ‘be in control’. Some feel stuck in a dependent role, can become institutionalised within mental health services and may find it threatening to move out of this.

*At one point I didn't want to do anything that made people think that I was recovered, because they'd expect something. Or they might expect too much from me. So you know, I held myself back as well, because recovery was too frightening. (PJB03, 643-654)*

Others feel a great urge to become independent, but may not recognise the importance of interdependent relationship-building or find it very challenging – and become isolated as a result. This is particularly true where people may feel a heavy burden of stigma. It is a challenge to develop an independent identity while recognising one's interdependence with others, rather than putting oneself into isolation.

*However much my friends had helped me, to some extent, they were actually holding me back. They were effectively, they'd got into the habit of treating me as ill, but expecting more from me despite that. (AH06, 553)*

The difficulty is that breaking out from a position of dependency depends on each particular relationship, and the willingness of both parties to allow this relationship to change. Moving towards assuming greater power and control over one's own treatment can be a way in which the relationship with mental health professionals can move from assumed one-sided dependency towards recognising interdependency.

*I was asked to escort this lady that was going to the computer class but she found it really difficult to get out... I thought: 'oh god, I can't do that. I know, I'll go to [named staff] and I'll go to [other named staff] and they'll sort of kick up a fuss and tell the tutor off.' And they just thought, 'oh, it's a very good idea.' [I thought:] 'No, it's not a good idea, it's a terrible idea.' Anyway, I supported her to get to the class and I felt so good that I... I didn't feel as I could support myself and it just made me feel that, you know, that I had something to offer. (PJB03, 82-115)*

Having a purpose and helping others can also be an important way for people to develop a new role in relationships – they feel empowered by reversing their feeling of dependence by giving some help to others. Peer and self-help groups can be important vehicles for this, as can voluntary or community engagement activities. Recovery is for many characterised by becoming independent in choosing and developing relationships which are not characterised by dependency only, but by a balance of the three states: dependence, independence and interdependence.

### Summary of recovery mediators

**Acceptance:** The issue of acceptance is crucial for personal recovery in respect to a range of issues to do with self and others. Many participants emphasised that the decision to accept an illness or pattern of distress was a turning point in seeking, and at some stage finding, solutions or ways to improve life. For some this included finding a diagnosis and treatments which were acceptable and effective. Some described how denial had been a coping strategy that prevented them from starting the process of recovery. The issue of acceptance also involved other people and their attitudes – how friends, family and colleagues reacted to them having mental health problems and the lack or



presence of support and encouragement. In this sense the negative responses of denial and rejection are similar negative expressions of acceptance at the contextual and personal levels.

**Locus of power and control:** Some people spoke of illness having developed when their assumed control over life was shattered by a crisis or event outside their control. Receiving psychiatric treatment often represented a complete loss of power and control – especially if under section or in prison. Moving into recovery signified abandoning a victim role, taking an aspect of control back, and recognising the personal responsibility for life's future course, in spite of rather than because of the past breakdown and failure. Some participants described how they found help in following personal self management regimes and the importance of recognising one's own limitations, and possible stress or trigger points.

Organising the physical space and environment could also be useful in assuming a sense of control to assist recovery – even when it meant starting with the small first step of putting in order the sock drawer.

### **Dependence, independence and**

**interdependence:** Many respondents referred to the importance of dependency and independence in aspects of their lives, including practical, financial, social and health. Being ill usually involved a feeling of loss of independence, as work, friends, family, health, plans, future expectations and sometimes homes were lost. Dependency was more difficult or destructive for some than others – some were acutely conscious of processes of learned helplessness and institutionalisation. Some responded by rejecting others as a defence against being rejected, becoming isolated in the process. This affected relationships with family, friends, colleagues and neighbours as well as the expectation and actual stigma from wider society.

Recovery seemed to involve an awareness of the importance of oneself and one's own needs, in relation to other people, and their needs - perhaps as partners, friends or carers. Some participants related how they sought to 'give something back' to society or had developed compassion for others through their own experiences. These were ways to re-establish interdependency and mutuality in social life. Participants frequently stated their motivation to be interviewed lay in their desire to use their own experiences to help other people through periods of distress and illness.

## Conclusions

This study places the person at the centre of the process of mental health recovery, demonstrating how contextual and personal circumstances work together to shape the individual journey. The findings highlight the impact of concrete circumstances and opportunities in the life of the person. While the personal attitude, motivation and 'drive' are critical for recovery, they are not the only elements required. Equally, recovery does not happen automatically as a result of any particular circumstances and the interventions or opportunities provided for the person.

While previous research has emphasised the individual struggle to embark on a journey of recovery (e.g. Pitt et al. 2007, Baker and Strong 2001) and other publications describe the support required for recovery to become a reality (Slade 2009), the main contribution of this study is to illustrate how both dimensions are important to consider. Personal factors such as the person's sense of self, having a purpose and being familiar with a range of coping strategies or self management techniques are all crucial. But recovery can only become a reality when the context and available opportunities allows the person to develop. This involves having basic needs covered, being in helpful relationships and receiving support and treatment to help control or minimise the impact of mental health problems.

The recovery mediators describe the dilemmas and challenges of living that meet the person in recovery, presenting a range of options as to how contextual factors and personal preferences may be combined to suit the individual situation.

**a. Acceptance:** It is crucial that the person feels accepted by others and finds a way to accept themselves and their condition in order to progress towards recovery.

**b. Locus of power and control:** Mental illness often leaves the person feeling deprived of any sense of having control over their own lives. Recovery involves gaining this, often by starting small through developing self-management techniques.

**c. Dependence, independence and interdependence:** Often people with mental illness feel dependent on others and on treatments. Finding a balance between regaining independence and recognising interdependency is essential to recovery.

Recovery is neither something done to the person nor something that can be achieved by the person in isolation. It is about how the person relates to their environment and the role that the environment allows for the person. Recovery happens in the space in-between person and context – context referring to personal relationships, physical space and other economic, social and cultural factors. In particular the role and quality of personal relationships were highlighted by participants as impacting on recovery.

Aside from these findings contributing to insight regarding mental health recovery, our development of an innovative research methodology provides an additional outcome from the study. Involving people with lived experiences in a collaborative reflexive approach proved highly successful in generating insightful findings and a new level of analytic sophistication. The combination of personal engagement in retrieving meaningful data and collaborative group examinations of similar and contrasting data examples provided additional validity of the findings. And it allowed a higher level analytic generalisation through the identification of the recovery mediators.

## References

- Anonymous (1989) 'First person account: How I've managed my chronic mental illness', *Schizophrenia Bulletin* 15: 635-640.
- Andresen, R., Oades, L. and Caputi, P. (2003) 'The experience of recovery from schizophrenia: towards an empirically validated stage model', *Australian and New Zealand Journal of Psychiatry* 37: 586-594.
- Andresen, R., Caputi, P. and Oades, L. (2006) 'Stages of recovery instrument: development of a measure of recovery from serious mental illness', *Australian and New Zealand Journal of Psychiatry* 40: 972-980.
- Baker, S. and Strong, S. (2001) *Roads to Recovery: How People with Mental Health Problems Recover and Find Ways of Coping. Mind.*
- Barrett, R.J. (1996) *The Psychiatric Team and the Social Definition of Schizophrenia: An Anthropological Study of Person and Illness*, London: Cambridge University Press.
- Bentall, R. (2003) *Madness Explained: Psychosis and Human Nature*. Allen Lane: London.
- Boyle, M. (1990) 'The non-discovery of schizophrenia? Kraepelin and Beuler reconsidered', in: RP Bentall (ed.) *Reconstructing Schizophrenia*, London: Routledge, pp. 3-22.
- Brown, W. and Kandirikirira, N. (2007). *Recovering mental health in Scotland. Report on narrative investigation of mental health recovery*. Glasgow: Scottish Recovery Network.
- Deegan, P. (1988) 'Recovery: the lived experience of rehabilitation', *Psychosocial Rehabilitation Journal* 19: 91-97.
- Davidson, L. (2003). *Living Outside Mental Illness: Qualitative Studies of Recovery in Schizophrenia*. New York: New York University.
- Diamond, R.J. (2006) 'Recovery from a psychiatrist's viewpoint', *Postgraduate Medicine, Special report: New directions in schizophrenia*: 54-62.
- Giddens, A. (1991) *Modernity and Self-Identity*. Cambridge: Polity Press.
- Hamilton, S. (2009) 'Money', in J. Wallcraft, B. Schrank and M. Amering (eds.) *Handbook of Service User Involvement in Mental Health Research*, pp. 213-226. Chichester: John Wiley & Sons.
- Harding, C.M., Brooks, G.W., Ashikaga, T., Strauss, J.S., Breier, A. (1987) 'The Vermont longitudinal study of persons with severe mental illness. I: Methodology, study sample, and overall status 32 years later', *American Journal of Psychiatry* 144: 718-726.
- Hopper, K. (2007) 'Rethinking social recovery in schizophrenia: What a capabilities approach might offer', *Social Science & Medicine* 65: 868-879.
- Isaac, M., Chand, P. and Murthy, P. (2007) 'Schizophrenia outcome measures in the wider international community', *British Journal of Psychiatry* 191 (suppl. 51): 71-77.
- Jablensky, A. (2009) 'Course and outcome of schizophrenia and their prediction', In M.G. Gelder, N.C. Andreasen, J.J. Lopez-Ibor and J.R. Geddes (ed.) *New Oxford Textbook of Psychiatry* (Vol. 1), 2nd (edn), pp. 568-578. Oxford: Oxford University Press.
- Jacobson, N. (2004) *In recovery: The making of mental health policy*. Nashville: Vanderbilt University Press.
- Larsen, J.A. (2005) 'Becoming mentally ill: Existential crisis and the social negotiation of identity', In V. Steffen, R. Jenkins, and H. Jessen (eds.) *Managing uncertainty: Ethnographic studies of illness, risk and the struggle for control*, pp. 197-223. Copenhagen: Museum Tusculanum Press.
- Larsen, J.A. (2007) 'Symbolic healing of early psychosis: Psychoeducation and sociocultural processes of recovery', *Culture, Medicine and Psychiatry* 31: 283-306.
- Lieberman, J.A., Drake, R.E., Sederer, L.I., Belger, A., Keefe, R., Perkins, D. and Stroup, S. (2008) 'Science and recovery in schizophrenia', *Psychiatric services* 59(5): 487-96.
- Mental Health Foundation (2002) *Spirituality and Mental Health. Updates* 4(6).
- Mossman, D. and Lehrer, D.S. (2000) 'Conventional and atypical antipsychotics and the evolving standard of care', *Psychiatric Services* 51: 1528-1535.
- Pitt, L., Kilbride, M., Nothard, S., Welford, M., and Morrison, A.P. (2007) 'Researching recovery from psychosis: a user-led project', *Psychiatric Bulletin* 31: 55-60.
- Riach, K. (2009) 'Exploring participant-centred reflexivity in the research interview', *Sociology* 43(2): 356-370.
- Ridgway, P. (2001) 'Restorying psychiatric disability: learning from first person narratives', *Psychiatric Rehabilitation Journal* 24: 335-343.
- Slade, M. (2009) *100 ways to support recovery: A guide for mental health professionals*. London: Rethink.
- Trivedi, P. and Wykes, T. (2002) 'From passive subjects to equal partners: Qualitative review of user involvement in research', *British Journal of Psychiatry* 181: 468-472.
- Whitehorn D, Lazier L, and Kopala L (1998) 'Psychiatric rehabilitation early after the onset of psychosis', *Psychiatric Services* 49: 1135-1147.
- Whitwell, D. (1999) 'The myth of recovery from mental illness', *Psychiatric Bulletin* 23: 621-622.
- Wisdom, J.P., Bruce, K., Auzeen Saedi, G., Weis, T. and Green, C.A. (2008) "'Stealing me from myself": identity and recovery in personal accounts of mental illness', *Australian and New Zealand Journal of Psychiatry* 42(6): 489-495.
- World Health Organisation (1979) *Schizophrenia: An International Follow-up Study*, New York: John Wiley & Sons.

# Appendix A

## Recovery narratives project – Interview schedule

### Introduce yourself (and your co-researcher)

Run through the following documents before starting the interview

#### 1. Information sheet:

- Ask if the interviewee has had a chance to read it
- Briefly go through the information sheet – summarising key points (Purpose of the interview: ‘The aim of this interview is to explore your understanding of recovery, and the different things that you have found helpful along the way’).
- Explain that the interview will be:
  - Anonymous – their names will not be written down on the tape or the transcript of the tape
  - Their name will not be linked to the transcript in any way
  - Confidential within the research team (However, if they should disclose to you that they might be at risk of harm or of causing harm to someone else, that you cannot guarantee confidentiality under those circumstances)
- Ask the interviewee whether they have any questions to ask you about the project

#### 2. Consent form

- Ask interviewee to read and complete/ sign the form

### Turn on recorder

### Own experience

Explain that you have personal experience of mental health services/ mental health problems.

#### 1. First of all, can I ask you a bit about yourself: Where do you see yourself now in relation to your mental health?

##### Prompts:

- How do you feel you got to where you are now?
- Is there anything that has helped you to get to this point?

#### 2. Looking back, can you identify any turning points (along the way)?

##### Prompts:

- Can you say what made this a turning point?
- What was different for you before / after?

**Turning point:** a time or situation in your life where things changed in a significant way

#### 3. Can you tell me about any people who have been important to you (along the way)?

##### [SHOW CHECKLIST 1]

##### Prompts:

- In what ways have they been important or helpful to you?
- Can you tell me a bit more about [that person] and how they were helpful to you?
- Does trust play a role?

#### 4. Can you tell me about any things that you have found helpful (along the way)?

[SHOW CHECKLIST 2]

##### Prompts:

- a) Medication
  - b) Looking after yourself
  - c) Interests, hobbies and activities
  - d) Spirituality
- In what ways has xx been helpful to you?
  - How important is xx to your mental health?
  - Have there been any surprises?
  - Have different things been helpful at different times?

#### 5. Can you tell me about anything that has been unhelpful to you?

[AGAIN, SHOW CHECKLIST 2]

##### Prompts:

- Can you tell me a bit more about that?
- In what way(s) has xx been unhelpful?
- Do you feel it has held you back?

#### 6. Is there anything that you wish had been there to help you (along the way)?

##### Prompts:

- Refer to Q4 or Q5
- In what way(s) do you think that might have helped you?

## Recovery questions

#### 7. Does the idea of recovery mean anything to you personally?

##### Prompts:

- Can you tell me a bit more about that?
- Do you consider yourself to be in recovery now?

#### 8. Is there anything that might represent recovery for you – or indicate that you are in recovery?

##### Prompts: *for example:*

- Do you have a goal or an aim that might mean recovery to you?
- Do you have an image or symbol of what recovery means to you?
- ... please describe it / explain what it means to you

#### 9. Is there anything you have gained from your experience?

##### Prompts:

- Positive change
- Things you have learned
- Change in values or attitudes

**10. Can you tell me about any achievements in your life? – anything you feel proud of?**

**Prompts:**

- How important was that for you?
- Is there anything you would like to achieve in the future?

**Ending questions**

**11. Looking back, can you identify anything that you would recommend to other people to help them on their journey?**

**Prompts:**

- Why...?
- Is there anything else you would recommend?

**12. Is there anything that you would like to have been asked about in this interview, that you feel we have missed out?**

**13. Looking back over the interview, are there any questions that you found:**

- interesting?
- difficult?
- thought-provoking?

**14. Are there any questions you would like to ask me?**

**Thank you!**

**[ends]**

**Checklist 1: People**

**Family and friends**

Friends	Support / self-help groups
Partner / Spouse	Other service users
Parents	Faith or community groups
Children	Colleagues
Neighbours	

**Professionals**

Psychiatrist	Social Worker
GP	Care Manager
Nurse / CPN	Voluntary sector staff
Occupational therapist	Helpline workers
Psychologist	Complementary therapists
Therapist	Other
Counsellor	

## Checklist 2: Strategies, activities and other things

These are some of the things that other people have found helpful at times. Is there anything on this list that you have found helpful?

Medication	Diagnosis
Looking after yourself	Appearance
Interests, hobbies and activities	Positive thinking (including self help)
Spirituality	Helplines / Online resource
Acceptance	Political activity
Environment – e.g. Housing, nature, gardening	Information
Therapies – e.g. talking therapies, Complimentary, Arts	Occupation, work, study
Pets	Money
Hospital treatment	Trust

## About Rethink

Rethink, the leading national mental health membership charity, works to help everyone affected by severe mental illness recover a better quality of life. We provide hope and empowerment through effective services and support to all those who need us, and campaign for change through greater awareness and understanding.

## Join us

Rethink works tirelessly to improve the lives of those affected by severe mental illness. If we are going to continue to succeed we'll need your help. You can support us in any number of ways for example becoming a member, making a donation or becoming a campaigner.

Please support us today to help transform the lives of generations to come. To find out how you can help visit [www.rethink.org](http://www.rethink.org), phone 0845 456 0455 or email [info@rethink.org](mailto:info@rethink.org)

### Information on mental health

For more information about Rethink publications and other products on mental health, please visit [www.mentalhealthshop.org](http://www.mentalhealthshop.org) or call 0845 456 0455.

### Make a donation

We cannot achieve our goals without the vital funds donated by supporters. Donate today by calling 0845 456 0455 or donate online [www.rethink.org](http://www.rethink.org)

### Acknowledgements

The insights presented in this report emerge from the experiences and reflections that the 48 research participants shared with us. For this we are immensely thankful, and we very much enjoyed the opportunity to meet them all. During engaging training workshops Alison Faulkner provided a generous and brilliant role model for how it is possible to use personal experience in research and become an expert in the field. Thanks also to the many mental health services and networks around the country which assisted us in recruiting participants and providing space and support for the interviews. Finally, we would like to thank AstraZeneca for providing a sponsorship grant towards this independent programme.

# rethink

Working together to help everyone  
affected by severe mental illness  
recover a better quality of life

A copy of this report is free to download from  
[www.rethink.org/intotheworld](http://www.rethink.org/intotheworld)

## Report authors

Sarah Ajayi, Terry Bowyer, Alice Hicks, John Larsen,  
Peter Mailey, Ruth Sayers, Roger Smith and two anonymous authors

For further information on Rethink  
Phone 0845 456 0455  
Email [info@rethink.org](mailto:info@rethink.org)  
[www.rethink.org/research](http://www.rethink.org/research)



Printed on 100% recycled paper



Registered in England Number 1227970. Registered Charity Number 271028  
Registered Office 89 Albert Embankment, London, SE1 7TP

Rethink is the operating name of National Schizophrenia Fellowship, a company limited by guarantee

© Rethink 2009  
RET0401