

University of Nottingham  
Institute of Work, Health and Organisations

**Doctorate in Clinical Psychology**

**2009/2010**

**Service-Users' Experiences of an Early Intervention in  
Psychosis Service: An Interpretative  
Phenomenological Analysis**

**Katy Harris**

Submitted in part fulfillment of the requirements for the  
**Doctorate in Clinical Psychology**

## **Acknowledgements**

I would like to take this opportunity to recognise all those affiliated with the University of Nottingham Doctorate in Clinical Psychology and the National Health Service Trust in which this research was conducted, who have supported me during the completion of this research thesis.

I would like to thank Christine Collinson for agreeing to supervise this study. I appreciate all the hard work and time she dedicated to making this research possible and for supporting me throughout the process.

Care co-ordinators for the Early Intervention in Psychosis service were instrumental in recruiting the participants for this study and I would like to thank them for all their time and effort.

I would also like to thank my academic supervisor Roshan das Nair for his time and advice throughout this thesis and his constructive comments throughout the process.

Importantly, I would like to thank the participants who took part for taking the time to share their stories with me and for making the study possible.

Finally, I would like to thank Jamie and my close family and friends for all their love and support during the last three years. I couldn't have done it without you.

## Table of Contents

	Pages
Thesis Abstract.....	1 - 2
Statement of Contribution.....	3
Journal Paper.....	4 - 32
References.....	33 - 36
Extended Paper.....	37 - 147
Extended Background.....	37 - 69
Extended Methodology.....	70 – 95
Extended Results.....	96 - 124
Extended Discussion.....	125 - 147
References.....	148 - 166
Appendices.....	167 - 213
Appendix A: Note for Contributors	
Appendix B: Participant Information Sheet	
Appendix C: Consent Form	
Appendix D: Full NHS Research Ethical Approval	
Appendix E: Semi-Structured Interview Schedule	
Appendix F: Reflective Diary Extracts	
Appendix G: Extract from Audit-Trail	
Appendix H: Demographic and Service Information Sheet	
Appendix I: Procedural Summary Flow Diagram	

## Thesis Abstract

**Objectives:** Previous research regarding Early Intervention in Psychosis (EIP), has mainly adopted quantitative methodologies. Studies have focused on researching the effectiveness of EIP services, compared to treatment as usual and their impact on reducing delay in the initiation of appropriate interventions. Personal experiences of psychosis have been widely explored using qualitative methodologies; whereas, studies focusing on services users' experiences of EIP services, are small in number. This study aimed to research service-users' experiences of being in contact with an EIP service; specifically to explore how this experience has impacted on their view of psychosis and their current life situation.

**Design:** Interpretative Phenomenological Analysis (IPA) was used to conduct an in-depth qualitative study of a small sample of EIP service-users, in order to explore their experiences of being in contact with the service.

**Method:** Semi-structured interviews were conducted with eight service-users who had been receiving a service from an EIP team for more than two years and were recruited using a purposive sampling method. Interviews were audio-recorded, transcribed verbatim and then analysed using IPA.

**Results:** Five super-ordinate themes, developed from the analysis, are discussed under the headings: *Stigma*, *Relationships*, *Understanding the experiences*, *Sense of agency* and *Impact on sense of self*. Sub-themes of these super-ordinate themes are also discussed. In addition, a minor theme, *An Intervention with a start and an end*, is also discussed.

**Conclusions:** The themes developed from the analysis were envisioned as representing an overarching theme of '*A personal journey of recovery*', which was influenced by participants' involvement with the EIP service. Themes are discussed both collectively and individually, in relation to previous research. Clinical implications include the need for EIP services, as with other mental health services, to find ways to promote recovery and create opportunities for agency and control. The extended discussion includes; an appraisal of both the strengths and limitations of the research, considerations for future research and a reflection on some of the wider issues related to the study.

## **Statement of Contribution**

### **Project design:**

Katy Harris, Christine Collinson and Roshan das Nair

### **Applying for ethical approval:**

Katy Harris, Christine Collinson and Roshan das Nair

### **Writing the review of the literature:**

Katy Harris

### **Recruiting participants:**

- Identifying potential participants: Christine Collinson
- Approaching potential participants: EIP service Care co-ordinators
- Recruitment (written consent): Katy Harris

### **Data Collection:**

- Conducting interviews: Katy Harris
- Collecting demographic data: EIP service Care co-ordinators

### **Data Analysis:**

- Transcribing interviews: Katy Harris
- Analysing transcripts: Katy Harris
- Constructing final themes for thesis/ journal article: Katy Harris, Roshan das Nair, Christine Collinson

## **Journal Paper**

### **Service-Users' Experiences of an Early Intervention in Psychosis Service: An Interpretative Phenomenological Analysis**

**Journal:** *Psychology and Psychotherapy: Theory, Research and Practice*

Recommended word count 5000 and abstract 250 (see Appendix A for 'Notes for contributors')

**Katy Harris <sup>1</sup> Christine Collinson <sup>2</sup> and Roshan das Nair <sup>3</sup>**

<sup>1</sup>Trent Doctorate in Clinical Psychology, University of Nottingham, UK.

<sup>2</sup> Early Intervention in Psychosis Service, Nottinghamshire Healthcare NHS  
Trust, UK.

<sup>3</sup>Institute of Work, Health and Organisations, University of Nottingham, UK.

Total thesis word count: **37, 388**

Journal article word count **4,999** (excludes tables, references, appendices and all references to extended paper/appendices)

Journal article word count total **5,288**

Journal abstract word count: **233**

## Abstract

**Objectives:** Previous research regarding Early Intervention in Psychosis (EIP) has mainly adopted quantitative methodologies, in order to study the effectiveness of EIP services. Research studies which have explored service-users' experiences of EIP services are small in number. This research aimed to explore service-users' experiences of being in contact with an EIP service, its impact of their experience of psychosis and current life situation.

**Design:** Interpretative Phenomenological Analysis (IPA) was used to conduct an in-depth qualitative study of a small sample of EIP service-users, in order to explore their experiences of being in contact with the service.

**Method:** Semi-structured interviews were conducted with eight service-users who had been receiving a service from an EIP team for more than two years and were recruited using a purposive sampling method. Verbatim interview transcripts were analysed using IPA.

**Results:** Five super-ordinate themes, developed from the analysis, are discussed under the headings: *Stigma, Relationships, Understanding the experiences, Sense of agency* and *Impact on sense of self*. Sub-themes of these super-ordinate themes are also discussed.

**Conclusions:** The themes developed from the analysis were envisioned as representing an overarching theme of '*A personal journey of recovery*', which was influenced by participants' involvement with the EIP service. Clinical implications include the need for EIP services, as with other mental health services, to find ways to promote recovery and create opportunities for agency and control. Future research directions are also discussed.



## **Background**

Early Intervention in Psychosis (EIP) services are specialist multidisciplinary teams, working with individuals between the ages of 14 and 35 (who experience their First Episode of Psychosis [FEP]) and are an integral part of mental health services (Department of Health [DoH], 2000; 2001), within the United Kingdom (UK). These services focus on reducing delay in receiving intervention for early psychosis and providing sustained intervention throughout the early phase (Reading & Birchwood, 2005). EIP services were developed following the 'critical period' hypothesis (Birchwood, Todd & Jackson, 1998) and take an optimistic view of recovery; aiming to address the symptoms of psychosis and the social context, whilst also considering how it is experienced by the individual (Sainsbury Centre for Mental Health, 2003). (See extended background).

Early access is crucial to the EIP model, which includes an assertive outreach approach to engagement and procedures to remove service barriers (DoH, 2001). Therefore, initial research focused on reducing delay in the initiation of treatments for FEP, however, this has produced mixed outcomes (e.g. Marshall et al., 2005), due to difficulties in accurate measurements and definitions. Other quantitative research focusing on the effectiveness of EIP services (e.g. Bertelsen et al., 2008; Garety et al., 2006), has also shown mixed outcomes and is an ongoing research area. (See extended background).

Although quantitative studies aim to establish whether or not services are effective, qualitative research is important in understanding why an intervention is effective (Medical Research Council [MRC], 2000). Qualitative research aims

to understand peoples' experiences as they encounter and live through the events (Elliott et al., 1999) and attempts to interpret the meanings people bring to them (Denzin & Lincoln, 2005). (See extended background).

Previous qualitative studies have explored peoples' subjective experiences of psychosis, how individuals recognise and respond to psychosis (Hirschfeld, Smith, Trower & Griffin, 2005; Judge, Estroff, Perkins & Penn, 2008), personal experiences of hope (Perry, Taylor & Shaw, 2007) and recovery (e.g. Ridgway, 2001) in psychosis. (See extended background).

In a recent publication (National Institute for Health and Clinical Excellence [NICE], 2009), narratives from people with a diagnosis of schizophrenia discussed the importance of good relationships with mental health professionals and service-user agency, in treatments decisions. There is a paucity of qualitative research exploring service-users' experiences of EIP services. O'Toole et al. (2004) conducted a focus group evaluation of service-users' experiences of a UK specialist intervention for FEP. Positive views included the 'human' approach, involvement in decision making and positive impact on confidence. The authors recognised the potential for bias due to the inclusion of self-selected participants. It is also suggested focus groups have a tendency to produce consensus and are not ideal for exploring individual experiences (Newton, Larkin, Melhuish & Wykes, 2007). (See extended background).

Larsen (2007) used a person-centred ethnographic approach, to study a Danish EIP service. The service was seen to offer support and explanations, which

helped service-users understand their difficulties. Both similarities and differences in the recovery models and therapeutic interventions offered by different staff were identified. However, this study only offers limited insights into a UK EIP model, as the author acknowledged the inevitable contextual differences between Danish and UK services. (See extended background)

Other studies have either focused on non-specialist services for psychosis, (Barker, Lavender & Morant, 2001; McKenzie, 2006) or have reported limited qualitative data from non-UK EIP services (Theuma, Read, Moskowitz & Stewart, 2007). EIP services are specialist teams which adopt a recovery-focused approach aiming to positively impact on service-users lives and views of their experiences, whilst also reducing stigma associated with psychosis and the barriers to accessing services (DoH, 2001). Due to the specialist team delivery and recovery focus of these services and the small number of qualitative studies identified, a more in-depth understanding of service-users' experiences of a UK EIP service approach was required. Therefore the aim of this current research was to:

- Explore what is it like from a service-users perspective to be in contact with an EIP service (UK model), using an in-depth qualitative research method.
- Specifically, to explore how being in contact with the service has impacted on their view of their psychosis and their current life experiences. (See extended background)

## **Method**

### **Participants**

Participants were recruited from a local NHS EIP service, comprising of two multidisciplinary teams (including a psychologist, psychiatrists and community psychiatric nurses) covering both the city and county. The service was established in 2005, in-line with national guidelines (DoH, 2001) and provides a three year service to individuals aged 18- 35. (See extended methodology)

Eight participants were recruited, using a purposive sampling method and had all been in the EIP service for between 2 years and 2 years and 11 months (due to changes in service provision in the last month). Those with the longest time in the service were approached first, as they had the most experience of the EIP service. The Interpretative Phenomenological Analysis (IPA) (Smith & Osborn, 2003) process was optimised by only including participants who could attend the interview, without the need for an interpreter. (See extended methodology).

### **Recruitment**

Potential participants who met the inclusion criteria, were identified by the EIP Clinical Psychologist and were approached by their Care co-ordinator (all service-users are allocated a staff member be their Care co-ordinator and their primary contact with the service), who provided them with an information sheet (Appendix B). Interested service-users gave verbal consent to be contacted by the lead researcher. Written consent (see Appendix C) was obtained by the lead researcher prior to the interview.

If for any reason (e.g. impact of medication/ symptoms of psychosis on cognition) the service-user was considered not to have capacity to make an informed decision, or was judged to be a significant risk to themselves or others, they were excluded from the study. Full NHS Research Ethical Approval (Appendix D) to conduct this research was obtained in advance. (See extended methodology).

### **Data Collection**

The lead researcher conducted all semi-structured interviews, which were audio-recorded and ranged from 45 to 110 minutes. Participants were told the purpose of the interview was to discuss their experiences of being in contact with the EIP service and interviews were flexibly guided by an interview schedule (Appendix E). (See extended methodology).

### **Analysis**

As participants were given the opportunity to talk about their experiences, the chosen method of analysis was IPA (Smith & Osborn, 2003). This approach aims to understand how participants make sense of and give meaning to their experiences and is concerned with the individual's personal perceptions of an event, as opposed to producing an objective record. The meanings people attach to their experiences are explored through the researcher engaging in a process of interpretation (Smith & Osborn, 2003).

Interviews were transcribed verbatim and analysed by the lead researcher, using the IPA method outlined by Smith and Osborne (2003) as a guide. Each

transcript was engaged with separately and initial notes were transformed into emerging themes. Connections between emerging themes were identified to allow the combination of separate themes into super-ordinate themes. A master list of themes was created for each participant and newly emerging themes were compared against earlier transcripts. Themes from interviews were combined to construct a final table of super-ordinate themes. (See extended methodology).

### **Quality Assurance**

As IPA relies on the researcher's interpretation of the data, it is important to ensure the interpretations given are as trustworthy and credible as possible.

Standards for conducting good qualitative research were applied where appropriate (e.g. Elliott, Fischer & Rennie, 1999; Lincoln & Guba, 1985). In order to show trustworthiness the lead researcher aimed to be as transparent as possible throughout the analysis and in reporting the results. Therefore direct quotations were used to ground themes within the text. A reflective research diary (Appendix F) was utilised to create an audit-trail of the analysis process (Appendix G) and to produce a critical reflective discussion (see extended discussion). The reflective diary was used to identify the lead researchers pre-existing assumptions and what influence and role they may have had in the interpretation process (Elliott et al., 1999). These reflective processes were important, as the lead researcher had previously worked in an EIP service and had their own experiences and beliefs about these services. (See extended methodology).

## Results

Five super-ordinate themes were developed from the interviews: (i) Stigma; (ii) Relationships; (iii) Understanding the experiences; (iv) Sense of agency; (v) Impact on sense of self. All themes are discussed individually, however are envisioned as overlapping. All identifying features in quotations have been altered to maintain anonymity (e.g. pseudonyms). The Participants Demographic and Service Details (Table 1) were provided by Care co-ordinators (Appendix H).

### **‘Stigma’**

This super-ordinate theme captures participants’ descriptions of the multi-faceted nature of the stigma related to their experiences, including *self-stigma*, *others’ judgements* and *stigma of services*.

#### **Self-stigma.**

This captures the participants’ rich accounts of personal shame and self judgement about their and other peoples’ experiences of psychosis. The following extract introduces this issue, as the participant expresses her distinction between different psychiatric diagnoses, which was echoed by other participants:

---

Table 1

*Participants Demographic and Service Details*

---

Participant	Age	Gender	Ethnicity	Length of time in EIP service <sup>a</sup>
1	37	Male	White and Black Caribbean	2 yrs 11 months
2	37	Male	White British	2 yrs 10 months
3	32	Male	White British	2 yrs 7 months
4	21	Female	White British	2 yrs 9 months
5	23	Male	White British	2 yrs 8 months
6	31	Female	White British	2 yrs 9 months
7	24	Male	White and Asian	2 yrs 9 months
8	29	Female	White and Asian	2 yrs 10 months

---

<sup>a</sup> Length of time since referral was accepted by the EIP service



P8: ... *I had psychosis, so I didn't like that. I mean depression's fine with me, but having psychosis isn't.*  
*...to me it means that it's something whacky and totally... serious*  
*and... well... I'm just ashamed of it really...*

This extract illustrates what was interpreted as an implicit hierarchy of psychiatric diagnoses, in which psychosis was deemed to be more serious and shameful than other diagnoses.

Participants also described how their own personal shame impacted on their ability to talk to people about their early experiences of psychosis, which was interpreted as an implied barrier to accessing the EIP service:

P5: ...*well I couldn't talk to her (Girlfriend)...*

Interviewer: *You said you couldn't talk to her about it?*

P5: *No because you just sound... too weird...*

### **Others' judgements.**

Participants described their experiences of other people's judgements about their diagnoses and behaviour and how these initially impacted on their willingness to talk about their experiences. This was interpreted as illustrating a link between the participants' personal feelings of shame and the judgments made by others and how collectively these created a barrier to the EIP service.

Participants gave multiple examples of ongoing feelings of being misunderstood and judged by others outside of the relationships formed through the EIP service. One participant explicitly connected her parents' shame to her own personal shame:

P8: *...I guess that wore off on me, made me a bit erm...  
ashamed as well. Maybe I wouldn't have been as ashamed  
of it as... I am if my parents hadn't been sort of the  
instigators of the shame...*

### **Stigma of services.**

Accounts suggested a pre-existing stigma surrounding traditional mental health services, with them representing power and control over people. This stigma was seen as being projected onto the EIP service and contributed to initial anxieties about their involvement. More specifically, participants spoke about the impact of the EIP services name on their feelings of shame and separation:

P8: *...the fact that it's not known and it's this little... little...  
specialised service... and your sort of in this group and  
you're not in sort of the mainstream I guess. It's the way I  
feel of it, it might very well be mainstream but I, I feel as  
though it's not, I feel as though it's some kind of little special  
group that needs to be taken aside cus they need that extra*

*remedial lesson type thing, like in school when you have to be taken out of class to go to remedial lessons.*

This participant highlights her distinction between mainstream services and EIP and implies this can create feelings of separation from other people with mental health problems. This was interpreted as an extension to discussions of an implicit hierarchy, by suggesting a hierarchy within mental health services, with some being more accepted than others.

In contrast, some participants discussed the impact of the EIP service on reducing stigma associated with services:

*P7: ...that's what EIP kind of does, it softens that relationship between mental health authority and the punters so to speak who use that service, cus they... I speak for myself, they did... they did change the way I think about it...*

Accounts suggested a need for the public and all professionals to be educated and knowledgeable about EIP services, as disseminating knowledge was viewed as a way of battling stigma. (See extended results)

### **'Relationships'**

Participants spoke in-depth about relationships that had assumed importance to them during their time in the EIP service.

## **Peer-support.**

Participants' described their experiences of attending peer-support groups (within the EIP service and through service links with external agencies) for people with psychosis or other mental health problems. All participants who had attended these groups stated they had been offered the opportunity by their Care co-ordinator.

Participants acknowledged the role of these groups in reducing feelings of social isolation:

*P1: ...a little coffee bar where a lot of ex-patients can come back in a see people and you get talking and that's helped me because I live alone and I, my parents live in (another country), so there's times when I don't really get to see anyone....*

Accounts suggested that in contrast to feeling judged and misunderstood, the relationships developed in the groups provided an opportunity to feel understood and created a sense of belonging. This belonging was interpreted as a vehicle to overcome feelings of shame and also instilled confidence in the participants. For example, the following participant's story about a peer group boat trip, illustrates how others openness acted as a catalyst to reducing his personal shame:

P5- ...there we're all these other people and said like oh why, what are you doing here? and one person says, I says, "oh we're a youth club" or something and... he goes "no we're not, were all loons, we've got mental health problems"

Interviewer: How did you feel when he said it?

P5- I felt like quite... liberated in way, just like, yeah that's me...

It was also interpreted that the groups provided an opportunity for participants to take on the role of the expert by becoming a 'helper' for others and is seen as over-lapping with the theme *Sense of agency*:

P1: ...people tell you what their illness is and what kind of, then you try to come up with something that will help them and they do it vice versa to you...

### **Care co-ordinator relationship.**

The super-ordinate theme '*Relationships*' also captures the nature of the participants' relationships with their EIP Care co-ordinators. In participants' accounts there was a consistent theme that the service was anthropomorphised, with Care co-ordinators representing the face of the service. This was interpreted as illustrating the importance of the relationship between participants and Care co-ordinators, on the participants' views of the EIP service.

For many participants, this relationship was their primary channel to support, knowledge about psychosis and recovery, involvement with other aspects of the EIP service and external services. Accounts suggested a sense of the participants often adopting the views of their Care co-ordinators and a willingness to extend their trust for their Care co-ordinator to others, in this participant's case accepting psychology involvement:

P1- *...I've been involved seeing Sam (Care co-ordinator) every fortnight or so, or every month, or however it seems to go for the time. And erm that was going well, so I thought well she mentioned it and I err, I, I, liked Sam, and I thought she's trying to help you so why not, I'll give it a go...*

(See extended results).

### **'Understanding the Experiences'**

This super-ordinate theme encapsulates the participants' attempts to understand their experiences of psychosis and how it was influenced by their involvement with the EIP service.

Participants discussed their explanations of why they had experienced psychosis, with childhood experiences, stress or societal pressures, all being examples of speculation regarding pre-disposing and precipitating factors. For some, their experience of being in contact with the EIP service was seen as a necessary experience in order to move forward as a person, which is connected to the theme *'Impact on sense of self'*:

P2: *...perhaps you thought you had got over things and that but perhaps its time to get things out the files and look through it and rectify everything and put you back to square one again, break you down to build you up again.*

Participants were interpreted as normalising their experiences, by identifying commonalities between themselves and other people who had experienced psychosis. Specifically, accounts acknowledged how the EIP service influenced this normalisation, as participants suggested early contacts with the service provided them with information about psychosis and their first sense of relief and optimism about their future:

P5: *...they just told me that the fact was, there are other people like you and you can get better from it...  
....yeah and that just, relief really and like before I just thought I never, OK the rest of my life not getting better...*

This was seen as demonstrating the value of normalisation in fostering a deeper sense of hope, regarding their experiences and the role of EIP in this process.

Beyond fostering a sense of hope, explanations offered by the EIP service also allowed participants to normalise their experiences by drawing comparisons between themselves and other people within the general population. This was interpreted as a way of participants re-identifying with the general public:

P8: *Yeah, you know everyone is susceptible...*

*...now I view it as part of everyone, everyone has the potential to become ill...*

However, some participants normalised their experiences beyond explanations offered directly by the EIP service, towards what was interpreted as more of a spectrum of psychosis, on which everyone is situated to different degrees:

P3: *...I think everyone is in psychosis; it's just what level you get to you know...*

This theme highlights the influential role of the EIP service in the participants' understandings of their experiences. However, it also demonstrates that participants were able to form their own personal frameworks for understanding, beyond those offered by the service. (See extended results)

### **'Sense of Agency'**

This super-ordinate theme captures the participants' contrasting accounts of feeling both a passive recipient and an active agent in their experiences.

### **Acceptance and control.**

Participants' accounts were interpreted as representing a shift from an initial avoidance of acknowledging their experiences, towards an acceptance of their presence. Initial contacts with the EIP service encouraged participants to



confront their experiences. Whereas, later on, the service provided an opportunity for some participants to talk about the experiences and develop ways of recognising symptoms, both of which were interpreted as initial steps towards an acceptance and control of their experiences.

When discussing her current situation, one participant used the word “*recovered*”, which she defined as:

*P8- Sort of living with my symptoms and dealing with it, accepting it.*

*...I've got chinks in my armour, because not all your body ever can be protected by armour, there's gonna be weak spots and there's gonna be times when you sort of slip and have a bit of wobble.*

This extract illustrates the participant's acceptance of her symptoms; an attitude which she suggested had been influenced by discussions with her Care co-ordinator. However, this was interpreted as representing a sense of being resigned to a life with psychosis and it being something to be endured. In contrast, other participants described a sense of active control over their experiences, which was supported by the EIP service, e.g.:

*P1- ...even if I do hear voices, I know that it's not actually people talking, I know its actually just going off in my own brain... I'm able to, to think, I can challenge it myself...  
... Jane (EIP Psychologist) helped with that as well...*

*... when I do hear the voices, I go straight to my list that I got off Jane and it works...*

This sense of agency was elaborated further, as although participants attributed aspects of their progress to the EIP services actions; they also recognised their own role and the importance of personal responsibility for their future:

*P3: ...they've (EIP service) offered me the psychology, they've offered me support in every area... but what they can't do is provide a solution yer see, they can only help,...there is no one who can actually provide the solution, other than yourself...*

### **EIP service involvement.**

This captures an alternative aspect of agency, in which the participants described their varied feelings of control over interventions, during their contact with the EIP service. Accounts suggested, upon entering the service, many participants were offered limited options regarding treatments, with medication being the pre-dominant or sole choice. Participants described feeling pushed into using medication and the negative impacts:

*P6: It feels as though... everything is being taken out of your hands and you just... feel worthless really.*

In contrast to feelings of powerlessness over treatments, other participants' accounts suggested a different view of the EIP service approach, as they described a sense of control over the pace and level of involvement:

*P7: ...force isn't a remedy, is something that like early intervention go by, like the, they don't force people... It's up to you how much involvement you have with them...*

One participant explicitly described a dramatic change in her level of control, from a sense of being a passive recipient of EIP services, to an active agent which she described as:

*P8: ...partnership working basically, erm... with my psychiatrist, erm and Emily (Care co-ordinator)...*

(See extended results).

### **'Impact on Sense of Self'**

This super-ordinate theme encapsulates participants' accounts of the impact of their experience of psychosis and their contact with the EIP service, on their view of themselves and their place within the world.

#### **A sense of discovery.**

This theme was interpreted as illustrating the participants' experiences of discovering a new and stronger self, following their experience of psychosis and

the service. It initially captures participants' positive appraisals of being in contact with the EIP service:

*P7: ... not everyone gets caught in the net and like, for me it was good to get caught in the net, because I faced everything...*

This positive appraisal of receiving the service was expanded further, as participants' described ways in which they had experienced positive changes in themselves:

*P7: ... cus I'm stronger now than I ever was...*

*P3: Because I was never really in touch with my feelings or emotions, things like that, yer know, never really in touch with them....*

As illustrated by this extract, some participants directly acknowledged how the EIP service had helped them to identify positive changes in themselves:

*P4: ...Sarah (Care co-ordinator) says... if I would have been bullied at (names hospital), when I came out of prison I probably would have smacked them back, I probably would have beat them up for just looking at me... and so I've calmed right down in that sense....*

## **Place within the world.**

Due to their psychosis, many participants had experienced dramatic changes in their lives, resulting in feelings of a detachment from their previous world. However, participants identified the ways in which the EIP service had supported them in trying to re-establish vocational and social aspects of their lives:

*P8: ...I'm gona start a new job on Monday err... yeah I got married whilst being in services, in EIP...  
... I've been through a lot with sort of EIP propping me up really, so that's good.*

*P1: ...with the help again of Sam (Care co-ordinator)...I keep in contact with friends and go round and see them and ask them round to come and see you...*

Conversely, some participants described a deeper and ongoing sense of detachment from their world. In particular one participant discussed his feelings of incompatibility with the world around him and a lack of understanding for his new found sense of self:

*P3: ... all the psychotic people are operating on the same frequency and all the people outside of that are operating on another frequency...*

*... you're really out-numbered yer know and (deep breath in) it's difficult for me to go out at the minute...*

This highlights that although participants identified positive changes and the role of EIP in helping to re-establish aspects of their lives, for some, there was a deeper sense of incompatibility with the world, which was not resolved by their contact with the EIP service. (See extended results).

## **Discussion**

This study aimed to explore service-users' subjective experiences of being in contact with an EIP service, its impact on their experience of psychosis and the meaning this has for them. Semi-structured interviews were conducted with eight service-users from an EIP service and five super-ordinate themes were developed during the analysis.

The themes identified in this study can be interpreted as representing an overarching theme of '*A personal journey of recovery*' which moved beyond symptom alleviation or management and was interpreted as being influenced by involvement of the EIP service. For participants the *journey* involved: overcoming stigma associated with psychosis and mental health services; normalising and developing an understanding of their experiences; accepting their experiences; gaining a sense of agency and control; discovering and trying to assimilate a new self concept.

The elements of this *journey* are not interpreted as linear stages; as necessary, or being achieved by everyone. Within the literature, there have been attempts to propose stage models of recovery from psychosis and other mental health problems (e.g. Andresen, Oades & Caputi, 2003; Young & Ensing, 1999). However, stage models could be viewed as incongruent with ‘consumer models’ of recovery and personal narratives (Bellack, 2006; Ridgway, 2001), in which psychosis and recovery are viewed as non-linear, personalised and part of an ongoing journey. These characteristics were evident across the interviews in this study.

Aspects of this *journey* have been previously identified within the literature, including the multi-faceted nature of stigma, described by participants (Dinos, Stevens, Serafty, Weich & King, 2004; Judge et al., 2008). However, participants in this study discussed the stigmatizing effect of the EIP service specifically. Accounts suggested the EIP service’s name had a powerful impact on their feelings of shame and separation from other people with mental health problems. Attitudes represented what was interpreted as an implied hierarchy of mental health services, where mainstream services were viewed as more acceptable than EIP. This has clinical implications for EIP services, as it suggests they need to take a similarly multi-faceted approach to overcoming stigma, in order to tackle self-stigmatizing attitudes and increase the public’s knowledge of specialised services.

The theme *Relationships* highlighted the influential role of peer-support groups and participants’ experiences were consistent with previous research (Newton

et al., 2007; Perry et al, 2007) and theories of group therapy, which emphasise the emotional release that can occur when experiences are normalised (Yalom, 1985). However, this current research offers an insight into the experiences of peer groups from service-users in an EIP service, which has not been previously studied. EIP services aim to provide an opportunity for service-users to attend peer groups (DoH, 2001) and this research suggests the potentially important and influential role of these groups, on people's *journey* of recovery. However, the appropriate methods of promoting and delivering these groups were not explored and could be studied in future research.

Many other elements of participants' *journeys* are consistent with research which has explored important aspects of recovery from mental health problems. This includes the importance of personal frameworks for understanding (Ridgway, 2001), hope (Perry et al., 2007), agency and control (Barker et al., 2001; Young & Ensing, 1999) and growth, which is a relatively under-explored area in psychosis (Andresen et al, 2003).

This study adds to this literature, as it explored the impact of being in an EIP service and the influential role of staff on this personal *journey*, which is predominantly overlooked in the current literature. The study suggests being in contact with the EIP service, participants were provided with an opportunity to form a personal understanding of their experiences, without necessarily adopting a medical model of psychosis. Some participants' descriptions were interpreted as being congruent with views of psychosis as a continuum, which



reject the notion of an unambiguous dividing line between the psychologically healthy and psychologically unhealthy (Bentall, 2003).

Relationships with Care co-ordinators were seen as influential in the participants' views of the EIP service, their engagement with other services, fostering a sense of hope, impacting on their personal understanding, their sense of agency and their sense of self. Previous research has noted a tendency for participants to talk specifically about their Care co-ordinators when referring to EIP services (O'Toole et al., 2004) and has suggested the influence of EIP staff views and professional backgrounds on the explanation of psychosis offered to clients (Larsen, 2007). However, the current research also suggested support offered by the EIP service had potential limits and was unable to resolve all the complex layers of the participants' ongoing *journeys*. (See extended discussion)

### **Clinical Implications**

The important and influential nature of the relationship between service-users and EIP staff and the impact of the service on their personal *journeys*, has important clinical implications. EIP services need to consider the personal and professional attitudes, values and behaviour of staff throughout recruitment, training and supervision. Care co-ordinators and other staff need to be supported by the EIP service to develop a conscious awareness of their potentially powerful influence and exercise it with care to promote recovery and provide opportunities for agency.

The importance of developing a sense of agency has further clinical implications, as mental health services operate within the Mental Health Act (2007), a powerful piece of legislation which can remove individual power and agency. Coercion within mental health services can operate at more subtle levels, (e.g. Lutzen 1998), and block the development of personal agency. EIP services, as with other mental health services, need to find ways of creating opportunities for personal agency, and where possible aim to prevent the need for sectioning under the Mental Health Act (2007). (See extended discussion)

### **Limitations**

This study's methodology allowed an in-depth engagement with the topic at a level which would have been difficult with less idiographic approaches. However, a potential limitation was that service-users were initially approached by Care co-ordinators and were still engaged with the service, at the time of the interviews. Due to the nature of these relationships, this may have influenced decisions to participate and unintentionally excluded those with more difficult experiences. However, the participant information sheet explained procedures for confidentiality, in an attempt to minimise this influence. A further potential limitation was the recruitment of participants from one EIP service. It is important to acknowledge that the particular ethos of this service and its staff may have also influenced participants' experiences. (See extended discussion).

### **Future Research**

Due to the influential role of the EIP service on participants' experiences, future research could explore Care co-ordinators experiences of fulfilling this position

in an EIP service, in order to illuminate this relationship further and identify any training needs. Secondly, further research could study peoples' experiences after exiting an EIP service, which could allow exploration of peoples' *journeys* beyond EIP involvement. (See extended discussion).

## References

- Andresen, R., Oades, L., & Caputi, P. (2003). The experience of recovery from schizophrenia: towards an empirically validated stage model. *Australia and New Zealand Journal of Psychiatry*, 37, 586-594.
- Barker, S., Lavender, T., & Morant, N. (2001). Client and family narratives on schizophrenia. *Journal of Mental Health*, 10(2), 199-212.
- Bellack, A. S. (2006). Scientific and consumer models of recovery in schizophrenia: concordance, contrasts and implications. *Schizophrenia Bulletin*, 32(3), 432-442.
- Bentall, P. (2003). *Madness Explained. Psychosis and human nature*. London, UK: Penguin Books.
- Bertelsen, M., Jeppesen, P., Petersen, L., Thorup, A., Ohlenschloeger, J., Le Quach., et al. (2008). Five-year follow-up of a randomised multicentre trial of intensive early intervention vs. standard treatment for patients with a first episode of psychotic illness: The Opus trial. *Archives of General Psychiatry*, 65(7), 762-771.
- Birchwood, M., Todd, P., & Jackson. (1998). Early intervention in psychosis: The critical period hypothesis. *British Journal of Psychiatry*, 172(33), 53-59.
- Denzin, N.K., & Lincoln, Y.S. (2005). *The sage handbook of qualitative research*. (3<sup>rd</sup> ed.). London, UK: Sage Publications.
- Department of Health. (2000). *The NHS plan: A plan for investment: A plan for reform*, Department of Health, London. Retrieved December 12, 2007, from [www.dh.gov.uk](http://www.dh.gov.uk)

- Department of Health. (2001). *The Mental Health Policy Implementation Guide*, Department of Health, London. Retrieved December 11, 2007, from [www.dh.gov.uk](http://www.dh.gov.uk)
- Dinos, S., Stevens, S., Serafty, M., Weich, S., & King, M. (2004). Stigma: the feelings and experiences of 46 people with mental illness: Qualitative study. *British Journal of Psychiatry*, 184, 176-181.
- Elliott, R., Fischer, C. T., & Rennie D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.
- Garety, P., Craig, T.K.J., & Dunn, G. (2006). Specialised care for early psychosis: symptoms, social functioning and patient satisfaction. Randomised controlled trial. *British Journal of Psychiatry*, 188, 37-45.
- Hirschfeld, R., Smith, J., Trower, P., & Griffin, C. (2005). What do psychotic experiences mean for young men? A qualitative investigation. *Psychology and Psychotherapy: Theory, Research and Practice*, 78, 249-270.
- Judge, A. M., Estroff, S. E., Perkins, D. O., & Penn, D. L. (2008). Recognising and responding to early psychosis: A qualitative analysis of individual narratives. *Psychiatric Services*, 59(1), 96-99.
- Larsen, J. A. (2007). Understanding a complex intervention: Person-centred ethnography in early psychosis. *Journal of Mental Health*, 16(6), 333-345.
- Lincoln, Y.S., & Guba, E. G. (1985). *Naturalistic Inquiry*. London, UK: Sage Publications Ltd.

- Lutzen, K. (1998). Subtle coercion in psychiatric practice. *Journal of Psychiatric and Mental Health Nursing*, 5, 101-107.
- Marshall, M., Lewis, S., Lockwood, A., Drake, R., Jones, P., & Croudace, T. (2005). Association between duration of untreated psychosis and outcome in cohorts of first episode patients. *Archives of General Psychiatry*, 62, 975-983.
- McKenzie, L.H. (2006). Service-users and carers' experiences of a psychosis service. *Journal of Psychiatric and Mental Health Nursing*, 13, 636-640.
- Medical Research Council. (2000). *A framework for development and evaluation of RCT's for complex interventions to improve health*. MRC: Retrieved July 10, 2008, from [www.mrc.ac.uk](http://www.mrc.ac.uk)
- Mental Health Act of 2007, c.12 (2007). Retrieved December 9, 2008, from [http://www.opsi.gov.uk/acts/acts2007/ukpga\\_20070012\\_en\\_1](http://www.opsi.gov.uk/acts/acts2007/ukpga_20070012_en_1)
- National Institute for Health and Clinical Excellence. (2009). *Schizophrenia: Core interventions in the treatment and management of schizophrenia in primary and secondary care (Update)*. NICE: London. Retrieved August 14, 2009, from [www.nice.org.uk](http://www.nice.org.uk)
- Newton, E., Larkin, M., Melhuish, R., & Wykes, T. (2007). More than just a place to talk: Young people's experiences of a group psychological therapy as an early intervention for auditory hallucinations. *Psychology and Psychotherapy: Theory, Research and Practice*, 80, 127-149.
- O'Toole, M.S., Ohlsen, R.I., Taylor, T.M., Purvis, R., Walters, J., & Pilowsky, L.S. (2004). Treating first episode psychosis- The service-users' perspective: a focus group evaluation. *Journal of Psychiatric and Mental Health Nursing*, 11, 319-326.

- Perry, B. M., Taylor, D., & Shaw, S. K. (2007). "You've got to have a positive state of mind": An interpretative phenomenological analysis of hope and first episode psychosis. *Journal of Mental Health*, 16(6), 781-793.
- Reading, B., & Birchwood, M. (2005). Early intervention in psychosis: Rationale and evidence for effectiveness. *Disease Management and Health Outcomes*, 13(1), 53-63.
- Ridgway, P. (2001). Restorying psychiatric disability: Learning from first person recovery narratives. *Psychiatric Rehabilitation Journal*, 24(4), 335-343.
- Sainsbury Centre for Mental Health. (2003). *A window of opportunity: A practical guide for developing early intervention in psychosis services*. Briefing 23. Retrieved December 11, 2007, from [www.scmh.org.uk](http://www.scmh.org.uk)
- Smith, J.A. & Osborne, M. (2003). Interpretative phenomenological analysis. In J.A. Smith (Ed), *Qualitative psychology: A practical guide to methods* (pp. 51-80). London, UK: Sage Publications Ltd.
- Theuma, M., Read, J., Moskowitz, A. & Stewart, A. (2007). Evaluation of a New Zealand early intervention service for psychosis. *New Zealand Journal of Psychology*, 36, 136-145.
- Yalom, I. (1985). *The theory and practice of group psychotherapy*. New York, NY: Basic Books.
- Young, S. L., & Ensing, D. S. (1999). Exploring recovery from the perspectives of people with psychiatric disabilities. *Psychiatric Rehabilitation Journal*, 22(3), 219-231.

## **Extended Background**

This section provides additional detail and information that is not included in the journal article. It explains many of the terms used throughout the research, provides more detail on the EIP service model, within the UK and critically reviews the literature relevant to the research. Finally, it expands on the justification for the study and its aims.

It is not the aim of this research to debate the existence of, or correct terminology of psychosis and/ or schizophrenia. The term psychosis is favoured within the current literature due to the negative connotations associated with psychiatric diagnoses (May, 2004) and is predominantly used by EIP services in the UK. Diagnosis can be difficult in the early phases; therefore EIP services aim to shift the focus from diagnosis to individual experiences (DoH, 2001). *Psychosis* is the preferred term used throughout this paper, unless other terms such as schizophrenia have been used specifically in the research articles included in the paper.

## **Background**

Psychosis is the generic term used to describe a mental state which involves a loss of contact with reality (Early Psychosis Prevention and Intervention Centre [EPPIC], 2006). It is suggested that the vast majority of first episodes of psychosis occur between the ages of 14 and 35, with the mean age of onset for psychotic symptoms being 22 (DoH, 2001). The effects of having psychosis has been shown to result in reduced opportunities to experience personal development (Chen, 1999) and have damaging effects on relationships, education and work opportunities (Addington, van Mastrigt, Hutchinson & Addington, 2002).

Schizophrenia refers to a type of psychosis in which the person experiences symptoms for at least six months (EPPIC, 2006) and is a psychiatric diagnostic category (World Health Organisation [WHO], 2007). There are many articles



which have provided prevalence and incidence rates of schizophrenia in the literature, however, based on a systematic review of 55 studies (covering 25 countries) (McGrath et al., 2004) the reported incident rate for schizophrenia was 7.7 to 43.0 per 100,000, with a median value of 5.2 per 100,000 (McGrath, 2005). However, there are many difficulties in measuring the incidence of schizophrenia as there is no one ideal measure and studies differ in their approaches (McGrath, 2005), which may be one explanation for the variation in incidence.

A diagnosis of schizophrenia has traditionally been regarded as a chronic condition with a poor outlook, with regard to returning to pre-morbid functioning (Bellack, 2006). However, over the last 20 years this pessimistic view has begun to change, as long-term outcome studies have identified the individual and variable nature of the course of schizophrenia or psychosis (Bellack, 2006). Additionally, there has been a growing 'consumer movement' among people with these diagnoses who have challenged the traditional assumptions about course and outcomes (Bellack, 2006) and have contributed to an evolution of service delivery and a shift towards recovery-orientated approaches. Focusing on individual experiences, compared to traditional diagnoses, is suggested to provide a better framework for understanding psychosis (Bentall, 2003; British Psychological Society [BPS], 2000) and counteracts the sense of powerlessness and hopelessness that a service-user can experience, as a result of the negative connotations of psychiatric diagnosis (May, 2004).

### **Early Intervention in Psychosis Services**

The early phase of psychosis (critical period of first three to five years), is important for improving access to a range of interventions and optimising recovery (Birchwood, Todd & Jackson, 1998). The need for early and comprehensive intervention highlighted the potential limitations of existing services and impacted on the development of new guidelines, for the management of FEP (Reading & Birchwood, 2005). EIP teams in the UK, offer a range of services including: psycho-social interventions and antipsychotic

medications, which are tailored to individual needs. With regards to models of service delivery it is recommended that EIP service are best provided by discrete, specialist teams, whose sole responsibility is working with people in the early phase of psychosis and which have an adequate skill mix to provide all interventions, including Psychiatrists, Clinical Psychologists, Social workers and Nurses (DoH, 2001).

The literature has begun to identify essential elements of EIP services within the UK (Marshall, Lockwood, Lewis & Fiander, 2004), which are based on the original DoH Mental Health Policy Implementation Guide (2001). This implementation guide recommended a number of key components of a UK EIP service, including: a focus on symptoms rather than diagnosis; comprehensive multidisciplinary assessment; developing meaningful engagement based on assertive outreach principles; providing evidence based interventions; promoting recovery during the early phase of psychosis; increasing stability and providing opportunities for personal fulfilment; providing a service which is culture, age and gender sensitive; service-user involvement in decision making; intensive support provided during times of crisis; and reducing the stigma associated with psychosis (DoH, 2001).

EIP services are currently promoted in many countries, with high profile services in Australia, Europe and North America (Edwards & McGorry, 2002). However, it recognised that there will inevitably be contextual and policy differences between countries, which impact on the way the EIP services are delivered (e.g. Larsen, 2007). Within the UK, the government made EIP services an integral part of mental health services, with a proposed plan that by 2004 50 EIP teams would be established, so that all young people who experience FEP would receive the early intervention and continued support they need (DoH, 2000). Additionally, NICE (2002; 2009) released guidelines for treating FEP and recommended that EIP services are developed, to provide an appropriate mix of specialist professions to intervene at the earliest opportunity.

The widespread support for EIP approaches has also been strongly influenced by the change in perception of schizophrenia and psychoses. Opinions have moved from traditional theories of schizophrenia being a degenerative and incurable disease, to the view that symptoms and the wellbeing of the individual can improve significantly with a range of interventions (Bentall, 2003; Cullberg, 2006). There is great diversity in the combination of models and treatments offered by EIP services, in order to achieve the aims of the approach; therefore it is seen as important to conduct research to determine what contributes to effective and appropriate care in early intervention (Theuma, Read, Moskowitz & Stewart, 2007). However, despite EIP generating vast interest and optimism, research into its effectiveness has shown mixed outcomes and still generates some debate (e.g. Pelosi & Birchwood, 2003; Warner, 2005).

### **Summary of Literature Review**

The focus of this literature review is to critically discuss the research which evaluates specialist EIP services, other services for FEP and experiences of psychosis. Due to the promotion of these services in the UK (DoH, 1999; 2001), research into the effectiveness of these services is important and highly recommended (NICE, 2002). NICE (2002) recommends that the effectiveness of EIP services should be evaluated using Randomised Controlled Trials (RCT) and should report clinical, social, occupational and economic outcomes. Additionally, research should evaluate the effectiveness of EIP teams when compared to standard Community Mental Health Teams (CMHT), which also provide services for people with early psychosis.

Despite RCT research being considered the 'gold standard' of measuring effectiveness of mental health interventions (NICE, 2002), government initiatives have suggested that the perspectives of service-users should play an important part in the evaluation of mental health services (DoH, 1999; NICE, 2002), as they can be important in evaluating the effective components of an intervention (MRC, 2000). Therefore, this review incorporates quantitative, qualitative and mixed methods research covering a range of topic areas

including outcomes from EIP services, the effects of EIP on duration of untreated psychosis (DUP), service-users' experiences of psychosis and service-users' experiences of services for psychosis.

### **Literature search strategies.**

In order to establish the literature for this review the major databases (e.g. PsycINFO, Medline, EMBASE, Web of Science) were searched for published literature using the specific terms *psychosis*, *psychoses*, *psychotic illness*, *schizophrenia*, *early intervention*, *EIP*, *qualitative*, *quantitative*, *subjective experiences*, *service-users perspectives*, in order to locate articles related to the experience of psychosis and research evaluating mental health services for psychosis. All relevant articles identified through this search were checked for citations of other publications containing the relevant search terms. This process was repeated for each new publication found. The findings of previous reviews which covered a number of studies relating to Duration of Untreated Psychosis (DUP) and experiences of psychosis were included to contribute to current understanding. Although the review aimed to critically evaluate the important literature on EIP services, the strategy used was not intended to be a systematic review of the literature.

It is important to acknowledge, that although this research is qualitative in methodology, the literature review also evaluates quantitative and mixed methods research. Due to NICE recommendations (2002) the evaluation of EIP services has mainly adopted quantitative methods; therefore, to ignore this type of methodology would be to ignore the vast majority of research in this area. All RCT studies have been critically appraised using the CONSORT Statement (Altman et al., 2001) checklist.

### **Quantitative Research**

This section of the review focuses on research measuring the effectiveness of EIP services compared to Treatment As Usual (TAU) and in reducing the delay

between onset of psychotic symptoms and accessing appropriate services. Research into methods designed to prevent the transition to psychosis are evolving (e.g. McGorry & Jackson, 1999; McGorry et al., 2002). However, this area of research is not directly related to my study and is not covered in this review.

NICE (2002) recommended that “... *early intervention services be evaluated using adequately powered RCTs reporting all relevant clinical, social, occupational and economic outcomes, including quality of life and longer-term outcomes.*” (p.140). In a hierarchy developed by Sackett, Rosenberg, Muir Gray, Haynes and Richardson (1996), ranking the strength of evidence related to the effectiveness of an intervention, RCTs are considered second only to systematic reviews. Additionally, the MRC provides a framework for the use of RCTs in assessing complex interventions (2000). However, despite recommendations and their proposed strength, there are limited numbers of RCTs of EIP and it has been suggested that there are problems and challenges associated with applying the simple RCT model to services which are defined as complex (Wolff, 2000) such as EIP services (Marshall et al., 2004). Therefore this section on quantitative research will review both RCT and non-RCT research.

### **Treatment as Usual.**

This section focuses on research which measured the effectiveness of EIP services when compared to TAU.

In recent RCTs of a specialized early intervention service (The OPUS study: Jorgensen et al., 2000; Nordentoft et al., 2004; Petersen et al., 2005) 547 first episode patients were randomised to a specialised service (n=275) or standard care (n=272). Results at year one revealed a significant difference between groups on psychotic symptoms (effect size 0.19) and negative symptoms (effect size 0.31) in favour of the specialised treatment group, which remained

significant at two years (effect sizes; psychotic symptoms, 0.16 and negative symptoms, 0.34).

However, researchers were not blinded to which treatment patients had been assigned, possibly leading to bias in measures of outcome. Following two years of specialised treatment the patients in the experimental group were transferred to standard treatment and followed up at five years (Bertelsen et al., 2008). Bertelsen et al., (2008) assessed patients three years after the transition from the specialist treatment to standard treatment. At five year follow-up (specialist treatment patients  $n=150$ , standard care patients  $n=151$ ) the primary outcome measures were psychotic and negative symptoms and social functioning. Secondary outcome measures included use of services, depressive symptoms, suicidal behaviour, housing situation and vocational situation. In contrast to the previous follow-up research all assessors were blinded to the treatment allocation, which is a strength of the study.

Results revealed that at five years follow-up the treatment effect seen at two years follow-up had equalized between the two groups (P-values= psychotic symptoms 0.83, negative symptoms 0.73, Global functioning [GAF] symptoms 0.96 and GAF functioning 0.51). However, the secondary measures showed that a significantly ( $p=0.02$ ) smaller number of patients in the specialised service group were living in supported housing (4%) when compared to standard treatment (10%) and were hospitalised for less days, compared to the standard care group (mean, 96 verses 123 days; mean difference, 27.4 days;  $P=0.05$ ). There was no difference between the two groups on measures of depressive symptoms, suicidal behaviour or vocational situation at five year follow-up.

Kuipers, Holloway, Rabe-Hesketh and Tennakoon's (2004) conducted an RCT ( $n=59$ ; specialist treatment  $n=32$ , TAU= 27) of the Croydon Outreach and Assertive Support Team (COAST), which is a specialist team targeting people in their first five years since their initial episode of psychosis. The research was strengthened as it described its randomisation procedure, which was conducted

by an independent administrator. Results revealed that although both groups improved statistically significantly (at six and nine month follow up) on several outcomes there was no significant differences for a variety of outcomes including symptoms, global functioning, quality of life, and depression, between COAST and TAU. Results suggested that COAST clients had 43% less bed use than the TAU clients; however this was not statistically significant. The authors acknowledged that participants in this trial may not have been treated early enough by the service to show clinically significant effects on outcomes.

Craig et al. (2004) conducted a RCT to investigate whether people receiving specialised care for early psychosis would have more frequent contact with mental health services, fewer relapses and fewer readmissions to hospital than clients receiving standard care, over an 18 month period. The study included all people aged 16-40 living in London, presenting to mental health services for the first time with non-affective psychosis. Non-English speakers were not excluded; however, the authors did not explain any interpretation processes which were used. Eligible clients were randomised to either specialist care (n=71) or standard care (n=73). However, the method of participant allocation is not explained, which is a limitation of the study. The specialised care service was the Lambeth Early Onset (LEO) team, which is established on principles of assertive outreach (DoH, 2001), with adaptations for early psychosis. Whereas the standard care service was provided by CMHTs, with no special training in the management of early psychosis. The study gave a detailed description of the LEO team and intervention which strengthened the study.

One hundred and forty four patients were included; however, data on number of relapses and readmissions were obtained from 136 patients over the 18 month period and for clinical status from 131 patients. Results showed that patients in the specialised care group were significantly less likely to relapse ( $p= 0.042$ ) and were more likely to be in recovery at follow-up ( $p= 0.035$ ) when compared to the control group. After adjustment for baseline differences between the two groups only higher contact with services and lower levels of readmissions during the follow up ( $p= 0.030$ ), in the specialised service patients, remained

significant. The research provided support for a specialised care service, but was limited as authors recognised it was underpowered (limiting the generalisability of the findings) and researchers relied on record systems for data on relapses (which are prone to bias and errors).

Studies of clinical interventions for people with psychosis have been criticised for focusing solely on data on relapses, readmissions and symptoms (NICE, 2002). In response to these criticisms, Garety et al. (2006) conducted a RCT of the LEO team, but strengthened the study by focusing on a broader range of outcomes. They used the same participants and methodology as in the Craig et al. (2004) study. However, Garety et al. (2006) gave a clear description of the method of randomisation (permuted blocks used by an independent statistician) which was a strength of the study. They used a variety of measures at baseline which were repeated again at 18 months. Information from case notes was obtained from 132 patients and only 99 patients agreed to take part in the interviews at 18 months (intent to treat analysis was used). Results were adjusted to allow for baseline differences and to account for missing data.

Results showed that at 18 months, the specialist service had superior outcomes in: time spent in vocational activity ( $P= 0.019$ ); global functioning ( $p= 0.01$ ); higher reported quality of life ( $p= 0.026$ ). The outcomes of this study support the government's policy of developing EIP services (DoH, 2001) and demonstrate that newly formed specialist interventions for EIP achieved improvements in a variety of outcomes, compared to generic teams. However, the participants in the treatment arm of the study showed no statistically significant improvements in insight, psychotic symptoms or on the depression scale compared to the non-experimental group ( $p>0.05$ ). In addition, all statistically significant differences in satisfaction with the service were lost once adjustments (using inverse probability weights for non-random patterns of missing data) were made. Methodologically, the study had many of the same limitations as in Craig et al. (2004) (underpowered study and reliance on recorded file data). In addition this study did not state the primary outcome measure, had poor follow-up rates and



was limited as assessors were not blind to the allocation of participants (which could have biased results).

### **Summary.**

Studies researching the effectiveness of EIP services compared to TAU have shown mixed results and have had several methodological limitations. Overall the research has shown that specialised EIP services may have a short term impact on symptoms or relapse. However, in response to criticisms (NICE, 2002) that focusing on only these aspects of recovery is too limited and does not account for other aspects of recovery other than clinical recovery (e.g. Bellack, 2006), studies have begun to research outcomes such as quality of life and social functioning. These studies offer support for EIP services in improving these types of outcomes and others aspects of recovery. However, this remains an area in need of further research on both areas of functioning (clinical and social) with larger participant numbers to allow greater generalisability.

### **Duration of Untreated Psychosis (DUP).**

It is suggested that untreated psychosis can have a negative effect and result in patients with a longer DUP having a poorer prognosis (Shietman & Lieberman, 1998). DUP has been a highly researched area and was one of leading arguments for the promotion and introduction of EIP services (DoH, 1999; 2001; Edwards & McGorry, 2002); however, research has shown mixed findings and there are methodological difficulties in researching DUP as a concept, including variation between studies in how DUP is estimating and defined.

Despite RCTs proposed strength (Sackett et al., 1996), studying DUP using RCTs would be considered to have ethical and practical difficulties. For example it could be considered unethical to offer information to the public regarding the harmful effects of long-standing psychosis and then request individuals to have delayed treatment for the purposes of an RCT (Melle et al.,

2004). Therefore the research covered in this section will mainly cover quasi-experimental methodology.

In 2005, Marshall et al. conducted a systematic review of first episode cohort studies to establish: whether they showed any evidence of an association between outcome and DUP; the extent to which pre-morbid adjustment explained any associations found. The sample consisted of 26 studies with 4490 participants (mean age at presentation 27.8 yrs, 39% women). The review explored correlational data; mean differences between long and short DUP, number of events in DUP groups and time to events in DUP groups. However, correlation data was the authors preferred data, due to difficulties in defining a cut-off point for short and long DUP and therefore conclusions about causality cannot be inferred.

The reviews main findings demonstrated convincing evidence of a modest association between a range of outcomes and DUP. The association was either small or non-significant at first presentation, but became statistically significant for all outcomes (positive and negative symptoms, symptoms of depression and anxiety, all symptoms, overall functioning, numbers achieving remission, time to remission, relapse, quality of life and social functioning), for data which was available at 12 month follow up. However, by 24 months follow up data was only available from two studies, but still showed correlations between longer DUP and worse outcome in three outcomes (overall functioning, positive symptoms and quality of life). When examining comparisons between long and short DUP, although based on smaller numbers, at six months there were statistically significant differences on four outcomes (all symptoms, overall functioning, positive symptoms and quality of life). Data on remissions showed that patients with longer DUP were statistically significantly less likely to achieve remission at all follow up points, compared to short DUP. When considering the effect of pre-morbid adjustment (in the presence of statistically significant association of DUP with one or more of the outcome measures) the review showed that out of 16 analyses for adjustment (from nine studies) 12 analyses showed that the

association between DUP and the outcome variable remained statistically significant after adjustment.

This review supported the presence of an association between DUP and outcomes, however due the majority of data being correlational it does not prove that longer DUP causes poorer outcome. Although the authors found little evidence to suggest that pre-morbid adjustment is a possible third variable (Marshall et al., 2005). The review has several strengths, including having clearly defined data sources, search strategy, data extraction and data synthesis. However it is limited as during the data synthesis, the authors used four clearly justified quality criteria for each study, which during the sensitivity analysis would be used to exclude studies. Although, the authors state that the sensitivity analysis did not affect the findings of any of the main outcomes, details of these results were not included in this paper.

In order to separate the effects of DUP on outcome, from other possible confounding variables, it is suggested that introducing early detection (ED) programs into clinical services and then comparing with patients in services without an ED program, could be a way of demonstrating causality (McGlashan & Johannessen, 1996). This has been the strategy used by the TIPS (early Treatment and Intervention in Psychosis) study (Johannessen et al., 2001), which developed ED strategies in healthcare sectors in Norway. The ED programme involved using media for intensive information campaigns, seminars and low threshold ED teams (Johannessen et al., 2001).

Based on the ED programs set up by the TIPS study (Johannessen et al., 2001), Melle et al. (2004) compared first episode patients from the ED area with first episode patients from two other healthcare sectors (with the same assessment and treatment programs, but without an ED program), using a parallel controlled design. Participants were followed up with interviews at three months, one year and two years; however only data from baseline and three months was reported in this study. Two hundred and eighty one patients aged 18-65 participated (141 ED area; 140 Non-ED area). The study measured

symptom levels, global functioning, misuse of drugs and alcohol and pre-morbid functioning, using well tested measures. A strength of the study was its clear descriptions of definitions used (DUP and onset of psychosis) and of checks used for reliability between assessors. Multiple linear regression analyses were carried out, to investigate whether differences between ED and Non-ED areas were due to confounding factors.

The key findings were that at baseline ED sector patients had significantly shorter DUP (median 5 weeks) than those from the Non-ED sector (median 16 weeks;  $P = 0.003$ ). In addition, patients from the ED area had significantly higher functioning levels and lower symptom levels across all measures at the start of treatment (e.g. positive and negative symptoms, GAF symptoms and functioning;  $P < 0.01$ ). Despite high levels of inter-correlation between DUP, ED and demographic and clinical factors, coming from an ED area still maintained clinical significance after the multiple linear regression analyses. Overall the study showed that it is possible for an ED program to influence DUP. In addition the design of the study makes sure that DUP differences are not caused by certain cohort effects. However, the study had several limitations, including observed group differences between ED and Non-ED groups, such as age at first contact. This could pose problems if there were interactions between age at onset and the effect of the ED program. Additionally, differences in DUP were not fully explained by the ED program and relationships between clinical status and DUP could still be found.

Larsen et al. (2006) reported their findings from the above study (Melle et al., 2004) at one year follow up, to research whether or not the ED area patients' advantages at baseline were maintained. Results showed that positive symptoms, general symptoms, global assessment of functioning, quality of life, time to remission and course of psychosis were not statistically significantly different between ED and Non-ED patients, at one year. However, outcome for the ED group was statistically significantly better for negative symptoms ( $p < 0.005$ ). Results were limited as authors acknowledged that the effect size was

small and further research will need to be done to confirm that ED programs can produce real secondary prevention.

More recent research on DUP and its relationship to symptoms, continues to show mixed findings, with no significant relationship found between DUP and symptom severity at intake or overtime (Theuma, et al., 2007) and no difference found between short and long DUP groups for positive or negative symptoms, or relapse rates (Uvcok, Polat, Cakir & Genc, 2006).

Similar to the above research, Norman, Malla, Verdi, Hassal and Fazekas, (2004) conducted research regarding the issue of DUP. However, they examined the pathways to care of 110 patients of a Prevention and Early Intervention Program for Psychosis, to identify the nature of any delays in receiving treatment. Both delays in contacting a helping professional and delay from such contact to the initiation of adequate treatment were equally identified in the sample. The authors suggest the importance of interventions which aim to both increase public awareness of symptoms and educate service providers and other professionals, in the importance of early identification.

### **Summary.**

Research findings surrounding DUP, despite being an initial influential argument in the establishment of EIP services (Edwards & McGorry, 2002), can still be considered inconclusive. Difficulties in finding effective ways of researching DUP, estimating and defining it, may have contributed to the inconsistent results found. However, additional research regarding the nature of DUP and reasons for delays are additional important research areas that require further exploration. Further research also needs to focus on the effectiveness of measures used to expedite pathways to care (Norman et al., 2004).

### **Limitations of quantitative outcome data.**

Although quantitative studies help to establish whether or not services are effective they neglect to establish why an intervention works and service-users' personal perceptions of the service they have received. Qualitative research is suggested to be important in understanding why an intervention is effective and is *"...helpful for identifying which are the "active ingredients" of the complex intervention, and which elements are not related to the treatment effect."* (MRC, 2000, p. 9). It is acknowledged that measures of outcomes, based on quantitative data are only part of the task and that qualitative methods can also help services tailor themselves to the specific needs of services users (Hollway, 2001).

### **Mixed Methods Research**

Mixed methods research, combining qualitative and quantitative methods, is considered a legitimate, stand alone research design (Creswell, 2002; 2003) and allows researchers to generalise findings as well as gain a deeper understanding of the area of interest (Hanson, Cresswell, Cresswell, Plano Clark & Petska, 2005). This section critically evaluates mixed methods studies researching service-users' and carers' experiences of services for psychosis (this will include both EIP services and services for psychosis prior to the establishment of an EIP model).

### **Experience of services.**

McKenzie (2006) conducted a survey to examine the experiences of people with psychosis and their carers, of accessing and receiving input from local mental health services in the UK (prior to the establishment of an EIP service). The study used two surveys (one for service-users and one for carers), comprising of a questionnaire with tick box responses and open ended questions, examining peoples' experiences of the current psychosis service. All respondents of the questionnaire were also invited to attend an interview

regarding their experiences. A total of 82 questionnaires were distributed with a response rate of 29% (12 service-users and 12 carers) with six respondents choosing to attend an interview. The study was limited as it provides no details about the content of the survey or interviews (how they were designed or conducted) or the process of analysis (any independent checking procedures) which makes replication of the study difficult. The second measure used in the study was a file audit, which involved studying four files of adolescents, with experience of psychotic episodes, aged between 16-18 years (three male one female). However, no detail of how this file audit was undertaken, or why certain files were chosen, was explained.

The key findings of this study were that: the experiences of recent service-users are more positive than those who first came into contact with services in the 1970s and 1980s; overall service-users and carers felt supported by mental health services; there is a need for more education in order to reduce the stigma attached to mental health services and the delay between asking for help and receiving it; there should be more access to psychosocial therapies; the importance of the inclusion of an EIP approach within services. This study offers support for a UK EIP model of working; however, it is only based on one NHS Trust and was conducted prior to the establishment of an EIP service. In addition, there are no details of the service on which the research was conducted and the small sample size makes generalisability of the findings limited. There is no distinction between the information derived from the questionnaires or interviews, which makes the whole study difficult to replicate.

There have been further attempts to evaluate the effectiveness of services for psychosis, which has included a study by Theuma et al. (2007), a non-controlled study which evaluated a New Zealand EIP service. The study used both questionnaires (closed and open ended questions) and interviews to research patient satisfaction. Participants were 100 patients (66 male, 34 female) 60 aged between 15 and 24 years and 40 aged between 25 and 40 years. Of the 100 patients 40 were sent questionnaires (who were current and discharged patients) and were invited to take part in an interview. Thirteen

responded to the questionnaire (quantitative method) and four participants (two male, two female) took part in an interview (qualitative method).

The study measured symptom changes over five time points (Intake, 3, 6, 12 and 24 months) using the Positive and Negative Symptom Scale (PANSS; Stanley, Lewis & Abraham, 1986) and the Health of the Nation Outcome Scale (HoNOS; Wing et al., 1998). A strength of the study was its clear discussion about the reliability of the measures used. Measures were only completed for patients in contact with the service at each time point (intake n=100, 3 months n=84, 6 months n=63, 12 months n=48, 24 months n=19). The research used a mixed model with repeated measures analysis which took into account the relationship between measures over time with the same person, but also allowed for incomplete data sets to be included in the analysis. The key findings from the non-controlled study were that: patients involved with the service had a significant decrease in severity of their positive and negative symptoms ( $p < 0.001$ ); and the patients had significant improvement in their daily functioning ( $p < 0.001$ ); improvement was significant within the first three months and improvement continued for those who remained in contact with the service. However, results of this study are inconclusive due to the absence of any control group and possible biases in outcomes, due to measures being completed by the EIP service staff.

With regard to patient satisfaction, limited detail was provided on the actual responses obtained in either the questionnaire or the interviews. Therefore, the key findings are based on the information which the authors decided to include. The key findings were indicated as follows: overall service-users were satisfied with the service they had received and the sensitivity of staff; service-users attributed some of their progress to the service; helpful aspects of the service included having people listen to you and understand; unhelpful aspects included feeling they were being fitted into diagnostic categories and feeling they were pressurised into doing things. It is important to acknowledge the small sample size used for both the questionnaires and interviews as a further limitation of this study. Furthermore, as this is based on a New Zealand EIP service it can



only offer limited insights into UK EIP services, as the EIP models delivered differ due to cultural differences between the countries.

### **Summary.**

Although the information obtained in the qualitative aspects of the above studies begins to offer an insight into service-users' subjective experiences of services, it remains limited. The studies seem to neglect any quality assurance measures, by failing to detail any of the processes involved in gathering and reporting the qualitative data. It is difficult to tell what information has been gathered quantitatively or qualitatively as they are reported together and the qualitative data also appears to take a back seat to the quantitative aspects of the study and therefore are not truly mixed methods research. This priority given to the quantitative aspects of the data has been previously recognised as a possible limitation of mixed methods research (Cresswell, Fetter & Ivankova, 2004).

### **Qualitative Research**

This section focuses on the research which has been carried out using purely qualitative methods and is divided into research covering service-users' experiences of their psychosis and research regarding service-users' experiences of mental health services and interventions for psychosis. Service-users' experiences of their psychosis is included as it directly relates to the aims of the research and also includes discussions around 'stigma' (and reducing stigma) and 'recovery' as these are important topics in the literature regarding psychosis and are related to the key aims of EIP services (e.g. DoH, 2001; Sainsbury Centre for Mental Health, 2003). Experiences of services for psychosis are included as it also directly relates to the research aims.

## **Experiences of psychosis.**

There is an accumulation of qualitative work which aims to understand the subjective experience of psychosis (Romme & Escher, 2000; Blackman, 2001; James, 2001; Georgaca, 2004). Davidson has used qualitative approaches for researching schizophrenia (Davidson, 1992; Davidson & Stayner, 1997), by outlining family and personal perspectives. In these accounts feelings of loss, loneliness and isolation emerged (Davidson & Stayner, 1997).

Barker, Lavender and Morant (2001) conducted a qualitative study which aimed to explore the narratives used by both clients and their family members when explaining: the process of developing schizophrenia; how it has impacted on the client's sense of self and social relationships; how narratives of health professionals has impacted on this process. Eight clients (six men and two women) aged between 25 and 50, all with a diagnosis of schizophrenia and eight close relatives (six mothers and two fathers), participated and were recruited from a rehabilitation and continuing care service in London (relatives were recruited by asking participants to name a close relative). Although the study outlines who participants were and how relatives were identified, there is no detail of the sampling procedure used to identify approach or recruit participants, which is a limitation of the study, as it makes replication difficult. Data was collected using a semi-structured interviews (approximately 40-80 mins) conducted by the first author. The study had several strengths which included: the interview schedule was clearly outlined and was developed from the initial research questions and from two pilot interviews; the data was analysed using grounded theory strategies and process of analysis was clearly described; strategies of quality assurance were clearly described.

The results were presented in four stages: events preceding the first psychotic episode; events around the time of the first episode; events around the first hospital admission; and current experiences. Both clients and family members produced narratives in which the first episode had been preceded by difficult life events and relationship problems. The authors suggested that this was in

accordance with previous research (Hatfield, 1989) and stress vulnerability models of schizophrenia (Warner, 1994). Almost all clients' narratives included accounts of developing a sense of self, which was viewed as central to improving their wellbeing. The paper suggested that findings indicate mental health services should be aiming to assist in the client's development of self and discussing issues with identity could be more meaningful than discussions of diagnosis. In their discussion, Barker et al. (2001) consider how the first author's training in clinical psychology may have impacted on their interpretation of the data. This reflexivity is an important consideration when conducting qualitative analysis and is a further strength of the research. The results of this study yielded information about service-users' and carers' experiences of services, which will be discussed in section 'experience of services'.

Barker et al. (2001) and other previous research has focused on adults experiences of psychosis, whereas factors such as being male, young and having experiences of psychosis, is an area that has been understudied (Harrop & Trower, 2001). Therefore, Hirschfeld, Smith, Trower and Griffin (2005) conducted a grounded theory analysis of transcripts of young men, talking about their experience of psychosis. Six men aged between 19- 29 years old (with a diagnosis of schizophrenia) were recruited by sending information to their key workers. All participants were in contact with mental health services, however, no details of these services are provided. The six participants were self-selected and the study does not explain how many service-users were approached in total or the inclusion criteria used to select eligible service-users, which is further limitation. Participants were interviewed twice during the critical period (three-five years) after the onset of psychosis (Birchwood, 2000). Transcripts were analysed using grounded theory and the authors provided clear details on the rationale for this approach and the stages of analysis (including discussions of cross checking and saturation of the data), which is a strength of the study. A further strength is the authors' recognition of the main researcher's personal experience of working with people experiencing psychosis and how the author would unavoidably use their personal frame of reference when analysing the data.

The analysis produced four key themes which were common to all participants: experience of psychosis; immediate expression of psychotic experiences; personal and interpersonal changes; and personal explanations. Within these themes, there were discussions of suicidal and depressive feelings and behaviours and descriptions of two distinct types of coping response. Additionally, multiple explanations about the factors which influenced the onset of psychosis are covered, including both internal and external factors. The authors acknowledge the possible implications of this study on the development of more clinically sensitive interventions, where the service-users' explanations are valued.

In a more recent study of the experiences of psychosis in young men, Perry, Taylor and Shaw (2007) used IPA to investigate the personal experiences of hope, in five men aged 19 to 25 who had experienced their first episode of psychosis, six to eight months prior to their participation. The participants were purposely selected from mental health teams in a British city and were identified by the psychiatrist from those teams. The participants took part in semi-structured interviews which focused on their experience of hope. The authors gave detailed descriptions of the interview schedule and how it was developed which strengthened the study.

The analysis produced three super-ordinate themes which were labelled using the participant's words. They were discussed in-depth and illustrated with multiple quotations, which increased the transparency of the analysis. 1) "What's it all about?" captured both the participants struggle to explain their personal understanding of their experiences and the researchers struggle to find meaning in the narratives, 2) "Banged up" described a shared experience of having spent time in an in-patient hospital setting and 3) "Belonging verses alone" captured the participants expressed need to belong rather than be alone. Overall the study explored the personal meanings and influences of hope and experiences which both contributed to, maintained and hindered feelings of hope.

It has been identified that the way in which people recognize and respond to emerging symptoms of psychosis is poorly understood and was therefore the basis for a qualitative study carried out by Judge, Estroff, Perkins & Penn (2008). Fifteen participants (diagnoses included seven with schizophrenia, five with schizoaffective disorder, two with schizophreniform disorder and one with psychotic disorder not otherwise specified) recruited from a public outpatient psychiatry clinic took part in two semi-structured interviews, designed to elicit information regarding participant's subjective experience of early psychosis and help seeking behaviours. Transcribed interviews were analysed using inductive principles including grounded theory and content analysis. Details on quality assurance and method of analysis were included in the article.

Results formed two conceptual categories both of which contained several themes. The first category of 'recognising changes' refers to alteration that the individuals noticed in themselves and how they identified and made sense of these changes. The second category of 'responding to changes' captured themes related to how participants responded to related changes in the self. The key findings of the study were that participants despite often being the first to notice changes within themselves normalized the experiences into their current view of the self. With regard to responses to psychosis, participant narratives highlighted; an avoidance of seeking professional help due to their views of schizophrenia as a stigmatizing illness; difficulty describing their experiences to others resulting in withdrawal; that all participants described a sense of coming to terms with psychosis, which reflected views of mental health consumers regarding recovery being a process of finding meaning in the experiences and forming an identity beyond someone with a mental health problem (Bellack, 2006). The results of this study relate to the literature on both stigma associated with mental health problems and the vast literature on the issue of definitions and experiences of recovery, which will be explored below.

### ***i. Stigma.***

A key component of an EIP approach is to “...*reduce the stigma associated with psychosis and improve professional and lay awareness of the symptoms of psychosis and the need for early assessment.*” (DoH, 2001). It has been long reported that people with diagnoses of schizophrenia, psychoses and other mental health problems endure stigmatization (e.g. Farina, 1998; Hayward & Bright, 1997). To-date qualitative investigations researching the experiences of stigma amongst individuals with psychosis have identified different dimensions of stigma, including the impact on social roles and public images of mental health problems (Schulze & Angermeyer, 2003). Other studies found that the experience of stigma can lead to a sense of lost identity, social exclusion (Knight, Wykes & Hayward, 2003), can impact on peoples help seeking behaviour (Judge et al., 2008) and can differ between individuals with different diagnoses (Dinos, Stevens, Serfaty, Weich & King, 2004). However, research has focused on participants recruited from a variety of mental health services and not specifically from an EIP service and have used purposive sampling to recruit participants who have reported the experience of stigma.

This research is important in highlighting the need for qualitative investigations into the subjective experiences of services-users with regard to stigma and its consequences. However, it does not focus on service-users’ experiences of stigma related to their experiences of being in contact with an EIP service. As EIP services are designed to reduce the stigma associated with psychosis, further research which allows for participants to voice their own experience of an EIP service approach could develop this literature further and identify the nature of any experiences of stigmatization within an EIP model.

### ***ii. Subjective views of recovery***

The concept of ‘recovery’ in psychosis and other mental health problems has become a much debated concept within the literature, as views on potential outcomes have altered (Bellack, 2006). Similarly, the definition of what recovery

means has been debated heavily, with views that recovery is a multifaceted concept which requires more than just symptom alleviation, but a focus on social and psychological recovery which involves “...*the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness.*” (Anthony, 1993, p. 527).

Qualitative research studies have begun to try and understand the subjective experiences of recovery in people with mental health problems (e.g. Davidson, 2003). Ridgway (2001) examined four published first person accounts of recovery from psychiatric disability using a qualitative methodology of a constant comparative method. Results identified eight common themes but a core narrative common to all accounts, which moved from sense of feeling stuck in their chronic disability towards a more complex story which the authors described using the metaphor of an ongoing journey. Overall the research supported contemporary ideas of an individualised recovery process which can be experienced by people with long-term mental health problems. Other qualitative studies have suggested models of the recovery process, based on subjective experiences of people with mental health problems (Young & Ensing, 1999).

Andreson, Oades and Caputi (2003) conducted a review of published qualitative accounts of recovery from people with schizophrenia and other mental health diagnoses, consumer articles on the concept of recovery and qualitative research on recovery. The results identified that the meanings of recovery used by consumers reflected a ‘psychological recovery’ from the consequences of their experiences. Results identified four key processes of recovery: i) finding hope; ii) re-establishment of identity; iii) finding meaning in life; iv) taking responsibility for recovery. These common themes were then used to construct a proposed model of recovery reflecting consumer personal experiences incorporating the following stages: i) moratorium; ii) awareness; iii) preparation; iv) rebuilding; v) growth.

The qualitative research on the concept of recovery is important as it tries to understand recovery from the point of view of the people who have or are experiencing mental health problems. However, although stage models are suggested to be important in being able to empirically research recovery as a concept (Andreson et al., 2003) it could be viewed as incongruent with the consumer movement's view that recovery is an individualised, non-linear process (Bellack, 2006). Additionally, with regard to EIP services, which adopt an optimistic view of recovery beyond the focus of symptoms, the research to date does not address the experiences of recovery in EIP service-users. Therefore, more research is necessary to understand the meaning of recovery to service-users who are in contact with recovery-orientated services.

### **Experience of services.**

Work by Lazare et al. (1972) paved the way for the view that service-users are seen as consumers of mental health services and therefore their views should be considered (Chadwick, 1997). In a recent publication NICE (2009) included a chapter on the experiences of individuals with a diagnosis of schizophrenia and their carers. Individuals who were approached were asked to consider several questions when composing their narratives, which included, *"...What is the nature of your experience of living with schizophrenia?...Was the treatment(s) helpful? (Please describe what worked for you and what didn't work for you.)... If your condition has improved, do you use any strategies to help you to stay well? If so, please describe these strategies."* (NICE, 2009, p. 43-44).

Narrative accounts were gathered from 2 men with a diagnosis of schizophrenia, who have been receiving treatment for more than 15 years, a woman who was first diagnosed in the 1980s, and five were written by carers (including two fathers, two mothers and one partner). The publication also includes findings from an independent RETHINK survey (Borneo, 2008) completed by 959 service-users. The survey asked people about their experiences of taking medication, care planning and decision making, physical healthcare and access to non-pharmacological treatments. Results from the



NICE (2009) publication suggested that overall narratives indicated that the overall care for people with experiences of psychosis had improved, due to factors including modernisation of services, greater choice of medications, policy changes and individuals own efforts in terms of peer-support.

In line with this publication, this section focuses on the qualitative research studies which have explored service-users' subjective experiences of receiving services and interventions for psychosis. This will include both EIP services and services for psychosis prior to the introduction of a specific EIP model.

### ***i. Service-users, families and professionals.***

With regard to experiences of services for psychosis, the literature has looked at both the service-users' perspectives but also the perspectives of family members, carers and mental health professionals. For example, in addition to looking at the experience of developing schizophrenia Barker et al. (2001) also gathered narratives of clients and family members' experiences of the rehabilitation and continuing care service. At the time of first hospital admission, both clients and relatives described feeling they were not being heard by professionals. Clients felt they were distant from the process of admission and that professionals were imposing their own descriptions of the symptoms they were experiencing. Relatives described feeling both grateful to services, but also feeling unheard. In comparison to the first hospital admission, clients' and relatives' views of service input were more positive, with the majority being complimentary of the support they received. However, feelings of not being understood by professionals still prevailed. This study begins to offer an insight into how services for psychosis can impact on the experiences of the service-users and their carers. However, the focus of this study was primarily on the experience of developing schizophrenia and participants were recruited were not from an EIP service.

In a more recent study Coffey and Hewitt (2008) interviewed both service-users with psychosis (n=20) and community mental health nurses (n=20), regarding

the nurses' responses to voice hearing. The study showed contrasting views between the two groups, with a clear difference between the service-users' needs and interpretation of help received and the interventions nurses were prepared to offer. This research focused solely on the responses of nurses to hearing voices and did not include other professionals or the impact of a whole service approach. However, despite this limitation it made a further step towards understanding how a service approach for psychosis can have positive and negative impacts on the experiences of service-users. It identifies a challenge in clinical practice, in trying to create congruence between the needs of service-users and the personal views of professionals working with them.

## ***ii. Services and specific interventions.***

Qualitative studies investigating adults' experiences of 'hearing voices' groups (Chadwick, Sambrooke, Rasch & Davies, 2000; Jones Hughes & Ormond, 2001) have shown results that are consistent with quantitative studies, suggesting that services-users benefit from sharing their experiences with other services-users' with similar experiences (Wykes, Parr & Landau, 1999). However, these studies are limited by focusing solely on adult populations and neglecting the younger age range (18 and below) also targeted by EIP services. In response to this limitation Newton, Larkin, Melhuish and Wykes (2007) conducted a qualitative investigation of the experiences of young people who engaged in Cognitive Behavioural Therapy (CBT) based groups for voices. Guidelines on the implementation of EIP services recommended that Cognitive Behavioural Therapy (CBT) be offered to service-users and can be of considerable benefit (DoH, 2001).

Eight participants (five female and three male, aged 17 or 18) who had completed a CBT group intervention were interviewed. Clear methods of sampling and the actual demographics of the participants were not provided in the paper, which are limitations of the study. Several strengths included: participants were interviewed by a researcher who did not attend any of the group sessions; interviews were taped and transcribed; semi-structured

interviews were guided by an interview schedule and the development of the schedule was clearly explained. However, the actual schedule used in the interviews is not provided. A clear justification for the use of semi-structured interviews is given and the method and value of using IPA is highlighted, which are further strengths of the study.

Two key themes emerged from the analysis which included 'A place to explore shared experiences'. This theme had four subthemes: a safe place to talk; normalising and de-stigmatizing properties of the groups; the importance of learning from and helping others; the important role of facilitators and the strategies used to 'make everyone feel special.' The second theme explored the cyclical relationship between the participants' experiences of hearing voices. These findings indicated that those with passive explanations for their voices may be more distressed, have fewer coping strategies and gain less from group interventions. The findings of this study indicated the important aspects of a CBT group for hearing voices and inform what reduces the distress of hearing voices. In addition, it offers support for groups such as this being offered for individuals with auditory hallucinations and touches on the perceived role of the facilitator in these groups.

Newton et al. (2007) focused on the experiences of a single intervention offered to individuals with psychosis. Therefore, an understanding of service-users' perceptions of an EIP service as a whole and its impact on their psychosis was not gained. However, two other research studies have attempted to gain an understanding of an entire service approach for FEP.

O'Toole et al. (2004) conducted the first systematic qualitative evaluation and recruited participants from the Southwark First Onset Psychosis Service (FIRST) which was set up in 2001 and was designed to incorporate elements of recommended 'best practice.' The service had been previously evaluated and quantitative measures indicated significant improvements in a variety of outcomes (Taylor et al., 2002). Twelve service-users (out of 29 clients who use the service) agreed to take part in a focus group evaluation. Demographics of

all service-users in the service and those who took part are provided in the paper, which strengthens the study by making it more replicable. However, all 12 participants were self selected, which the authors highlight as a possible source of bias, with participants who took part possibly having higher functioning and more confidence than those who did not participate.

Three focus groups took place (four participants in each) and were organised and run by an independent facilitator, each lasting between 35 and 60 minutes. Focus groups were led by a topic guide intended to aid discussions; however, no details are given regarding its construction or content. Focus groups were audio-taped and transcribed ready for analysis. IPA was carried out by an independent researcher trained in the use of IPA. The authors give a clear description of the stages of analysis and a rationale for the method chosen, which is strength of the research. Some of the following key elements were identified as positives of the service: flexibility of the service; reduction in symptoms; being treated in context; and nurse to patient ratios.

The findings of this research indicated that participants appreciated the service they received and they provide positive support for elements of a UK EIP service model. Participants were recruited from a service which was set up in January 2001 and designed to incorporate elements of 'best practice'. However, it is not indicated that the service was designed in-line with national guidelines for EIP services (DoH, 2001). As discussed earlier, the recruitment of participants could be seen as a limitation of the study and may have contributed to the fact that the study only yielded positive attitudes regarding the service. Additionally, the authors give a justification for their use of a focus group methodology; however, they do not acknowledge its limitations. Although focus groups can allow for a topic to be explored in depth, using other methods such as semi-structured interviews, allow for features to be extended and revealed in even greater depth (Newton et al., 2007).

The second study by Larsen (2007) used a person-centred ethnographic approach to study a Danish EIP (OPUS) service, which involved two year

participant observation and repeated interviews with clients. The aim was to illuminate the key functions in the process of an EIP service, which is regarded as a 'complex intervention'. The authors recognised that although EIP interventions are promoted and supported by clinical outcome data and there are guidelines available on how to deliver the service (e.g. in the UK; DoH, 2001), there was a lack of empirical research on how the services are actually delivered. This social evaluation was conducted in at the same time as an RCT of the OPUS service and involved two years field work and follow-up interviews (covering a time period of three and a half years in total), with the aims of evaluating the social aspects of the OPUS experimental intervention. The author employed a multi-method approach including documentary analysis, individual interviews, focus groups, surveys, observations and reflections. Fifteen clients were selected by the author to take part in interviews (every six months) to explore the experimental effectiveness of the intervention for clients. However, the structure and content of these interviews and demographic information about the participants was not detailed in the article, making replication of this study difficult. Similarly, the results section provided limited extracts from only a small number of service-users who took part in the interviews.

The author concluded that the research provided an insight into the workings and therapeutic process of a complex intervention. However, a limitation of this study was its use of clients from an experimental EIP intervention, where service-users agreed to receive an intervention from the EIP service as part of a RCT evaluation study. The experimental nature of the EIP service means the study does not offer an insight into the experiences of service-users in a real EIP service context. This was highlighted as the authors acknowledged that one client explicitly stated that he only attended his initial appointments with his case manager from the EIP service as he “...*felt morally obliged to, as he had agreed to take part in the intervention and the research.*” (Larsen, 2007, p. 340). This obligation to attend the EIP service does not reflect a real world context, in which service-users have a choice regarding engagement and the level of engagement with EIP services and therefore, does not explore service-users’

experiences of a real-world EIP service. Additionally, the main focus of the research was on gaining a deeper understanding of how a complex EIP service works and less on what it was like for clients to be in contact with an EIP service.

### **Summary.**

Despite its importance, qualitative research in the area of service-users' subjective experiences of services and interventions for psychosis is extremely limited. Research into the experiences of CBT for psychosis has highlighted both helpful and unhelpful features of this model delivered in a group format; however, this is only one aspect of an entire service approach. Qualitative research which focuses specifically on service-users experiences of an EIP approach is limited with only two studies being identified in the current literature. The research has provided an insight in to the aspects of an EIP service which were appreciated by service-users (O'Toole et al., 2004) and provided insights into the socio-cultural workings of an intervention (Larsen, 2007). However, limitations including the use of focus group methods, self selected samples, service-users from an experimental EIP context, and inevitable differences between EIP models delivered in different countries (Larsen, 2007). Therefore, due to EIP services recovery-focused and specialised service approach to psychosis, more research is necessary which adopts a method which allows in-depth exploration of individual experiences of being in contact with a UK EIP service and how this has impacted on their view of their psychosis.

### **Overall Summary**

The vast majority of research in the area of EIP has focused on evaluation of outcomes such as relapse and the effectiveness of reducing DUP. Research which has considered a wider range of outcomes such as patient satisfaction or quality of life has produced mixed findings. Difficulties in estimating and measuring concepts such as relapse and DUP and the limitations identified in methodologies used; results in EIP services being backed by inconclusive

findings. The attempts made to incorporate qualitative data into quantitative methods, has produced narrow insights due to poor methodological rigor. Whereas, research which aims to understand service-users' experiences of EIP services, using qualitative methods, is limited. Previous attempts have provided support for an EIP model of working and have begun to illuminate the key functions in the process of this type of intervention (Larsen, 2007; O'Toole et al., 2004). However, the limitations of these studies indicate that more research is required in order to provide in-depth exploration of individual experiences of being in contact with UK EIP services and the meaning this has for service-users.

## **Research Aims**

The development of EIP services are viewed as a response to the change in how psychosis is viewed and the consumer-movement which has challenged the pessimistic view of outcomes in psychosis (Bellack, 2006). In contrast to previous services for psychosis, EIP services are delivered by specialist teams and have a recovery-orientated focus, aiming to reduce stigma and positively impact on people's lives, experiences and views of psychosis. The literature regarding the effectiveness of EIP services is predominantly quantitative in methodology and neglects the exploration of service-users' personal perceptions of the specialist recovery-orientated service they have received. Within the context of psychosis, using qualitative methods is important as it has been recognised that service-users may evaluate the effects of treatment and services differently, based on their first hand experiences (Bentall, 2003). (see Journal article for aims).

The findings of this research could illuminate potential positive and negative aspects of an EIP approach and how the specialist recovery-orientated approach is experienced by those who are in contact with the service. It could contribute to a national debate regarding the value of the EIP model and researching EIP as a concept. To date no published research has been identified which solely uses qualitative interviews to gain information about

service-users' personal experiences of a UK EIP approach, the meaning of being in contact with the service and its impact on their experience of psychosis.



## **Extended Methodology**

This section provides additional information and detail that is not included in the journal article. In addition to providing more detail regarding the research method, it also outlines the research study's epistemological stance, the rationale for the chosen methodology, a discussion regarding quality assurance measures in research, ethical considerations of the research and challenges during data collection.

### **Qualitative Research Rationale**

Qualitative and quantitative research adhere to different epistemological positions and often within the mainstream sciences, quantitative research has been given greater priority than qualitative methodologies (Denzin & Lincoln, 2005). Qualitative methodologies have been criticised for the space that is often afforded to the role of the researcher and their subjectivity (Madill, Jordan & Shirley, 2000). However, it is recognised that both methodologies have different research aims. Following the increase in research utilising qualitative methodology in the field of psychology, it has been recognised that different qualitative methodologies have very different yet often overlapping epistemologies and theoretical emphasis (Smith, 2004), with no distinct or singular paradigm, or set of methodologies that are entirely its own (Denzin & Lincoln, 2003).

Although there are a variety of different approaches to qualitative psychology, behind each is a common concern with people's grasp of their world (Ashworth, 2003) and with a purpose of revising and enriching current understanding (Elliott et al., 1999). By contrast quantitative research aims to test hypotheses, measure causal relationships between variables and enable phenomena to be quantified and generalized (Denzin & Lincoln, 2005). Qualitative researchers study the phenomena in its natural setting and attempt to interpret them in terms of how the experience is created and the meanings people bring to them (Denzin & Lincoln, 2005).

The current study aimed to understand how the participants make sense of their experiences of being in contact with an EIP service and how this has impacted on their view of psychosis, which is well suited to a qualitative methodology. The research aimed to be exploratory, not to test pre-determined hypotheses (Barker, Pistrang & Elliott, 2002). Additionally, qualitative research places the participants at the centre of the research and aims to generate knowledge that is informed by the service-user's perspective (DoH, 2005).

The vast majority of research regarding psychosis and specialist psychosis services has focused on evaluation of outcomes, such as relapse and the effectiveness of reducing DUP and has adopted mainly quantitative methodologies. However, it is important to recognise that people with psychosis may value their experiences differently from those who are experiencing it second hand and therefore may evaluate the effects of treatment and services differently (Bentall, 2003). Additionally, government initiatives have suggested that the perspectives of service-users should play an important part in the evaluation of mental health services (DoH, 1999; NICE, 2002). To date, qualitative studies have shown a clear place for this methodology in researching the experience of both psychosis and specialist services, however, it has been under-utilised (see extended background). Therefore, the lack of qualitative research in this area and the appropriateness of qualitative methodology's epistemological positioning formed the basis and rationale for this study.

## **Epistemology of the Research**

The following considers the epistemological stance of the current research by discussing the epistemology of both the research methodology and psychosis, which is the subject material of the research. In order to be in contact with the EIP service all participants will have experienced psychosis, therefore the epistemology of psychosis is discussed, as it is debated in the literature.

## **Epistemological position.**

When carrying out research there are three questions which need to be answered to determine the research paradigm, 1) The ontological question, what is the form and nature of reality? What is there to be known? 2) The epistemological question, what is the relationship between the researcher and what can be known? (Guba & Lincoln, 1994). Epistemology is concerned with the theory of knowledge and attempts to answer the questions of how and what can we know? (Willig, 2001). 3) The methodological question, how can the researcher go about knowing what can be known? (Guba & Lincoln, 1994).

### ***Positivism.***

The *Positivist* paradigm is often termed as *Realism* or *Naïve realism* and assumes that there is an apprehendable reality which exists (Guba & Lincoln, 1994) and that this real world is knowable (Madill et al., 2000). It is based on a correspondence theory of truth, which suggests that a belief is true if it matches reality (Barker et al., 2002). Its epistemological position suggests there is a relationship between the world and our perceptions and understandings of that world and the goal of research is to produce objective knowledge (Willig, 2001). The researcher and the investigated object are seen as independent entities, and it assumes that the researcher can study it without being influenced by it, or influencing it (Guba & Lincoln, 1994).

### ***Constructivism.***

In contrast *Constructivism's* ontological view of *Relativism* assumes multiple, apprehendable realities (in contrast with the assumption of a single objective reality), which are the product of human constructions; therefore, realities are dependent on the individual holding the construction about reality (Guba & Lincoln, 1994). With regard to its epistemological stance, constructivism views knowledge as being created in the interaction between the researcher and the researched (Guba & Lincoln, 1994).

### ***Critical realism.***

This study used IPA (Smith, 1996) as its methodology, which has its roots in critical realism (Bhaskar, 1978). Critical realists believe that there is both an external world which is independent of human consciousness (which can be seen as similar to positivist ontology) and at the same time there is our socially determined knowledge about that reality (Danermark, Ekstrom, Jakobsen & Karlsson, 2002). Therefore, a critical realist stance suggests that a reality does exist, which is independent of human perception (McEvoy & Richards, 2003), but at the same time adopts a critical stance towards 'factual truth' and accepts that observations are fallible, as they are shaped by our conceptual frameworks. Adopting a critical realist viewpoint, it is not reality itself which is socially constructed, rather it is the theories we have about that reality and the methods we adopt to investigate it (Pilgrim & Bentall, 1998). Therefore, it is these human interpretations which need to be studied (Danermark, et al., 2002). Critical realism is referred to as a less naïve form of realism and is seen as having much in common with *Constructionist* approaches, as it recognises the role of subjectivity, in the production of knowledge about the world (Madill et al., 2000).

This study aimed to understand how the participants had subjectively experienced and made sense of their shared phenomenon of being in contact with an EIP service. Therefore, the critical realist stance is congruent with the aims of the research, as it is concerned with the participants' experiences of reality, not the reality itself. With regard to 'truth' the participants' accounts gathered in this study, are viewed as truthful accounts of their experiences, as a critical realist stance would accept multiple equally plausible truths. Therefore, if the participant provides what they deem to be a truthful account of their experiences, this is accepted as truth.

## **Psychosis.**

With regard to psychiatric diagnoses, such as schizophrenia, there are different epistemological viewpoints and discourses which are outlined by Pilgrim (2007). *Medical Naturalism* begins with the premise that mental disorders and diagnoses such as schizophrenia are labels for phenomena which exist in reality and are independent of human beings. A contrasting view of mental health diagnoses, held by *Radical Constructivists*, is that “mental illnesses” are a by-product of human activity, are context specific and do not exist as an objective entity. A third view point, which is seen to bridge the gap between these two opposing views is the *Critical Realist* stance. This stance is the epistemological position of this study and suggests that there is an external reality of unusual experiences or distress, but this is represented by shifting subjective activity and should be critically evaluated. Pilgrim & Bentall (1998) consider that the unusual experiences or distress experienced by individuals should not be dismissed as purely a by-product of human activity and construction; however, the validity and reliability of diagnostic labels as helpful concepts are highly criticised.

## **Research Methodology**

There are a vast number of qualitative approaches, which can be adopted in research, each of which is seen as being informed by different ontological and epistemological stances (Willig, 2008). Therefore, different methods were considered when deciding on the appropriate methodology for answering the aims of the research.

As this study aimed to phenomenologically explore service-users' experiences of an EIP service, Grounded Theory (GT) (Glaser, 1992; Glaser & Strauss, 1967) was not considered an appropriate research method. GT methods consist of guidelines for gathering, synthesizing and analysing qualitative data in order to construct theory (Charmaz, 2001). GT is distinguished by the researcher's simultaneous involvement in both data gathering and analysing, with the aim of

developing theory (Charmaz, 2008). Although GT can answer questions concerning personal experiences, the aims of theory generation in GT, was seen as incongruent with this study's aims, which were to flexibly explore service-users' experiences of being in contact with an EIP service, not to generate theory. Service-users' experiences of UK EIP services and the impact on their experiences of psychosis has not been studied in-depth in the current literature, and remains poorly understood, therefore the aims of the current research were more exploratory than attempting theory construction.

In addition to GT, Narrative Analysis (NA) was also considered as a possible method for answering the aims of this research. This analysis is concerned with the way in which people sequentially link events and make them meaningful to others (Reissman, 1993). NA can be seen as similar to IPA as it is concerned with the way in which people make sense of the world (Murray, 2008), regardless of whether or not the stories are an objective representation of reality or 'true' (Lawler, 2002). A narrative can be defined as "*...an organised interpretation of a sequence of events... an account with a beginning, a middle and an end.*" (Murray, 2008, p.113-114). As the participants in this study would still be in contact with the EIP service and could possibly describe themselves as still having ongoing experiences of psychosis, it suggests that their story might not yet have an end or might be considered a story which cannot be completed or is ongoing. Therefore, although there was overlap between these two approaches, IPA was considered the more appropriate for studying the aims of this particular research.

A further methodological consideration was the potential use of Discourse Analysis (DA) (Potter & Wetherell, 1987). IPA and DA are similar with their emphasis on the importance of language and qualitative analyses, however; IPA differs in its view of cognition (Smith, Jarman & Osborn, 1999). Whereas DA views verbal language as behaviours in their own right, which is contingent on the context of the situation (Smith, 1996), IPA is concerned with understanding what the participant thinks and believes about the phenomena

(Smith et al., 1999), which was considered a more appropriate method for the research aims.

### **Theoretical Underpinnings of IPA**

IPA is seen as a suitable approach, when a researcher is trying to find out how individuals perceive situations they are experiencing and how they are making sense of their personal and social world (Smith & Osborn, 2008). The aim of research, which adopts IPA is to flexibly explore in detail an area or phenomenon, rather than to test pre-determined hypotheses. Both of these elements of IPA were seen as congruent with the aims of this research and as discussed, IPA was deemed to be the most appropriate method for the aims of the research.

Theoretically, IPA aims to carry out a detailed exploration of participants' personal lived experience and how they make sense of that experience and the meanings particular experiences and events hold for them (Smith & Osborn, 2008). IPA draws on the philosophies of *phenomenology* and *hermeneutics* (Smith, 2004).

Phenomenology is a philosophy founded by Edmund Husserl and is concerned with the researcher's attempt to understand an individual's experience in terms of their perceptions and meanings (Ashworth, 2003) and requires the researcher to enter the 'lifeworld' (the way a phenomena is experienced in everyday life [Giorgio & Giorgio, 2008]) of the research participants (Willig, 2008), with the aim of clarifying situations lived through by individuals in everyday life (Giorgio & Giorgio, 2008). However in terms of phenomenology as a method, it has not reached a unified approach and has been formed from the contributions of many philosophers (Le Vasseur, 2003). Husserl (1969) believed that phenomenology begins with the notion of setting aside and bracketing prior knowledge about a phenomenon and it is experience and human meanings which are the key to studying lived experiences, rather than causal variables (Ashworth, 2003).

IPA is phenomenological, as it is concerned with individuals' personal perceptions of objects or events, rather than attempting to produce an objective record of the object or event itself (Smith, 1996), which can be seen as contrasting with research informed by a positivist epistemology. IPA involves detailed exploration of the participant's lived experience (Smith & Osborn, 2008) and aims to explore the participant's view of the world and to adopt an insider's perspective (Conrad, 1987) of the experience being studied (Smith, 1996).

However, Heidegger (1962), a student of Husserl, began to recognise the influence and significance of the researcher's past experiences and that bracketing was an unattainable ideal (Walters, 1995). Therefore, IPA also recognises that while the researcher attempts to get close to the participant's personal world, this cannot be done directly or completely. It is complicated and influenced by the researcher's own assumptions and conceptions, which are used to make sense of the person's world through the process of interpretation (Smith, 1996). A two stage interpretation process, or a double hermeneutic is adopted, where "The participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world." (Smith & Osborne, 2003, pg. 51). Therefore, as IPA recognises the role of the researcher in attempting to make sense of that event or experience (Smith, 2004), it has strong connections with the interpretative or hermeneutic traditions (Smith, 2004), which emphasise how prior knowledge and understandings shape the interpretative process (Denzin & Lincoln, 2005). This can be seen as congruent with a *Constructivist* epistemological stance, as it recognises the subjective role of the researcher, in the creation of knowledge (Guba & Lincoln, 1994).

With regard to hermeneutics, IPA is seen as combining empathetic hermeneutics, which is consistent with its phenomenological origins, as it tries to understand experiences from the point of view of the participant (Smith & Osborn, 2008). However, it can also adopt a hermeneutic of questioning, in that



the analyst can ask critical questions of the participant's text that may not be acknowledged by the participant themselves (Smith, 2004).

In addition to influences of both phenomenology and hermeneutic traditions, a further important theoretical hallmark for IPA is *Symbolic interactionism* (Denzin, 1995), which was seen as a rejection of the positivist paradigm (Smith, 1996). Symbolic interactionism suggests that the central focus should be on the meanings people attribute to events, however, these meanings are seen to result from social interactions and can only be accessed through the use of interpretation (Smith, 1996).

### **Key features of IPA.**

IPA is considered to have three characteristic features. IPA is strongly *idiographic* as it is concerned with a case by case detailed examination. Cross-case analyses which look for emergent themes, which the participants share and those which are unique to the individual, are only attempted once this has been achieved (Smith, 2004). Secondly, IPA is *inductive* as it employs techniques which are flexible enough to allow unexpected topics and discussions to emerge during data collection and analysis (Smith, 2004). Therefore, IPA does not attempt to verify existing literature or hypotheses, but aims to collect expansive data. Finally, IPA is considered to be *interrogative*, as the results of the analysis aim to contribute to the existing psychological literature, by interrogating the current research base (Smith, 2004).

## **Method**

### **Sampling.**

When IPA is the proposed method of analysis sample sizes can vary from 1 to 15 participants, with 5 or 6 participants being recommended as a reasonable sample size (Smith & Osborne, 2003), therefore, eight participants were recruited and took part in an interview. This is also in line with other research

which has used IPA to study people with psychosis (e.g. Newton et al., 2007). IPA rests heavily on the premise that the participants involved have all experienced the phenomena of interest and are able to provide detailed and rich descriptions of their experiences (Smith & Osborne, 2003). Therefore participants were recruited using a purposive sampling method, as it allowed the researcher to find a homogenous sample, for which the research questions were applicable (Smith & Osborn, 2003). Purposive sampling is in contrast to a random sampling methodology, typically seen in quantitative methodological studies and involves the deliberate selection of participants based on specific demographics or experiences (Patton, 1990). All participants who met the inclusion criteria were approached sequentially to minimise the possibility of having to exclude people due to excess numbers (i.e. more than eight service-users wanting to participate).

### ***Inclusion criteria.***

The following two inclusion criteria were used to identify suitable EIP service-users.

#### ***1. Between two years and two years and 11 months in the service***

Service-users within this period were still considered to be in their critical period (Birchwood, Todd & Jackson, 1998) and still had regular contact with the service after the interview. Service-users who were in their last month prior to discharge from the EIP service were not included in the study. The EIP service has a three month discharge handover period and during the final month, contact with the service becomes less frequent. Therefore, by not including people who are in their last month, this ensured that all participants had access to the same follow up procedures and support.

#### ***2. English speaking***

Only service-users who had enough English language to take part in the interviews without the use of an interpreter, were included in this study. This was decided by whether or not the service-user was able to attend EIP service reviews without the need for an interpreter. This indicated that the individual would have enough English language to take part in a one to one interview. The reason for this criterion is that IPA is a two stage interpretation process (Smith and Osborne, 2003) and the interpreter would have unavoidably used their interpretation of the participant's meaning, resulting in the participant's meaning possibly being lost.

### ***Exclusion criteria.***

Service-users were excluded from the research if they met either of the following criteria:

#### ***1. Lack of capacity to consent***

Prior to the interview, the researcher spoke to Care co-ordinators regarding the potential participant's capacity to consent. Capacity to give informed consent was judged by following guidance set out in the Mental Capacity Act (2005).

#### ***2. Any significant risk issues***

Throughout the recruitment process and during the interview the researcher and Care co-ordinators made judgements regarding whether or not there were any potential risk issues either to the client themselves (self harm or suicide) or others. Prior to the interview, the researcher made contact with the Care co-ordinator, during which the Care co-ordinator was asked to judge if there were any significant risk issues at that time. If any service-user was considered to be at significant risk, then it was considered inappropriate to include them in an interview process which discusses potentially upsetting information.

### ***Semi-structured interview schedule.***

The interviews were facilitated by an interview schedule which included specific questions and a series of prompts which were used flexibly with each participant (Appendix E). Using a semi-structured interview schedule allowed for the interview to be flexible and go into novel and interesting areas that the participants discussed. The questions and prompts were designed to guide the participants to discuss their experiences of psychosis which led them to come into contact with the EIP service, their experiences of entering the service and how they view their current situation. In addition, the questions also aimed to try and understand what it is like to be in contact with an EIP service. Although the researcher was interested in the participants' experiences of an EIP service the questions were designed to be open enough that participants could discuss other contributors, significant others or events that have impacted on their experiences.

The interview questions were piloted on other NHS professionals prior to any interviews taking place. This allowed the questions to be formed into a logical order, for the wording of questions to be finalised and for the first author to role-play potentially difficult answers or scenarios. Any questions that were identified as being potentially difficult to answer were then given appropriate prompts.

### **Study procedure.**

A summary diagram of the full procedure is shown in Appendix I.

### ***Participants Identified.***

Potential participants were identified through the EIP service's computer database which stores the demographic and service details of all clients using the service. To protect service-users' confidentiality, the researcher was not granted access to the complete database. A list of all service-users (initials only) and their allocated Care co-ordinators, who met the inclusion criteria, was

provided to the researcher by the EIP Clinical Psychologist. Prior to recruiting any participants the researcher attended an EIP service meeting and discussed the research and the content of the information sheet with all Care co-ordinators.

### ***Participants approached.***

Potential participants were then initially approached by their Care co-ordinator either during a routine visit (usually weekly) or during another arranged appointment. Care co-ordinators provided the potential participants with the information sheet (Appendix B) and outlined what was involved in the research. During this stage, Care co-ordinators informed service-users of their right to not participate and withdraw from the research at anytime. They also highlighted that the researcher was independent of the service, therefore any information gathered during the interview, or choosing not to take part would have no impact on the service they received.

### ***Consent.***

When gathering initial verbal consent for the researcher to make contact with interested service-users, Care co-ordinators followed guidelines to assess the client's capacity to give consent. When gathering written consent (Appendix C) the lead researcher ensured participants had had the opportunity to read the participant information sheet (and ask any questions). Participants consented to the following:

- to take part in a one-off interview, lasting approximately one to one and a half hours
- for the interview to be digitally-audio recorded and transcribed, with identifiable information removed
- for the researcher to use direct anonymised quotations in the write up of the research

- for the lead researcher to gather demographic and service related information (Appendix H) from Care co-ordinators

As a professional of the NHS Trust and a practicing Trainee Clinical Psychologist, the researcher used their clinical and professional judgment to assess the service-user's capacity to give informed consent. Additionally, all participants were aged 18 and over, so parental consent was not required.

### ***Participants recruited.***

All service-user's who gave given initial consent to be contacted were telephoned by the researcher within 10 working days (minimum of 24 hours). During the telephone conversation participants had the opportunity to ask any questions regarding the research. A convenient time and place for an appointment to take written consent and conduct the interview was then arranged and confirmed in a written letter. During the time prior to taking consent and conducting the interview the researcher remained in contact with Care co-ordinators, as they were able to provide information regarding any change in circumstances, which could have impacted on the service-users participating in the research.

On the day prior to the appointment the participants were contacted by the researcher by telephone, in order to confirm the date, time and venue of the appointment.

### ***On the day of the interview.***

All interviews were conducted by the lead researcher at a time and place that was convenient for the participant. Risk issues regarding home visits were discussed with Care co-ordinators, prior to arranging appointments. If home visits were used the researcher followed the Trusts Lone Worker Policy. To prevent any possible risk, the times and locations of all interviews were known by the EIP teams Clinical Psychologist and the researcher made telephone

contact with them after each interview had finished. If a home visit was not deemed appropriate an NHS location was used for the interviews.

### ***Immediately after the interview.***

Immediately after the interview participants had an optional 15 minutes with the researcher to discuss the interview and ask any questions they may have regarding the research. If the participant showed signs of upset or distress following the interview, the researcher was able to make telephone contact with Care co-ordinators, who could then offer ongoing support to participants. In addition, during the interview, if the participant disclosed any information which could lead the researcher to break confidentiality then their Care co-ordinator was contacted. After the interview participants were given the opportunity to request a follow up appointment with the EIP service Clinical Psychologist, to discuss any issues arising from the interview. Participants were also able to request further information regarding the research, via their Care co-ordinators.

### ***Following the interviews.***

Following the interviews all digital-audio recordings were transcribed with all identifying information anonymised (including the participant's name and other persons mentioned during the interview). Each transcript and audio-recording was allocated a participant number and a list of names and corresponding participant numbers were kept separately from the audio-recordings and transcripts. In addition all demographic and service data gathered, was labelled with a participant number to prevent identification. Following the end of the research, digital-audio recordings, transcriptions and any other data was stored in a locked cabinet in a University of Nottingham building, which is locked and alarmed at night. They are labelled and dated, stored for seven years and then destroyed. This is in-line with University of Nottingham Research Code of Conduct.

### ***Demographic details.***

This information allowed the researcher to establish details about the participants and what aspects of the service they had been in contact with, which may have impacted on their experience of an EIP approach. This also allowed for comparison with participants in other similar research.

### **Ethical Considerations**

“Ethical principles are concerned with protecting the rights, dignity, and welfare of research participants.” (Barker, et al., 2002). In accordance with guidance on the ethical issues which can arise in research (van Deventer, 2007), the following ethical considerations were addressed prior to the research commencing. In addition, this research study was reviewed and given favourable opinion and approval by an NHS Research Ethics Committee and the NHS Trust Research and Development Department (Appendix D).

### **Risk of harm.**

Although interviews covered material the service-users were familiar with discussing throughout their time in the EIP service, certain aspects of the interview could have potentially been upsetting. Participants were informed about: their right to refrain from discussing any topics or experiences they did not want to share; their right to withdraw from the study at anytime without any negative repercussions; the NHS complaints procedure. Additionally, immediately after the interview participants were given an optional 15 minutes with the researcher to discuss the interview and its content and were informed of their options for follow-up (see ‘immediately after the interview’ above for further details). If during or immediately following the interview the researcher considered there to be any significant concerns regarding the participant, then telephone contact could be made with Care co-ordinators to offer ongoing support to participants.



### **Informed consent.**

Informed consent refers to the researcher's disclosure to participants, prior to their direct involvement, of what will happen during the research and any other information which could affect their decision to take part (Barker et al., 2002). This enables participants to make an informed decision about becoming involved in the research (Barker et al., 2002).

Informed consent (Appendix C) to participate in the research was obtained from all eight participants, prior to the interview commencing. They were given the participant information sheet (Appendix B) prior to providing initial verbal consent and had the opportunity to discuss the research, with both their Care co-ordinator and the researcher, prior to the interviews. Participants were informed about confidentiality issues (storage of data), procedures and boundaries, the necessity of digitally-audio recording and transcribing interviews, the use of anonymised direct quotations in the write up of the study, their right to withdraw from the research at any time and potential risks and benefits of taking part.

As the study aimed to interview service-users about their experiences of an EIP approach, it was unavoidable that participants would have either experienced an episode of psychosis or have a diagnosis of a psychotic illness. Prior to the interview, the researcher spoke to Care co-ordinators regarding the potential participant's capacity to consent. Before taking part in the interview, the researcher judged if the service-user had capacity to give informed consent. This was done by following guidance set out in the Mental Capacity Act (2005) regarding capacity.

### **Confidentiality and anonymity.**

All participants were informed that the content of interviews were confidential and that confidentiality would only need to be broken if the researcher considered anything the participant said to be an indication that they are a risk

to themselves or anyone else, or if there were any child protection issues. However, it was explained that every attempt would be made to discuss this with them prior to talking to anyone else.

The interviews were all conducted with the participant alone either in their own home or in a private room in an NHS building. This insured that the interview was undisturbed and its content remained confidential. Throughout the research, a lot of personal information regarding participants was gathered. Written consent was obtained and participants were informed of the processes in place for the use and storage of all information (see '*Following the interviews*' above for more detail).

### **Service related issues.**

This research provided an opportunity for participants to talk about their experiences of a service they were still involved with. Therefore, it was considered that participants may have felt uncomfortable about highlighting possibly negative aspects of the service. In order to address this, it was highlighted that the researcher was completely independent of the service. They were informed of their right to withdraw from the research, at any point and any information gathered during the interview, or choosing not to take part, would have no impact on the service they received. If the participant was upset regarding any aspect of the interview, they were advised to make contact with their Care co-ordinator or General Practitioner. In addition, interviews were confidential and all identifiable information was omitted during transcription and write-up.

### **Analysis**

#### **Transcription.**

Smith and Osborne (2003) suggested that for IPA, the level of transcription is at a semantic level, including all words spoken including false starts, laughs,

significant pauses and other features worth recording. The audio-recordings from the interview were listened to several times and transcribed by the lead researcher.

The process of analysis is a idiographic approach, which involves starting with a detailed examination of one transcript, until a degree of closure is achieved and then moving on to the next transcript (Smith, 2004).

### **Stage one.**

Each transcript was read several times which together with the repeated audio prior to transcription, helped the researcher to immerse themselves within the data (Smith, Jarman & Osborn, 1999). Initial notes were made in the left hand margin about interesting or significant responses. Following this, in the right hand margin, initial notes were transformed into emerging themes, which captured the meaning of what was being said by the participant. This process of interpretation was grounded in the specific things said by the participant, by staying close to the spoken words within the transcript.

### **Stage two.**

The researcher then looked for connections between themes in order to identify clusters of themes and identify super-ordinate themes. Once again the transcript was checked for connections between the theme clusters and the primary source. Participant quotations were compiled in order to support the themes generated.

### **Stage three.**

Themes were then ordered into a table or diagram and cluster themes were given names and represented super-ordinate themes. The table listed all themes which went with a super-ordinate theme and were organised so that instances of each theme could be identified in the original text. During this process certain themes were dropped, due to a lack of rich evidence within the text (see Appendix G, for an example of this process).

#### **Stage four.**

Emerging themes from each transcript were used to orient the analysis of the next, whilst remaining open to new and unexpected themes. The aim was to look for ways in which accounts were both similar and different to each other.

#### **Stage five.**

When all transcripts had been fully analysed a table of super-ordinate themes was constructed. Super-ordinate themes were decided on by both the richness of the passage and the extent to which the theme helped to illuminate the other aspects of the account. The aim of the analysis was to finish with a collection of core themes and an understanding of the participants' meanings intrinsic to their experiences.

### **Quality Assurance Measures**

Qualitative research has long been described as lacking scientific rigor and criticised for being subject to researcher bias, difficult to replicate and generalise (Kock & Harrington, 1998). This has contributed to the issue of validity in qualitative research, which has been discussed and debated for over half a century (Atkinson, Coffey & Delamont, 2003). There has been considerable debate about whether or not qualitative and quantitative methods can or should be evaluated and assessed by the same criteria of quality (Mays & Pope, 2000). It's suggested that in their current form, criteria used to evaluate quantitative research (e.g. generalisability, objectivity, reliability and validity) are not applicable to qualitative research (Willig, 2008), but are often still imposed on this type of research (Kock & Harrington, 1998).

There are several reasons why quantitative evaluation criteria are not deemed applicable to qualitative research. Firstly, there is a fundamental difference in the perceived role and influence of the researcher, for example quantitative research aims to minimise any impact of the researcher on the data, in order to obtain an unbiased observation of reality (as far as possible), whereas qualitative research embraces the inevitable influence of the researcher

(Yardley, 2008). Therefore, concepts such as inter-rater reliability, which assume objectivity, would be viewed as meaningless (Seidel & Kelle, 1995). Other fundamental differences are the concepts of generalisability and reliability, which would be seen as important evaluative criteria for assessing quality of quantitative research (Yardley, 2008); however, qualitative research is more concerned with context, individual differences and would not expect replication in other samples.

Within the literature there are ongoing discussions around the potential development of quality assurance measures for qualitative research specifically. Qualitative research can be based within different epistemological and ontological frameworks and different methodologies are based on different assumptions, about the knowledge they aim to produce, their assumptions about the world and the role of the researcher in the process (Willig, 2008). Therefore it is argued that the evaluation criteria used to assess qualitative research needs to reflect the epistemological standpoint of each particular research study (Willig, 2008). It is suggested that attempts to establish a consensus on a set of qualitative criteria for qualitative research is likely to fail, due to this lack of a single methodology or method, which can be described as qualitative research (Rolfe, 2006).

Within the current literature there are several different sets of guidelines and criteria for assessing and evaluating the quality of qualitative research. Each is seen to be informed by different qualitative traditions (Willig, 2008), such as Henwood and Pidgeon (1992), Elliott et al. (1999) and Lincoln and Guba's (1985) criteria of credibility, transferability, dependability and confirmability. Lincoln and Guba's (1985) criteria aimed to establish trustworthiness in qualitative research, whilst moving away from positivist language. It is argued that the concept of validity in qualitative research should focus more on trustworthiness and making the processes of analysis visible and auditable, rather than issues such as 'truth' and 'value', which are seen as more intrinsic to a positivist position (Sandelowski, 1993).

*“IPA operates at a level which is clearly grounded in the text but which also moves beyond the text to a more interpretative and psychological level.”* (Smith, 2004, p. 44). Although standards for conducting good qualitative research were considered throughout this study, the different criteria suggested are not seen as rigid rules to be followed, but instead are themselves open to interpretation (Yardley, 2000). The following discusses some of the quality assurance measures considered and used throughout the research.

### **Epistemological position.**

It is suggested that to enable readers to evaluate any qualitative study, the researcher needs to be clear about their research question, their epistemological stance and needs to utilise methods that are compatible with their epistemological position (Willig, 2008). Therefore, the aims of this research, a discussion about the epistemological stance of the research and a discussion about the appropriateness of the methodology have all been provided for the reader.

### **Researchers own perspective/ reflexivity.**

Reflexivity refers to the need for sensitivity on the part of the researcher, with regard to the ways in which the researcher and the research process have impacted on the data collected (Mays & Pope, 2000). Qualitative research and analysis is a personal process and requires a level of interpretation on the part of the researcher (Smith, Jarman & Osborn, 1999). In order to make the research credible and trustworthy it is vital that the researcher identifies their own values, biases and assumptions and the role they play in their understanding (Elliott et al., 1999). It is important that the research address reflexivity issues and acknowledge how the researcher's perspective will have shaped the research data (Willig, 2008). This has been particularly suggested for methods which draw on phenomenological and hermeneutic interpretation, as they acknowledge and embrace the role of the researcher (Willig, 2008).

Prior to the research commencing the first author kept a diary of their own personal experiences, training, beliefs and assumptions about psychosis and EIP services. The reflective diary was also used after each interview in order for the interviewer to discuss any reflections on the interview process, topics covered and their reactions to the participant. Additionally, the research diary was utilised throughout the analysis in order to acknowledge the researcher's own assumptions and their potential impact on the analysis of the data and the construction of themes (see Appendices G and F for sample extracts). However, this diary was not used to bracket the author's assumptions, as IPA utilises a double hermeneutic, therefore, it was used so the author was aware of their impact on the analysis (Smith & Osborne, 2003).

During this study the lead researcher also held an additional role of being a Doctorate in Clinical Psychology trainee, who had undertaken their first year foundation training placement within both an EIP and Assertive Outreach (AO) service. It was the researcher's experiences during this placement which had led to their interest in the current research topic. Therefore, it is important to acknowledge that the researcher already had their own preconceived notions about being part of an EIP team and how this approach impacted on the lives of the clients she came in contact with. In order to be aware of the researcher's influences the reflective diary was essential to identify when the researcher was potentially drawing on their own previous experiences of a similar service and client group. (See Appendices F and G for extracts).

### **Grounding in examples.**

Within qualitative research, transparency is important as it illuminates the analytic decision making processes and makes it both accessible and auditable (Baxter & Eyles, 1997). During the analysis the research diary was used to create an '*audit-trail*' of the decision making process during analysis, which included the process of moving from data collection, to emerging themes and final interpretations and super-ordinate themes. (Appendix G). Multiple extracts are also provided within the results, in order to ground the themes within the

interview text. This transparency in the analysis process allows for readers to assess the interpretations made and conceptualise other alternative meanings and interpretations from the data (Elliott et al., 1999).

In order to provide a method of reviewing the transparency of the audit-trail, following analysis of the data, two independent researchers (both employees NHS Trusts) reviewed emergent themes and categories, to make sure no aspects of the data had been over or under represented by the author's interpretations, that all themes are clearly grounded and identifiable within the written transcripts and the process of theme construction is clearly visible.

### **Credibility checks.**

A commonly utilised method of minimising any data misinterpretations are member checks (Lincoln & Guba, 1985). This involves checking the accuracy of interpretations and findings with either the participants who provided the data or different members of the same population. This is often recommended as an important stage in checking the credibility of the research, as the participants are seen to be able to authenticate the data and identify any gaps, or misinterpretations. However, this method was not utilised in this study.

It is possible that participants may have disagreed with the researcher's interpretation of the data. However, this disagreement does not mean the researcher's interpretation is incorrect, due to the epistemological stance and theoretical underpinnings of IPA (Smith, 2003). Therefore, if member checks were used the researcher would need to have determined which interpretation would endure. Therefore, the double hermeneutic of the researcher's interpretation of the participant's interpretation was used to develop conclusions for this study (Smith & Osborn, 2003). Additionally, the participants themselves may change their opinions in light of new information or events since the interviews were conducted. With regard to conducting member checks with other members of the same population, as well as the above argument, this was



also not considered appropriate as it could have compromised confidentiality, if service-users from the same service were used.

Another commonly utilised method to increase the validity of qualitative research is triangulation, which “...compares the results from either two or more different methods of data collection...or, more simply, two or more data sources...The researcher looks for patterns of convergence to develop or corroborate an overall interpretation.” (Mays & Pope, 2000, p. 51). Similar to member checking, triangulation is seen as another technique which can be used to capture a more consistent and objective picture of reality (Mathison, 1989). Triangulation is used in more realist positions as a means of obtaining convergence, which in turn is seen to represent reality (Willig, 2008).

Therefore, despite being commonly used methods of validation, neither member checks, nor triangulation were used in this research, as it is suggested that utilising these two methods, can be seen as pursuing and seeking a more objective and accurate ‘truth’ (Cho & Trent, 2006). They are suggested as carrying positivist implications (Guba & Lincoln, 1989), both of which were seen as incongruent with the epistemological stance of this research.

## **Challenges and Difficulties**

This section addresses some of the difficulties and challenges that the lead researcher encountered and overcame during recruitment and data collection.

1. Difficulties in finding appropriate rooms in NHS locations to conduct interviews, when home visits were inappropriate.

- Solution: Appointments were organised at least a week in advance and information was gathered regarding all appropriate NHS sites, where interviews could take place.

2. Making sure a digital-audio recorder was available for interview appointments, as there was a limited number available.

- Solution: The lead researcher liaised frequently with the course and other trainees, to make sure interviews were booked at times when a recorder was available.

3. Making sure potential participants were approached promptly by their Care co-ordinators and given the participant information sheet.

- Solution: The lead researcher attended the EIP service regularly and met with Care co-ordinators in person to provide them with the information sheets and to discuss the research study.

4. Building rapport with participants in the short amount of time available, prior to the interview.

- Solution: Telephone contact was made with all participants on at least two occasions prior to the interview. Additionally, the lead researcher utilised their current training as a Clinical Psychologist, to help build rapport prior to the interviews commencing.

5. Participants discussing important information after the interview had finished and the recorder had been turned off.

- Solution: The researcher verbally contracted with the participants that the audio-recorder would be left running, until the participant left the room.

## Extended Results

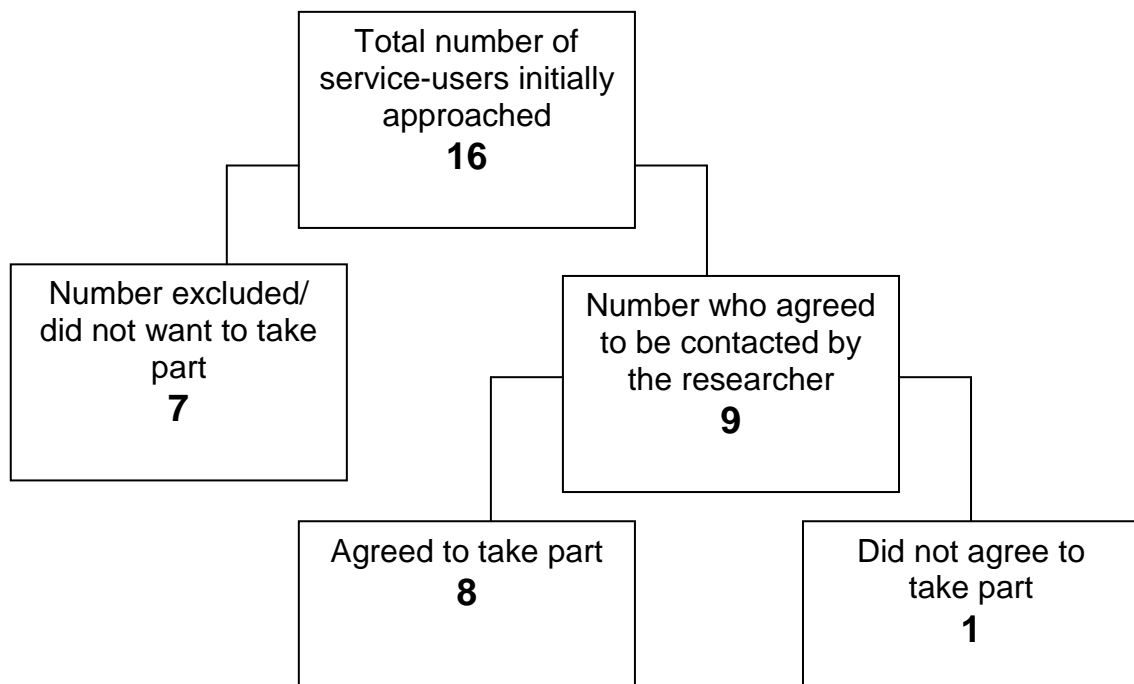
This section provides additional detail that is not included in the journal article. It includes further demographic and service details regarding the participants (which supplement those provided in Table 1) and information about recruitment. It provides additional verbatim extracts from participants' interviews in order to further illustrate the five super-ordinate themes developed from the analysis, including further discussion which could not be included in the journal article. Finally this section also discusses a *minor* theme which was developed from the analysis, but was not included as a super-ordinate theme.

### Participants

This study aimed to recruit eight participants and as discussed in the extended methodology, participants were recruited sequentially to prevent interested service-users not be able to take part in the study. Diagram 1. Recruitment Flow Diagram shows the process of recruitment.

Diagram 1

*Recruitment Flow Diagram*



### **Sample Demographic Details**

Demographic and service details were collected from Care co-ordinators following the interviews. All participants read the demographic and service details sheet (Appendix H) and consented for the information to be collected, by the researcher, from their Care co-ordinators. Table 2 includes Additional Participant Demographics and Service Details, to those detailed in the journal article.

### **Super-ordinate Themes**

Themes that were developed from the analysis of each transcript were compared in order to present a collection of core themes and an understanding of the participants' meanings intrinsic to their experiences. Table 3 details all super-ordinate and ordinate themes developed from the analysis.

Themes reflect both shared and contrasting experiences of the participants. Predominantly, this section includes additional verbatim extracts for each of the five super-ordinate themes in order to illustrate the interpretations and ground them within the text. This transparency allows for readers to assess the interpretations made and conceptualise other alternative meanings and interpretations from the data (Elliott et al, 1999). However, further discussion regarding specific extracts is included, in addition to other aspects of the themes which could not be included in the journal article.

As in the article pseudonyms have been used for all names included in the verbatim extracts and other identifiable details have been changed or omitted. Each super-ordinate theme is to be read in conjunction with the results section of the journal article.

Table 2

*Additional Participant Demographic and Service Details*

Ppt	Marital Status	Employment status	EIP Team	Psychiatrist EIP <sup>a</sup>	OT	Service involvement				Change in CC <sup>c</sup>
						Dual Diagnosis	Crisis Team	Admissions (Hospital) <sup>b</sup>	Clinical Psychology	
1	Single	Unemployed	City	Yes	Yes	No	Yes	4	Yes	No
2	Single	Volunteer	County	Yes	Yes	No	Yes	0	No	No
3	Single	Unemployed	City	Yes	No	No	Yes	2	Yes	No
4	Single	Unemployed	City	Yes	Yes	Yes	No	2	No	No
5	Single	Student	City	Yes	Yes	No	Yes	0	Yes	No
6	Divorced	Unemployed	County	Yes	No	No	Yes	2	No	No
7	Single	Student	City	Yes	Yes	Yes	Yes	1	Yes	No
8	Married	Employed	County	Yes	No	No	No	0	No	Yes

Note: (Ppt) Participant; (OT) Occupational Therapy; (CC) Care co-ordinator

<sup>a</sup> Does the participant have a psychiatrist whose sole responsibility is the management of people with psychosis?

<sup>b</sup> Number of hospital admissions since referral to EIP service, including any admission directly prior to EIP referral

<sup>c</sup> Any change in Care co-ordinator since receiving a service from the EIP service?

---

Table 3

*Super-ordinate and Ordinate themes*

Super-ordinate theme	Ordinate themes
Stigma	Self-stigma Others' judgements Stigma of services
Relationships	Peer-support Care co-ordinator relationship
Understanding the experiences	
Sense of agency	Acceptance and control EIP service involvement
Impact on sense of self	A sense of discovery Place within the world

---

## **‘Stigma’.**

Additional information about the super-ordinate theme *Stigma* is provided here and will cover all three ordinate themes *Self-stigma*, *Others’ judgements* and *Stigma of services*.

### ***Self-stigma.***

The distinction between diagnoses is further highlighted by another participant:

*P5: ... I know depression... and err... but that I sort of thought, I didn’t know there were such things as psychosis...  
... and you hear these loons thinking they’re Jesus and stuff and you think fucking hell that’s not gona be me... and then it just happens don’t it.*

This participant also makes a distinction between depression and psychosis. This extract is typical of descriptions used by participants to express their own judgments of people with psychosis. This particular participant used his own description of “loons”, however, the account was also interpreted as suggesting the potentially powerful influence of the public awareness and knowledge of psychiatric diagnoses and how this influences people’s acceptance of mental health problems.

One participant spoke about the influence of social expectations of gender on his feelings of personal shame:

*P2: I didn’t understand why I’d gone like that, that’s really confusing. You think I’m a bloke I shouldn’t feel like this, where’s this all come from, how is it I’ve got like this, how have, how have I ended up like this? And then you’d feel... belittled by yourself.*

This participant's extract illustrates the possible distinction between being male or female and how acceptable it is to have a mental health problem. For him, having psychosis has led to him questioning himself and adds to his self-judgment.

Participants spoke about how their personal shame and judgements about their experiences impacted on them being able to talk to people about their early experiences:

P8: *...well, no, there was no one else who I thought would understand, I mean, even, I didn't even speak to my husband about it, cus it was that, it sounds crazy, doesn't it? That's, that's what it is.*

P6: *...I spoke to... I couldn't speak to anybody...*

### ***Others' judgements.***

Participant 3 was interpreted as further expanding on this theme by discussing the reactions of close friends to his behaviour:

P3: *I'd go down to the snooker hall and I had a lot friends down there... yer know... everybody seemed to shy away from me during this time as well, when I was psychotic, nobody wanted to come near me...*

This participant described how people would physically distance themselves from him when he was experiencing delusions and he goes on to discuss how this impacted on his ability to socially interact with others, but also how it led to the feelings of being misunderstood:



P3: *...the more bizarre things I kept saying the more bizarrely people looked at me... which led me to feel more isolated and more... as if nobody really understands you know...*

These extracts are typical of descriptions used by participants, when discussing ongoing feelings of being misunderstood and judged by others outside of the EIP service context:

P4: *Because like people are out there and they don't know half of what's going on with ya and they just like, sometimes they bully you or... say nasty things... (Interviewer: Yeah) and it makes you feel bad.*

P5: *...I keep quiet about it and its quite funny cus, if erm... other people are just like blatantly... "yer I've got mental health and don't care" but I feel like people can judge you on it and stuff and I'd rather just... keep it quiet and forget about it (Interviewer: yeah) and get on with my life....*

Participant 5 elaborates further on the consequences of others' judgments and how it contributes to people feeling unable to talk about their experiences. This participant had expressed a desire to want to forget about the experiences, which was fuelled by the judgment of others. He also highlights a difference between himself and other people with mental health diagnosis and identifies how other people appear less affected by the actual or potential judgment of others, which was echoed in other participants' accounts.

The above extracts highlight a shared experience of being judged negatively by other people due to having psychosis. The participants go on to highlight how this shared experience results in very individual consequences, such as social isolation, emotional upset and a barrier to accessing the EIP services.

### ***Stigma of services.***

The ordinate theme of '*Stigma of services*' captures the participants' experiences of how mental health services create a sense of stigma surrounding EIP services. They also discuss ways in which the stigma of mental health services is and can be potentially broken down by EIP services.

Participant seven introduces the issue by providing an example of the stigma surrounding the mental health authority:

*P7: ...I can only speak on behalf of everyone I know who would agree with me, but probably in the hundreds like who are scared of the men in white coats and like it's us and them, you don't want, you don't want people like... taking away your freedom and telling you that you're crazy...*

Here the participant explained his view of a shared belief and a stereotypical view of mental health services being the "*men in white coats*" who are seen as powerful people with the ability to take you away and label you. This fear of an implicit power imbalance was described by several participants. This participant goes on to further elaborate this, with an example of a friend, who was suffering with mental health problems and the response of his mother:

*P7: ... She didn't want him to go to hospital and sort of like, in that sort of sub-culture it's like erm... that... sort of been involved, going into hospital is sort of a taboo thing, you don't go to hospital, you sort it out in the family, you keep it there, you sort it out.*

These extracts encapsulate not only the unmentionable nature and shame of being in contact in services, but also implicitly highlight this as a barrier to people accessing services. This implicit barrier to accessing services was previously highlighted above, in peoples' reluctance to discuss their

experiences due the actual and anticipated judgments of others and their own personal shame. Within participants accounts there were multiple examples of a reluctance to talk to mental health services which is illustrated by these extracts:

P2: *...but you think to yourself, should I say anything, if I do say something, what's going to happen to me...*

P4: *It was horrible cus I thought that if I start talking to them... they was going to diagnose me with something and I was just scared...*

The participants identified the fears and anxieties which are behind their reluctance to talk openly or approach services. These anxieties include the fear of the unknown and a fear of being labelled. Participant 4 explicitly identified a fear of being diagnosed as a barrier to her being able to talk about her experiences of psychosis.

This sub-theme was interpreted as being extended further by the participants' accounts of the impact of negative previous experiences of mental health services. Participant 2 provided an example of how his previous indirect experiences of mental health services, due to his brother's involvement several years before, had impacted on his view of services and his willingness to approach them:

P2: *...then when you become unwell and you start having them stupid thoughts and visions and seeing things, you become reluctant to go to a health service, because you saw how he was and he was being treated, cus he was like a fucking zombie.*

P2: *...Oh yeah, with all that with Neil (brother) I was bit reluctant to go to the doctors and mention anything, because of how he*

*was treated. And I thought, oh if I go and say something, they'll be "oh it runs in the, it can run in families and genes" and be like tarred with the same brush, so I was reluctant to say anything. And erm... and then when they got, they got the psychosis team, you know it's got NHS on the thing, I thought arrrggg, look they're coming to get me, I'm gonna be on the ward or something, you know, how he was.*

This second extract directly relates previous experiences to the current anxieties about EIP service involvement and being labelled. This can be interpreted as representing the participant's belief that he would not be treated as individual, separate to his brother.

Participant 8 provided an example of how this theme was further developed. She explicitly described her feelings of shame regarding her involvement with the EIP service:

*P8: ...but I'm still really ashamed of erm... of sort of being in EI, EIP, err... because its, the name is really sort of... its early intervention in psychosis, so to me it means... they were intervening early in my psychosis and I had psychosis...*

This highlights the importance of the name of the service and what the name EIP actually represents for and about those service-users who are in contact with the service. For this participant the name of the service was enough in itself, to create a feeling of being labelled as having psychosis. The importance of the name of the service was discussed by other participants for example:

*P7: ...like she's part of this thing called EIP, and even though you've not actually ...like going into the EIP services a typical user, like cus early intervention it's like intervening early in the stage of psychosis but I'd already been sectioning...*

For this participant the name of the service was important in him distinguishing himself from the typical user of the service, as he takes the name of the service very literally and implies that he had already been sectioned, therefore, the service was no longer intervening early. This further illustrates how the participants interpreted their own meaning in the name of the service and used that meaning to create a sense of separation between themselves and other people within mental health services.

Contrasting accounts discussed the ways in which EIP services had helped reduce the stigma associated with services.

*P7: ...I think like the fact that one person goes through a system and comes out of it well, it's like, I've said to lots of my mates, yer know if you're feeling like you're gonna go that way, like give this person a call, or like give EIP a call, because I've been through it and then just because they know I went through it and I'm sound with it, " well then if he knows them, then it's alright"...*

These extracts are an example of how some participants felt that the EIP service being available is already providing a means of overcoming the stigma and stereotypes, of mental health services. For this particular participant, this breaking down of stigma was at a very micro-level, with his friends and family. Whereas, others felt that more was needed at a macro-level to create an awareness of the EIP service. For example:

*P8: ...I feel that, people should sort of, not advertise it, but for want of a better word, advertise that these services do exist and...  
...I kind of like want people to know that this service exists...*

*Interviewer: You say sort of advertise it sort of like, do you mean the general public or?*

P8- No, to, to, to erm... healthcare people, so that they know that this service exists and yer know that can refer other needy people (Interviewer; ummmm) to the service, because it's... it's been good.

Interviewer: Yeah, so you just wish it was more widely known about?

P8- Yeah because if it's not widely known about, it is a bit shameful, cus people go "so who's that person who comes around your house very two weeks" and you're like well she's with early intervention in psychosis, erm... "and what's that?" they don't know... yer know.

### **'Relationships'.**

The label of this theme captures two ordinate themes *Peer support* and *Care co-ordinator relationship*.

#### ***Peer support.***

During the interviews it became explicit that access to these groups was provided by the service-users' Care co-ordinators. This in itself is a potential barrier that service-users may face in having access to these groups, as it is dependent on their Care co-ordinator creating awareness. Participant 8 described a desire to meet people who have shared her experiences and expressed a lack of knowledge about the existence of these groups:

P8: Yeah and I'm sure I must not be the only one who feels this way, I'm sure there must be other people that are, or even if it was an internet forum at least it was some kind of, some thing

*you can trade sort of stories and you know get to know somebody else who's been through the same things as you.*

Interviewer: *How do you think that would make you feel sort of sharing you know people sharing their stories of what they've been through?*

P8: *I think it would be good, I think it would help me come to term and understand mine and understand theirs and the gist of it that you know, I wouldn't feel so alone and that's all that...*

Groups provided an opportunity to feel understood and created a sense of belonging within a group. The following extract was taken to illustrate this:

P5: *That's the best thing that's helped me the most (Interviewer: right) because you can relate to people then... obviously if your stuck in a hospital and your surrounded by people with mental health its hard to get better, but I mean if you go out in the real world, you can visit loads of people with mental health once a week or something... then you can, you're back in like normality... but you can still relate to people who have it, so it's quite good.*

Participant 5 was interpreted as identifying two distinct needs for social integration, firstly a need to be in the “*real world*” but also acknowledges a need to feel that he belongs, which is satisfied by having access to people who have shared his experience of psychosis.

The groups offered an indirect form of alternative coping as is shown in this extract where the participant views the group as alternative to taking illegal drugs:

P7: ... *it's a good way of coping with shit, instead of slamming another fucking 5 mil into your arm...*

and a more direct participant involved form of coping, where the service-users would actively try and offer advice to each other:

P1: ...*we've all been unwell, so if you are feeling a bit down or something, like you are hearing some voices or something, you've got a friend there to say you know it is not real Jim, its just your own mind, that will go away soon, you'll get your mental health back together, so its kind of like using other patients to, to feed off.*

For one participant attending the peer groups allowed him to identify with and trust mental health professionals, not just other service-users, by providing an opportunity to interact with professionals in a non-clinical environment:

P7: ...*they were all sound as fuck, even people I might have distrust for, there weren't anyone there, like people at first I might have been like "I'm not going to say anything to you or whatever" but they were all proper sound, the staff were ...*

### ***Care co-ordinator relationship.***

Within an early intervention service model, service-users are assigned a Care co-ordinator when entering the service, which represents their main and consistent contact with the service (preferably throughout the three years).

Participants' accounts illustrated the evolving nature of their relationship with their Care co-ordinator, for example this participant's account illustrates how he was initially reluctant to engage:



P1- *Yeah, so much, yeah, from the first instance of meeting them, Sam (Care co-ordinator) and Gary (EIP worker) I told to go away, when I was on (names ward) the doctor, I was nearly laughing at, (Interviewer: uumm) yer know, it's come along way.*

Participants also spoke more generally about the varied role that their Care co-ordinator played in their lives, which included emotional support, practical support and providing a role in the person's life that was not filled by friends, family or other services. This participant illustrated that for him, his Care co-ordinator took the role of a 'listener' which he felt was absent from his life prior to being involved with EIP:

P3: *Yeah, with the services and that, yeah definitely, seeing them kind of people and knowing that there's people out there who are ready to listen, yer know, that's been great (Interviewer: yeah). Yer know, cus amongst friends, it's always been a competition you see, always been a competition, you know what men are like, they're very competitive yer know, and, yeah I've never really, never really had... anybody to truly listen (Interviewer: ummm) (4 second pause) and its makes a difference yer know (Interviewer: ummm), when somebody sits and listens, yer know, to you, yer know, rather than you listening to them all the time, yer know, cus I've always been a good listener yer know (Interviewer: yeah) always, and it's, I only feel like this last three years I've been speaking more, yer know rather than listening, I've been speaking more...*

### **'Understanding the experiences'.**

These participants directly expressed the need to know why they had experienced psychosis:

P2: *What's all this about, where we going to, what happening to me? Why have I got, why have I ended up like this?*

P3: *Err... but I had to go away and try and figure out what that meant, yer know, I mean that's a whole other story, yer know I could go on... forever (laughs). Cus that's, that's, how much thinking I've done, yer know what I mean (Interviewer: ummm, yeah) it's like I've not come away from hospital and ignored it, yer know....*

For some participants there was a deeper understanding which was interpreted as a potential need for the experiences of being in contact with the EIP service and their psychosis:

P3: *Well the whole, the whole thing you know, me getting psychosis and everything, I still to this day... I don't think it was a test from God or Jesus, what I think it was, was... I think it was myself yer know, I beat myself up so much that... I had to get off the path, do a defrag of my mind basically and be re-born and that's what it feels like I've been re-born, and that's... mentally it feels like I've been re-born.*

The influence of EIP contacts on their views of their experiences:

P8- *I felt a little relieved, I felt a little relieved that I wasn't alone and that they'd (EIP service) seen it before basically and they didn't seem to sort of veer back and go god you no, that sounds totally out of, yer know, ridiculous and everything, they, they were quite calm about it and erm... basically said, you're not alone and that, that, those words just made me feel a lot of relief...*

P3- *Well I obviously have Sam from the services, the psychiatric nurse, she comes round and, and she's been really the only person I can really, outside of my immediate family and friends, who I've been able to really talk to and get some feedback at least, some feedback from what I'm saying and what's actually happening.*

Interviewer: *What sort of feedback? What do you mean by that?*

P- *Just like, yeah good feedback, good clarification that some of the things that I'm saying are actually right, (Interviewer: right, yeah) (laughs), and I'm not totally losing the plot or not lost the plot still, yer know what I mean.*

This theme also encapsulates the participants' accounts of drawing comparisons between themselves and other people within the general population:

P7: *I think anyone's got the capacity, no matter how like, if they've got a mind like a steel trap, they've still got the capacity to go...*

And drawing out what was interpreted as a spectrum of psychosis:

P7: *...we are all deluded in some way, some more than other, but you can't not be, no one is all knowing, you know what I mean...*

**'Sense of agency'.**

***Acceptance and control.***

Role of EIP in helping participants to recognise their symptoms:

P1: *...but I noticed in myself, because you do what's called a relapse signature, with your, EIP CPN (Community Psychiatric Nurse), and erm that basically, as it sounds, a relapse signature, it's erm, yer know, you feel yourself relapsing so what, what actually happens (Interviewer: yeah) and you get all that written down so you can know yourself....*

This person gave the example of a relapse signature as his method being able to identify and recognise changes within himself.

During the later stages of their contact with the EIP a sense of recognition moved more to sense of the participants knowing and understanding themselves:

P7: *...my head got like completely dismantled, like in the way if you bought a kit car like you build it up, you know every piece of it, or a car you've had for a long time sort of thing and you know really well and intimate... its like if you took it apart, or something went wrong with it, or something started to go wrong with it, you'd probably know, you' click onto it and you could always drive into a bus without knowing, but at the end of the day you're pretty sound with it, and that how I see it... I can tell when signs are coming on, cus over the last three years, they've got less and less like... like sort of little flash backs of that way of thinking...*

P7: *...like I know my limits*

This participant uses a metaphor of a car being dismantled and put back together again, as a way of describing his new found understanding of himself as a person.

Participants' progression from avoidance and shame of their experiences towards a sense of acceptance of their presence within their lives was illustrated:

*P2: ...but I'm not embarrassed about it, whereas one point the embarrassment would be so great it would send my err anxiety levels sky high...*

*P2: I'm not bothered about anybody knowing about anything now...*

The participants all identified the methods that they used to accept and cope with their ongoing experiences or symptoms. For many participants there was a need to talk about their experiences, which had been offered during their contact with the EIP service:

*P4: I talk about it a lot cus of the staff here, so I'm always talking about it, always talking about my past and stuff, but... when I talk about my past I think it helps me from that day, when I get it out the way, that day just feels better.*

*P3: I've been able to really talk to and get some feedback at least, some feedback from what I'm saying and what's actually happening.*

This illustrates the importance of providing people with a forum to be able to openly discuss their experiences and how for many participants this had been offered by the EIP service.

Several of the participants described what was interpreted as a progression from a sense of passive coping and acceptance, towards more of an active control over their symptoms, which was supported by EIP: e.g.

P1: ...it was all new to me (psychology involvement), I had no idea what to expect but I'm glad the work we did do, erm has err, has helped off because its reaped rewards for me (Interviewer: yeah) yer know, when she said about challenge the voices, that there not really there, you cant really have a conversation with them, I mean, I still go off that today, it helps me a lot.

P3: ...so its kind of like being psychotic but not, trying to control it, to better myself yer know, some of those profound moments I had in my psychosis, I try and... just capture them and use them...

P3: ...yeah they feel like little moments of psychosis but controlled...

P2: I used to get all sorts of daft things going on "go on climb to the top of the tree, show em how good you can climb, go on, go on, go on" I used to think, sometimes think, yeah and then hold on a fucking minute, no I aren't'.

The participants gave many examples of the important role the EIP service had played in their progress, for example:

P5- Err... it's been, I wouldn't be where I am now if they didn't do that... (Interviewer: Ummm) as in positive, where I am... I would, I don't think, I think I'd still be suffering, yeah if I wasn't, err...

P1: *You know, yeah, I can't believe I've been that unwell, I've come a long way and its been all with the help of EIP, but I really have come along way.*

In contrast, participants also recognised the importance of their own role in their experiences and progress and a sense of personal responsibility:

P4: *...the groups that I've done, like cooking group, or cinema group, or swimming, or going to the gym, that's what I do myself to help me (Interviewer: yeah).*

P5: *Its quite daunting but you've got, you've got to do it ain't ya... you've got to get out of your comfort zones, cus you're not, otherwise you gonna sit in this house all day for the rest of your life, do you know what I mean?*

### ***EIP service involvement.***

Examples of limited options regarding treatments:

P8: *...if you do start anti-psychotics, it will help and basically their line was that erm... pushing the medication forward, erm, I guess, in hinds, look back at it, now, I would probably have appreciated more offering something alternative to medicines...*

For this participant she expressed a desire to have been offered alternative intervention options. This description of being offered only medication is echoed by other participants:

P5: *Well it's the only option, it's the only way out want it?*

Interviewer: *Is that what you felt, it was your only option?*

P5: *Yeah, yeah.*

Interviewer: *Why do you think you felt it was your only option?*

P5: *Because, I just wanted to get better and I'd do anything to get better, so... yeah.*

For participant 5 this lack of choice coincided with early feelings of desperation to “*get better*”.

In contrast, other accounts suggested a gradual and non-forceful approach which was appreciated by participants:

P1: *...I can remember what happened was they didn't rush me, they didn't say yes you've got to see us, they just went away and left it for a time and I got, then I got brought to the (names hospital and ward) and slowly they came back on the scene, came up to me, by this time, I was feeling much weller and I talking with them and I can always remember feeling that, yer know, just that they didn't rush me (Interviewer: right) they let it all happen at my own pace (Interviewer: yeah)...*

Many of the participants had experienced being in an inpatient ward of a hospital, as a result of their experience of psychosis. Due to this alternative experience, the participants made comparisons between the level of control they experienced being with the EIP service, compared to an inpatient environment. Participant 4 described her experiences in the inpatient ward:

P4: *They was, they was talking like doctors and I just couldn't... understand it (Interviewer: Ummm) and like... it was awful cus I knew what they was trying to say but they way they was talking about it, it made me feel really, really, it made me feel down and, yer know... it's like, its like, when they're talking they*



*should try and put it across what you're trying to say first before making any big decisions about stuff, that the other person might not know about...*

P4: *Erm... I felt like a kid, I felt horrible...*

She highlights the negative impact of this sense of powerlessness and lack of control on her well-being. This was echoed in other participants' accounts, for example:

P1: *...these specialist doctors (in hospital) are coming in and telling you you're unwell and it was, it was really quite harrowing, I, I can remember, you know, that's the darkest period that I went through really, it's nearly as bad as having the illness (Interviewer: yer) having people saying that you're not well, although, Martha (EIP service psychiatrist) wasn't pushy either really, (Interviewer: umm) Martha was, yer know, she wouldn't challenge you like I said, she would just leave it and just, yer know, let you say what you want and think what you want...*

#### **'Impact on sense of self'.**

##### ***A sense of discovery.***

This theme initially captures the participants' positive appraisal of having psychosis and being in contact with the EIP service, e.g.

P7: *I mean a lot of people bend and they really do bend, but not everyone snaps and sometimes it's better to snap because then you can be fixed...*

This theme is expanded further as the participants discussed what they had learnt from their experiences and how they felt they had changed or grown as a person following psychosis and their contact with the EIP service. These extracts illustrate this:

*P3: I mean the whole experience has opened parts of my mind that I didn't have before, especially... the way I perceive things now...*

*P2: I don't get it as strong now, no because my mind is stronger...*

*P3: ...way I perceive things has changed for the rest of my life...*

*P7: ...if something happens I just don't get phased by it, like it... that something that's changed as well, I used to like fret about stuff, but it's like I don't really fret about anything now...*

One participant spoke about what was interpreted as a change in his view of what happiness is, for example:

*P3: ...with all this, these services and, and now I'm here two years on nearly three, with no work, no life, no nothing really, no money all gone, given it all away but I feel a lot happier than I've ever done yer know, (Interviewer: Ummm) and that's a weird thing about it...*

This theme could be seen as an extension to the previous theme of 'A sense of agency' in which the participants' accounts suggest not only the potential for a sense of control and mastery over their experience but the possibility of the discovery of a new and potentially stronger self concept.

### ***Place within the world.***

Many of the participants suggested a sense of connection with their psychosis and other people with similar experiences and a sense of growth as person however, there was also a need to a feel sense of belonging to the rest of the world:

*P5: I'd rather just be a human being, rather than someone with mental health, if you see what I mean (Interviewer: ummm) just fit in.*

Following their experiences many participants had changed their social activities and friendship groups, resulting in a detachment from their previous lives:

*P7: I don't hang around with them now, cus it was part of the psychosis you know what I mean like...*

*P4: ...but I'd like to go out everyday... like I could years back, but I can't, I just get too scared and err, getting too scared make me just think, I'm not going out, I'll just stay in.*

For participant 4, she described being afraid of her old friends and her old life. For her, the decision to detach from her peer group resulted in her feeling isolated and alone at times.

Accounts suggested some apprehension and anxieties about returning to work but at the same time a feeling of being judged by others and criticised for not working:

*P1: I'm a bit apprehensive, yeah, because I'm still not feeling as well enough for me to be back in a work environment, and I'm just not sure when that, when I think that will come, I've been*

*thinking about it, but I'm just not sure when I think I will be well enough to go to a work environment again.*

P3: *...cus in this society I've got no choice, but to, to go and earn money...*

P7: *It bears the dilemma, if you come off your incapacity benefit and then you fuck up, cus they say "oh you're just milking the incapacity"...*

Participants discussed how EIP services had supported them in re-establishing both vocational and social aspects of their lives:

P7: *...erm, going to start doing 3 hours a week sessions with like naughty kids, with some of the lads from (names voluntary agency connected with EIP service), who've like took loads of drugs and fucked up and come out of it and got a bit of time on their hands.*

## **Minor Theme**

In addition to the five super-ordinate themes developed from the analysis, a minor theme '*An intervention with a start and an end*' was developed. This theme although present within the interviews, the discussions and descriptions which illustrate the theme was not considered to be as rich or as in-depth as the other themes and therefore is included as a minor theme.

### **'An intervention with a start and an end'.**

This minor theme has dual meanings and describes the participants' accounts of *Entering* and *Exiting* the EIP service.

### ***Entering.***

This theme encapsulates the participants' accounts of both the timing of the intervention and the role that others did or should have played in their involvement with services. This theme can be envisioned as overlapping and extending the previous discussions about the stigma of mental health services and the potential barriers that are created, by people's shame and others' judgments.

Participants spoke about their escalating symptoms prior to their referral to the EIP service; however, participants' accounts also suggested a reflection on the timing of the EIP intervention, which is illustrated by these extracts:

*P1: Yeah, yeah, they should have moved a bit quicker. To have a doctor and a social worker there, yer know, the EIP service slowly coming on board (Interviewer: yeah) that should have worked out a lot quicker I think.*

*P4: I'd been feeling poorly for... (Exhales) since I was fifteen, for about five years. (Interviewer: right) and it took nearly three years for someone to say you are poorly, which was the police.*

This illustrates a shared experience among many of the participants, of there being a delay between them beginning to experience their psychosis and them actually being involved with EIP services. Participants described a sense of not knowing what was happening to them and having difficulty in being able to communicate with others about their experiences. Participants 3 and 7 described how they were unable to help themselves during this time:

*P3: I'm not able to look back and question it, this was what was puzzling, I could remember it, I could remember what just happened but I wasn't able to say to myself... hang on a minute what just happened there, you know, are you perceiving err...*

*err... have what you just perceived, is it reality or... what was it, you know I wasn't able to ask myself that question...*

*P7: Yeah different people said I was unwell at different times, like when I was alright, and that's the whole point, you don't know when your mad and when your not...*

This theme was interpreted as being further expanded to capture the participants' reflections on the possible role that other people could have played in their referral to the EIP service:

*P1: ... but it still took a while before I got involved with the doctors, you would have thought they'd notice at the hospital, I mean at the police station cus they've got a nurse there on site (Interviewer: Oh, right) would actually have picked up on it, or had a word with me and yer know, but they left it for quite a while.*

*P3: ...and even my mates, they were, they couldn't understand what was happening yer know, they never said anything to me they just... obviously I must have been acting strange to them obviously yer know... but no one ever actually came up and says Graham (refers to self) are you OK? Yer know I never got that kind of feedback ever... and I think that maybe if I'd of had got that early on... somebody just shake me up a bit and say can you see what's happening here....*

This illustrates the frustration experienced by the participants on their reflection of other people's lack of action during this early stage. This highlights the importance of other people in being able to identify and act early on.

### ***Exiting.***

Participants described their feelings about their up-coming exit from the EIP service and the meaning of this transition. One participant gave multiple descriptions, which were interpreted as an ambivalence about leaving the service, in which exiting would represent closure, but also highlighted her anxieties about being independent from the service. This anxiety about being independent from the service was echoed by other participants, for example:

*P7: Yeah that's it, there's erm... you're not sure whether or not you're gonna fuck up again, so if you get off incapacity and I'm out of the system of EIP and like all of this sort of thing, if it fucking up again...*

Participant 7 illustrated an anxiety and fear of relapse after leaving the service. When compared to the previous theme of '*A sense of agency*' this captures potentially mixed emotions with regard to being independent and embodying a sense of control and mastery over their ongoing experiences.

A final aspect of this theme overlaps and extends the earlier discussion about Care co-ordinator relationships. For many of the participants when discussing their anxieties about leaving the service, accounts suggested a sense of loss regarding their relationships with members of the EIP service. This extract illustrated this point:

*P1: ...it's not that nice knowing that you've worked so closely with someone, you've built up a good relationship with them and then you have to, kind of like probably start all over again, with a new worker (Interviewer: yeah, umm)... so yeah I find that I bit of a shame...*

## Extended Discussion

This discussion section expands on the discussion included in the journal article. Within the journal article the super-ordinate themes are conceptualised within an overarching theme of '*A personal journey of recovery*'. Therefore, this extended discussion considers the themes individually in relation to previous research in this area. It also focuses on how the themes expand on previous research and add to the body of knowledge, regarding EIP services. Clinical implications of the individual themes are discussed, as well as expanding on the overall clinical implications considered in the journal article. The limitations and strengths of the research and suggestions for ongoing and future research directions are discussed. This section concludes with a reflective critical discussion regarding some of the central issues raised by the research.

### 'Stigma'

Participants' accounts were interpreted as describing their personal shame and self-stigmatizing attitudes. Whereas, the theme *Others' judgements* captured an alternative type of stigma experienced by participants from the negative judgements made by others. This distinction between self-stigma and public-stigma has been previously been documented in the literature (Corrigan, 2000; Corrigan & Penn, 1999). The personal shame participants described, was related to the specific experience and the self identified label of psychosis. Accounts were interpreted as implicitly describing a hierarchy of mental health problems, in which some diagnoses (e.g. psychosis) are seen as more shameful than others (e.g. depression). This is harmonious with research that suggests there are statistically significantly more negative perceptions of schizophrenia, than of depression, (Mann & Hemelein, 2004).

Although different experiences of stigma have been researched in individuals with different mental health diagnoses (Dinos et al., 2004) the accounts in this study illustrated how participants in an EIP service constructed their own meaning of what was acceptable and what was not, with regard to having a



mental health problem. This suggests the stigma experienced by participants was a consequence of a specific psychiatric diagnosis rather than having a mental health problem in general. The participants' own shame and self-stigma was also amplified by the actual and perceived judgements of others, as a consequence of their experience of psychosis. The ongoing negative reactions and judgements of others were from both the general public but also from close family and friends. The experience of the negative impact of others' judgements has been previously identified in research with people with FEP (Knight et al., 2003).

The impact of severe mental health problems on individual's sense of self and self identity has been extensively discussed in the literature (Davidson & Strauss, 1992; Andresen et al., 2003). With regard to the participants' shame and self-stigmatizing attitudes, this research highlighted the impact of the experience of psychosis on people's gender identity. With regard to gender issues in stigmatizing attitudes, research has suggested that males have less mental health knowledge, higher mental health stigma (Mann & Hemelein, 2004) and are less likely to access mental health services, when compared to same age females (Chandra & Minkovitz, 2006). This mirrors the experience of one particular participant, whose personal shame was interpreted as being a consequence of his pre-conceived views about the male gender role.

The combination of personal shame regarding their experiences and the reactions of others, jointly contributed to what was interpreted as a barrier to the participants accessing the EIP services, early on in their experiences. This barrier to mental health services was further elaborated in the ordinate theme '*Stigma of services*', in which accounts suggested that mental health services themselves, fuelled judgmental attitudes about mental health problems. Mental health services were seen as representing an inherent power imbalance between the providers and consumers of these services. This perceived power imbalance contributed to the descriptions of a reluctance and fear of engagement with services. It is interesting to note that the perceived sense of power imbalance, which was described by Foucault (1972/ 2006), is still seen

as a major barrier to care. The impact of the stigma associated with mental health problems and services on help-seeking behaviours is in-line with previous literature (Dinos et al., 2004; Judge et al., 2008).

Accounts suggested contrasting views regarding the stigmatizing effects of EIP services. This is important, as a key component of EIP services is reducing the stigma associated with mental health problems and offering services in the least stigmatising settings (DoH, 2001). The findings of this research illuminate a potential barrier to this aim, as the name in itself and the specialised service delivery model, can add to feelings of separation.

Overall the super-ordinate theme of '*Stigma*' highlights a need for the education of the public and professionals with regards to mental health problems, such as psychosis, which has been discussed in previous research (Corrigan, et al., 2001; Norman, et al., 2004), but also specialist mental health services such as EIP. However, with regards to clinical implications, it highlights a particular need to target groups with high referral rates (such as universities, colleges), in order to tackle the self-stigmatizing attitudes of individuals with regard to psychosis and services, particularly as research suggests stigmatizing attitudes can start early in life (Chandra & Minkovitz, 2006). Additionally, as a family and carer focus is suggested as a key component in EIP services (DoH, 2001), this research highlights the importance of this focus on family involvement, potentially as a method of addressing the negative judgements of close others. Furthermore, this theme relates to the aims of EIP in reducing DUP (Reading & Birchwood, 2005) and interventions aimed at reducing DUP (e.g. Johannessen et al., 2001), with the participants' accounts highlighting barriers to accessing appropriate EIP services. If both self-stigma and other peoples' stigmatizing behaviours are seen as a barrier to accessing EIP services, as was interpreted in these participants' accounts, there is a need to address these attitudes if DUP is to be decreased. With regard to clinically practical methods regarding how to challenge and change stigmatizing attitudes, research has suggested that both education and direct contact with people who have experienced

mental health problems (and being able to interact with them), have been shown to have positive effects on attributions (Corrigan, et al., 2001).

### **‘Relationships’**

Participants gave rich descriptions of the role peer-support groups had in their lives and on their view of their psychosis. The peer groups attended by participants varied in nature and content and included informal discussions, psycho-education, activity centred and more formal discussions related to specific topics. The EIP service, from which participants were recruited, offer a range of these groups either in-house via EIP service staff, or externally through connections with voluntary groups.

It was interpreted that the groups offered an opportunity for a sense of belonging, which has been reported in other research (Hirschfield et al., 2005). Furthermore, the peer groups also appeared to impact on participants’ feelings of agency and mastery, as they adopted a ‘helper’ role for other service-users. This was interpreted as contrasting with their previous role within the service as being the ‘helped’ and was seen as a move from a passive recipient role towards an active giving role.

EIP services aim to provide opportunities for service-users to attend service-user groups (DoH, 2001) and have been identified as an essential element of an EIP approach (Marshall et al., 2004). This study identified a role these groups could play in reducing feelings of shame and the stigma. This is consistent with previous research, which has identified the role of formal therapy groups in reducing stigma through the process of normalisation (Newton et al., 2007). However, this study also identified a potential barrier to peer group attendance. All participants acknowledged that they had been offered the opportunity to attend a peer group by their EIP Care co-ordinator, whereas one participant expressed a desire to attend peer groups but was unaware of their existence. This highlighted the role of the Care co-ordinator in being the link between the service-user and the peer groups and the

importance of consistency. This could be viewed as an unnecessary barrier that some service-users may face, in accessing peer-support groups.

When considered in-line with the previous theme of '*Stigma*', participants' accounts were interpreted as representing the potential impact of gender identity, on self-stigmatizing attitudes. This highlights a potential clinical implication with regard to the focus of peer-support groups. If EIP services are aware of the potential impact of psychosis on people's identity, peer support groups could be a forum to potentially re-build people's sense of identity. This implication has been previously highlighted in previous research, which also discussed potential issues regarding identity (Barker et al., 2001).

A key component of EIP services is their use of an 'assertive outreach' type approach to relationships with service-users (DoH, 2001). The aim is to develop meaningful relationships, which can then be used as a vehicle for change. The relationship participants developed with staff reflected this 'assertive' approach. They described the evolving nature of their relationship with Care co-ordinators, which is congruent with other research exploring the workings of an EIP service (Larsen, 2007). Therefore, this suggests that an assertive approach, to the relationship, was beneficial for the participants in this current study and was potentially powerful and influential in nature.

### **'Understanding the Experiences'**

The participants' accounts suggested that their contact with the EIP service had created an opportunity for them construct a sense of commonality and normality regarding psychosis, both within all individuals who experience psychosis, but also by drawing comparisons between themselves and the general public. This sense of the participants actively trying to normalise their experiences can be linked to the application of psychological therapeutic strategies, such as Cognitive Behavioural Therapy (CBT), to psychosis. These strategies have highlighted the role of normalising, in attempting to overcome

the mystery often associated with psychosis and to create a sense of commonality (Kingdon & Turkington, 1994).

Previous qualitative studies have explored how individuals with psychosis make sense of their experiences of psychosis (Hirschfield et al., 2005; Judge et al., 2008; Perry et al., 2007) and have suggested the importance of a personal framework of understanding, in the context of recovery (Ridgway, 2001). The participants' accounts in this study expand on this literature by exploring the personal frameworks developed by service-users, in an EIP service and how this service model impacted on this experience.

Several participants explicitly discussed the shared vulnerability of all humans to psychosis, whereas for some participants, their explanations extended beyond those offered by the EIP service. This was interpreted as a '*spectrum*' of psychosis, on which all humans exist to differing degrees. The interpretation of a '*spectrum*' of psychosis can be seen as contradictory to the epistemological view of psychiatric diagnoses being objective entities. It can be viewed as being more congruent with a constructivist stance, where psychiatric diagnoses are context-specific, human products (Pilgrim, 2007). This view of a spectrum of psychosis, can be seen as breaking down the 'us' and 'them' divide between the mentally well and the mentally unwell, which has been extensively discussed (Bentall, 2003). However, for those situated at the 'wrong' end of this spectrum, negative consequences can include being denied a voice (Bentall, 2003). This possibly represents a modern day version of the power imbalance described by Foucault (1972/ 2006).

Developing a sense of hope, has been extensively documented in the literature (e.g. Andresen et al., 2003; Perry et al., 2007; Ridgway, 2001; Young & Ensing, 1999) and is seen as an important process in recovery. However, participants' accounts were interpreted as exploring this further, by discussing the role of the EIP service in fostering that sense of hope. For many participants, the initial few contacts with the EIP service offered them a sense of hope and optimism about the future, which contrasted with their previous anxieties and feelings of

hopelessness. This highlights the importance and powerful influence of those initial contacts with EIP for the participants forming a framework of optimism and recovery, which is a key element of an EIP model (DoH, 2001).

### **‘Sense of Agency’**

The super-ordinate theme ‘*Sense of agency*’, represented participants process of moving from being a passive viewer and recipient of their experiences, towards being an active agent, with the power to manipulate their experiences or change their perceptions of them. The importance of accepting symptoms of psychosis is discussed extensively within the literature (e.g. Ridgway, 2001; Young & Ensing, 1999), as is the value of expression of experiences rather than avoidance (Hirschfield et al., 2005). Acceptance and ‘integration’ of the experiences, is suggested to result in more positive outcomes and levels of functioning in people with FEP, compared to individuals who separate their experiences from the rest of their lives (Thompson, McGorry & Harrigan, 2003). This view of recovery being an acceptance of symptoms, contrasts with traditional views that define recovery as symptom alleviation (Bellack, 2006).

Participants’ accounts also described a sense of active control over their experiences of psychosis, which was supported by EIP staff. These included descriptions of feeling able not only to recognise and accept the presence of ‘voices’, but also feeling able to challenge and exert influence over them. A progression towards active coping and talking control has been previously explored (Barker et al., 2001; Ridgway, 2001) and is suggested as a central aim of early psychological adjustment to psychosis (Birchwood & Tarrier, 1994). This current study expands this literature, as it explored the role of the EIP service in providing opportunities to achieve a sense of acceptance and agency.

This theme also encapsulated the participants’ descriptions of their sense of control over EIP service interventions. Previous studies have discussed the negative consequences of a lack of choice regarding their ‘treatment’ options,

in services for psychosis (Barker et al., 2001). In this current study, accounts were interpreted as describing a shared experience of restricted EIP interventions. Most were only offered medication initially, which impacted negatively on their self esteem and sense of control. This focus on medication may reflect the dominance of the medical model regarding the aetiology of psychosis (Bentall, 2003).

In contrast, accounts also suggested the EIP approach in general was gradual, non-forceful and individualised. This was expanded further as participants' compared it to their experiences of inpatient services. The transition from inpatient services to community services such as EIP highlights a further clinical implication. EIP services may need to counteract the negative effects of inpatient services, when attempting to foster feelings of power and control in service-users.

### **'Impact on Sense of Self'**

Previous literature has identified re-discovery and re-construction of a sense of self as an active agent, as an important aspect of recovery from enduring mental health problems (Davidson & Strauss, 1992). In-line with this previous research, some participants in this current study were interpreted as achieving a sense of discovery of a new self, and re-connecting themselves with the world around them. These processes were also seen as been influenced by their involvement with the EIP service, as it offered practical support in re-establishing social and vocational aspects of their lives.

The experience of discovering of a new self, following the experience of psychosis, has been previously identified in other research (Barker et al., 2001; Hirschfeld et al., 2005; Young & Ensing, 1999). Growth has also been suggested as a possible final stage in models of recovery in psychosis (Andresen et al., 2003). Additionally, there is a growing body of evidence that suggests positive psychological changes can result from experiences of trauma (Linley & Joseph, 2003) and the concept of post-traumatic growth has begun to

develop a strong and extensive base within the literature (e.g. Woodward & Joseph, 2003). It is suggested that there can be three possible outcomes from traumatic experiences: survival, recovery or thriving (O’Leary & Ickovics, 1995). Within the psychosis literature the concept of mental health problems such as psychosis being more than just something to be cured, endured or managed (Anthony, 1993), is compatible with both the consumer movement and the literature regarding growth following trauma.

This current study also highlighted potential difficulties in participants feeling a sense of re-connection with their world, at a deeper and less practical level. Results described a potential ongoing difficulty, for some participants, in trying to re-integrate their new found sense of self within the world. This was viewed as something, in contrast to practical re-integration, that the EIP service had been unable to help the participants fully resolve. The literature on post traumatic growth following childhood abuse, has explored how growth following trauma is achieved (Woodward & Joseph, 2003) and suggests the role of both the individual and the role of others (through acceptance and validation of the person). Therefore, it is possible to suggest that EIP services could have a role in supporting service-users in this deeper and more complex re-connection with the world. However, whether or not they are able to, or the way in which EIP services facilitate these potential processes, was not explored in this current study. This would require more detailed exploration to determine an appropriate role (if any), for EIP services.

### **Minor Theme**

This section focuses on the minor theme, which was developed during the analysis and discussed in the extended results section.

#### **‘An intervention with a start and an end’.**

This minor theme captured the participants’ descriptions of both their entrance into the EIP service and their up-coming exit from the service. With regard to



entering the EIP service, participants' accounts were interpreted as highlighting both the issue of timing of the intervention and the role of others. Participants' accounts suggested a delay between initial experiences of psychosis and being actively involved with services. As previously discussed, this research has highlighted the potential role of stigma as a barrier to people accessing services. However, some participants identified, that in addition to their own stigmatizing views of EIP services and psychosis, they also felt unable to recognise the changes in themselves, during their initial experiences of psychosis. Previous research has identified that often, initial experiences of psychosis are normalised and accommodated into the persons life and are not recognised as being important (Judge et al., 2008).

The participants' accounts suggested the role of others in helping people access EIP services. Participants reflected on the lack of action of people around them (including family members, friends, doctors, the police), during their initial experiences. When considered in line with DUP research (e.g. Marshall et al., 2005), it suggests that attempts to reduce DUP need to address more than just the stigmatizing attitudes of those experiencing psychosis. There is potentially a need to educate the general public, not only about some of the myths that surround psychosis, but also the potential role they play in supporting people gain access to EIP services. More specifically, this research highlights the importance of other professions being aware of mental health problems such as psychosis and the importance of early access to services.

This theme also captured participants' views of their up-coming exit from the EIP service. As all participants had been in the service for longer than two years, they were all approaching the end of their three years within the service. Following three years, depending on their assessed needs, service-users are referred to other services (e.g. community mental health teams, assertive outreach or GP). Participants in this study spoke about their up-coming exit and their ambivalent feelings about leaving the service. Accounts suggested that several participants were anxious about relapsing and losing the support that EIP had provided.

Previous research has suggested that service-users attribute their confidence and ability to cope to the support received by staff (Barker, et al., 2001; O'Toole et al., 2004), which could account for participants' anxieties. However, the accounts in this current study also were interpreted as overlapping with the previous theme '*Relationships*' as participants related their discussions about leaving the service, to their relationships with their Care co-ordinators. For some participants', their accounts suggested a sense of loss that was inevitable on their exit from the service and their anxiety about having to build new relationships with other professionals. Therefore, it could suggest that anxieties about exiting the service are due to mixed feelings of independence and loss.

This illuminates an important clinical implication for EIP services, in that it is important for EIP staff to create not only a meaningful and supportive relationship, but also to foster a sense of independence in service-users. This overlaps with discussions about the importance of creating opportunities for a sense of agency and control. An important role of EIP staff is to ensure service-users are aware early on that the service is time-limited and with inevitably end. This is something not to be avoided or delayed and could be integrated into the service-user's support.

### **Summary of Clinical Implications**

The previous section discussed each of the five super-ordinate themes and a minor theme with regard to the previous literature. Additional clinical implications to those identified in the journal article were considered within these discussions, which are briefly summarised here:

- Due to the multifaceted nature of stigma, EIP services need to take an equally multifaceted approach to trying to reduce stigma, particularly focusing on groups with high referral rates and family involvement within the EIP approach.

- It is important that all service-users are given equal opportunities to access varied peer-support groups. Additionally, these groups may provide a forum for tackling issues such as identity.
- EIP services need to create opportunities for service-users to gain a sense of control and agency, over both their experiences of psychosis and the therapeutic interventions offered.
- It is important that the time-limited nature of EIP services is clearly identified early on and should be integrated into the support offered.

## **Strengths and Limitations**

It is inevitable that all research will have limitations; regardless of how well it is designed and carried out. Therefore, this section discusses some of the key strengths and limitations of this research, in addition to those identified in the journal article.

### **Research design.**

The research design adopted provided an opportunity to expand on a previous qualitative investigation of a UK EIP service (O'Toole et al., 2004). It also attempted to overcome the limitations associated with focus group methods by using semi-structured interviews, which are suggested to enable participants to offer a deeper and richer account of their views (Willig, 2001). However, IPA relies on the researcher being able to make valid interpretations of the participants' accounts, which is achieved through the researcher's own conceptual framework (Smith & Osborn, 2003). Therefore, in order to assure the quality of the analysis, several quality assurance measures were adopted (including the use of a reflexive diary, an audit-trail and direct quotations in the results to ground the interpretations in the text) to ensure the transparency of the analysis.

IPA also makes an assumption that the participants involved are able to articulate their thoughts, perceptions and feelings, about the phenomenon being researched (Smith, 1996). This could have been a potential problem for this study, as prior to the interviews commencing, the researcher had no knowledge to what degree the participants had previously discussed their experiences. Potentially, participants may have found describing abstract and subjective experiences challenging. However, with careful preparation of the interview schedule (phrasing of questions and appropriate prompts) and piloting the schedule on colleagues, all participants appeared able to engage reflectively in the interviews. Additionally, participants used different types of descriptions such as metaphors and similes to convey their experiences.

This study offered an opportunity for service-users to talk about their own personal experiences. Many service-users had attended peer support groups, which is a forum to discuss experiences. However, several participants expressed that attending the interviews had been useful for them in reflecting on their progress. Although the research aimed to provide an opportunity for individuals to talk openly about their experiences, this illuminates a function and strength of the research, which was unintended and additional to the aims.

### **Participants and sampling.**

A purposive sampling method was used to recruit eight participants, who were homogenous in their experience of receiving an EIP service for more than two years. However, although this homogeneity is important in IPA, it also means that all the participants entered the service within five months of each other. Therefore, it only provides a snapshot of the experiences of the service delivery during that time. It is important to acknowledge that the experiences of service-users entering the service at different times may be different. However, this is the nature of qualitative research and is not viewed as a limitation in itself. Additionally, due to the double hermeneutic adopted in IPA (Smith & Osborn, 2003) service-users who required an interpreter for EIP service reviews, were excluded from the study. This resulted in these individuals' views potentially

being overlooked in this research. Future research could aim to recruit service-users who do not speak English as their first language, in order to explore their experiences.

A similar potential limitation of this study is that all participants were recruited from the same EIP service. It could be suggested that although based on the same national guidelines (DoH, 2001), EIP services will differ in their ethos and will have their own service culture, influenced by staff and cultural variations, with regard to the services geographical location. Therefore, although this research offers an insight into service-users' experiences of an EIP service, this experience could potentially have been influenced by that specific services ethos. As a result, service-users from other EIP services may vary in their experiences of being in contact with this type of service.

In using a purposive sampling method, it is possible that the service-users who took part may have been motivated by having perceived their experiences in a predominantly positive light. This is suggested, as previous literature has discussed the difficulties in measuring services users' views of healthcare services, as predominantly positive attitudes can reflect a loyalty towards the NHS rather than levels of satisfaction (Staniszewska & Ahmed, 1999). Additionally, a previous study of service-users' experiences of an EIP service (O'Toole et al., 2004) produced consistently positive views and experiences, despite attempts to elicit both positive and negative experiences.

However, in contrast to previous research, this study did not aim to explicitly evaluate positive and negative experiences, or service satisfaction. Therefore, by making participants aware of the focus of the research and using a flexible method of interviewing, participants' accounts appeared to represent the full spectrum of experiences. Furthermore, the researcher attempted to create an environment where participants would feel able to express their perceptions without fear of reprisal. This included outlining procedures in place for confidentiality and anonymity and the researcher's independent status from the EIP service.

## Recommendations for Future Research

This section discusses future research directions highlighted by the results of this study. The aim is to expand on the future research directions already identified in the journal article (a and b) and discuss other possible directions (c and d).

**a)** The super-ordinate theme '*Relationships*' discussed the nature and role of the relationship between Care co-ordinators and participants. This relationship was interpreted as being both important and influential in service-users' experiences and their access to other services. Future research could aim to explore Care co-ordinators' subjective experiences of fulfilling this position in an EIP service and their view of their relationships with service-users. There is the potential that Care co-ordinators may have similar or contrasting views of this relationship, which would be interesting to explore. Similarly, as discussed in the current study, it was interpreted that the views and actions of EIP service staff (particularly Care co-ordinators) could potentially have important implications for service-users' feelings of agency and their sense of optimism about recovery. Previous research has suggested that Danish EIP service staffs use of recovery models impacted on service-users' appraisals of their experiences (Larsen, 2007). Therefore, interviewing Care co-ordinators from a UK EIP service about their views of recovery could illuminate this relationship further.

**b)** Interviewing people who have left the EIP service may allow for the exploration of ex-EIP service-users' experiences of their psychosis. Additionally, interviewing service-users who have moved to a different mental health service (e.g. assertive outreach), could allow for exploration of any impacts of this change in intervention. Interviewing people after exiting the EIP service could also avoid the potential limitation of this current research, in interviewing people who are actively involved with the service under discussion. However, an ethical consideration would be to consider the support networks in place for participants who are no longer receiving any form of mental health

intervention (as there is the potential for participants to become upset during interviews).

**c)** The theme '*Relationships*' also discussed the role of peer-support groups for EIP services-users. The research identified potentially multiple roles that peer groups can fulfil, including reducing feelings of isolation, fostering a sense of belonging and mastery over their experiences. The results suggested that these types of groups are an important component of EIP services. However, this research did not explore experiences of different types of peer-support groups or how these groups should be provided or promoted. At present peer-support groups can be offered in-house by EIP service staff, or by outside charity/ volunteer services. Groups can adopt a variety of formats including a formal psycho-educational format, or an informal forum with no set agenda. Future qualitative research could aim to explore positive and negative aspects of different group formats, with the aim of understanding appropriate ways of delivering them.

**d)** Previous research has explored the experiences of services for psychosis, from the perspectives of families and carers (Barker et al., 2001; Coffey & Hewitt, 2008). However, family and carers experiences of an EIP service approach are not evident in the current literature. EIP services aim to involve services users' families and/or carers and/or significant others, throughout the process of assessment and intervention (DoH, 2001). This current research suggested that the negative judgements' of others (including family and friends) was linked to participants own feelings of shame and self-stigmatising attitudes. Therefore, future research could explore service-users' families and/or carers' experiences, of their involvement with EIP services and its impact on their views of psychosis.

## **Critical Reflective Discussion**

This section of the discussion critically and reflectively discusses some of the wider issues raised by this research study. The discussion is orientated by

extracts from the researcher's reflective research diary (Appendix F) and also discusses the study's epistemological stance with regard to these wider issues. As this is a reflective component as well as an avenue for critical discussion, this section was flexibly guided by the Rolfe, Freshwater and Jasper (2001) model of reflection. This model encourages the individual to describe the issue being reflected on, construct knowledge about the issue and then consider future actions. However, as this is a critical discussion, it is important to acknowledge that although the researcher actively uses reflection in her clinical practice (and will continue to do so), there is little evidence to support the integration of learning through reflection into actual clinical practice (Lowe, Rappolt, Jaglal & MacDonald, 2007).

### **What?**

#### Reflective diary extract

*I have just been discussing my table of super-ordinate themes with a colleague and started to think about this issue of the stigma associated with mental health services and how this impacted on participants anxieties about the EIP service. Discussions around stigma seemed to be related to psychiatric diagnoses and in particular psychosis and schizophrenia. Why are these diagnoses still used, particularly if they add to feelings of stigma? What purpose do they serve and are they scientific? Also how does the use of psychiatric diagnoses relate to the epistemological position of this research?*

### **So what?**

Debates about the legitimacy and use of psychiatric diagnosis are long standing and still ongoing (Pilgrim, 2007). Kraepelin characterized three main features, which became the paradigm for western psychiatry, that mental "illnesses" were naturally occurring categories that precede the subject and are embodied within the sufferer, they were inherited conditions with a predicable and deteriorating course, and that they were caused by diseases of the brain. (1883 as cited in Pilgrim, 2007). Some of these features can be viewed as



being congruent with a *positivist*, or *medical naturalism* epistemological view of mental “illness” (Pilgrim, 2007). In contrast, during the 1960’s and the ‘anti-psychiatry’ movement, many psychiatrists themselves, argued against the notion of mental illness being an observable objective entity. Szaz (1961) argued that mental illnesses were socially constructed by those who would benefit from their existence, namely the psychiatric profession, which can be seen as congruent with a *constructivist* epistemology (Guba & Lincoln, 1994). Additionally, during this time Meyer offered a view of continuum approach to mental illness and a focus on a psycho-biological approach to individual cases was offered (Double, 1990). This continuum approach can be viewed as congruent with the views of some participants interpreted in this current research. Accounts suggested that psychosis could be viewed as a *spectrum*, on which we are all situated to different degrees.

Psychiatric diagnoses can be viewed as being based on the epistemological view of their being an objective entity of a mental illness, which is attainable and independent of the diagnostician (Pilgrim, 2007). However, a contrasting view suggests that as diagnoses are constructed predominantly from what the individual communicates and how they behave, an interpretative hermeneutic philosophy is a more suitable approach (Ingleby, 1980). This relates directly to the epistemological stance of this research study, as it utilised an IPA approach (Smith, 1996) which has its roots in critical realism (Bhaskar, 1978) and acknowledges the double interpretation involved in the construction of knowledge.

More recent critics of the diagnostic label schizophrenia tend to mirror that of Meyer (see Double, 1990) and reject a categorical approach to diagnosis. Instead, they argue for an individualised case by case approach, which would in itself negate the need for a diagnosis label (Bentall, 2003). There is also ongoing debate about the validity of schizophrenia as a psychiatric diagnosis. It is suggested that a diagnosis of schizophrenia lacks both aetiological and treatment specificity; however despite this, the same treatments are often applied to all service-users (Bentall, Jackson & Pilgrim, 1988). This approach to

intervention was interpreted within this current study's findings, as most participants described being pre-dominantly or solely offered medication as a treatment option. Bentall et al. (1998) argued that continued attempts to increase the reliability of schizophrenia as a diagnostic category, is not a sufficient condition for validity.

### **Now what?**

This raises several scientific and ethical issues about the continued use of psychiatric diagnoses. As a clinician practicing with the field of mental health, it is inevitable that the researcher will continue to work in services which adopt a diagnostic approach to mental health problems. It is suggested that psychologists focus more on formulation whereby, theory is applied to practice and collaborative hypotheses are created, allowing for a more person-centred approach (Butler, 2006). This collaborative approach to working with service-users is important in the context of some of the issues raised in this research. Particularly, as findings suggested the importance of mental health service professionals creating opportunities for service-user agency. Psychiatric diagnoses could be viewed as placing the psychiatrist in an expert position, over and above the individual experiencing the symptoms (Bentall, 2003). In contrast, this reflection has further encouraged the researcher to continue to adopt a collaborative approach in her practice as a Clinical Psychologist. The researcher hopes that this approach will empower her clients, by identifying them as experts in their own experiences.

### **What?**

#### Reflective diary extract

*Prior to getting to involved with starting interviews and analysing data, I want to think about why I am even doing this research in the first place, what led me here? I think this is important due to the reflective nature of IPA and the role of interpretation. So why am I doing this research? I guess it would be for several reasons. My placement in the EIP team during my first year of training had a*

*huge impact on my clinical work and my thoughts about my future career directions. I enjoyed this placement very much and felt that the EIP philosophy was very congruent with my own views of both psychosis but also the issues with existing services. However as is the case with many things in the NHS service-users' views and experiences are often not valued as much as formal outcome measures when determining the value of services. I guess this has been a bit of a 'bee in my bonnet' for a long time now and probably also influenced my choice of this research. However, although I can think of some reasons for why I'm doing this research, I guess there will be other influences which I am not fully aware of yet, or maybe never will be.*

### **So what?**

The above diary extract is just one example of the researcher's attempts to be reflective about their own views, beliefs and influences on the research and the data collected. This extract considers the researcher's understandings of why they chose to research this topic over the multiple other potential research avenues. These reflective diary entries created throughout the research leads the researcher to critically discuss some of the other influences they will have had throughout the study.

The creation of the semi-structured interview schedule is an important element of the entire research study and it self will have been influenced by the researcher. When creating the schedule the researcher was very careful to ask open questions which did not label people or assume things about their experiences. For example although the study aimed to explore the impact of the EIP service on the participants' lives and views of their psychosis, this question was never directly asked. The reason being that the researcher did not want to assume that the EIP service had influenced the service-users in anyway, as this may not have been the case. However, this conscious effort to be open and non directive leaves the researcher wondering what responses might participants have given if more direct questions had been asked? Would

this have led participants into feeling they needed to talk about the influences of the EIP service and not what was really important in their own journeys?

In IPA the researcher is seen as an integral and necessary component within the analysis of the data gathered, therefore, the researcher will have inevitably influenced the development of themes within the research. As a trainee clinical psychologist, the researcher has always adopted a reflective stance within clinical work, whereas this has previously been absent from research endeavours. The reflective journal (Appendix F) and audit trail (Appendix G) offered an opportunity for the researcher to have an awareness of some of these influences and the reasons behind them.

Within the results the sub-theme 'EIP service involvement' captured the participants varied feeling of control over the services and interventions they received from the EIP team. Within this theme there was an overwhelming sense of forced and limited options being offered, with medication being the dominant route. These experiences described by participants reflected some of the researchers own experiences and frustrations from working as a trainee clinical psychologist with service-users in an EIP team. Despite the philosophy of EIP teams to offer choice, psychological interventions and collaborative decision making, medication was still often the sole or pre-dominant option for many service-users. This sub-theme is a good example of the inevitable influence of the researcher on the analysis. When participants began talking about an issue which was close to the researchers own experiences, IPA offered an opportunity to use the researcher's experiences to enhance the understanding of the participants' own stories and experiences.

### **Now what?**

Conducting this study has offered the researcher an opportunity to embrace a qualitative methodology and a hermeneutic philosophy which embraces the influences of the researcher instead of trying to set them to one side. This approach has proven to be a rich method of understanding a person's

experience, whilst always being open and aware of other influences within the process. Therefore the researcher aims to always consider the importance of self reflection beyond just a clinical setting, to include the world of academia and research.

## **What?**

### Reflective diary extract

*I have just had a final meeting with my field supervisor about the research. During the meeting she asked me whether or not I was planning on presenting the research findings to the EIP service it was conducted on. I feel really pleased that the format of this thesis means I have a journal article ready to be send for publication, as I have had so many conversations with psychologists who have said they never actually got round to publishing their thesis findings. This made me start thinking about dissemination of research in general and whether or not is ethical to conduct research with people and then never present the findings?*

## **So what?**

Guidelines for conducting ethical research suggest several requirements, which discuss the need for research to have; scientific value and validity, fair subject selection, favourable risk benefit ratio, independent review, informed consent and respect for participants (Emanuel, Wendler & Grady, 2000). The researcher, prior to conducting this study, addressed the ethical considerations raised by the research. However, as this research came to an end the issue of dissemination of the research findings required consideration. It has been suggested that the dissemination of research results should go beyond the typical scientific routes, by including a further channel of directly presenting results to participants (Fernandez, Kodish & Weijer, 2003). It is suggested that this channel enhances the dissemination of research findings and the value of the research itself (Fernandez et al., 2003).

## **Now what?**

The researcher aims to submit the research journal article for peer reviewed publication. However, with regard to the issue of dissemination to participants, the researcher has agreed to present the study findings to the EIP service in which it was conducted. All staff and service-users, including the participants of the research, will be invited to attend. All participants will also be offered a written summary of the results. By taking these actions the researcher aims to disseminate the results beyond the academic world, to the people who may feel they have a deep and personal connection with the research topic.

## References

- Addington J., van Mastrigt S., Hutchinson J. & Addington D.  
(2002) Pathways to care: help seeking behaviour in first episode psychosis. *Acta Psychiatrica Scandinavica*, 106, 358–364.
- Altman, D. G., Schulz, K.F., Moher, D., Egger, M., Davidoff, F. & Elbourne, D.  
(2001). The Revised CONSORT Statement for Reporting Randomized Trials: Explanation and Elaboration. *Annals of Internal Medicine*, 134, 636-694.
- Andresen, R., Oades, L., & Caputi, P. (2003). The experience of recovery from schizophrenia: towards an empirically validated stage model. *Australia and New Zealand Journal of Psychiatry*, 37, 586-594.
- Anthony, W. B. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, 16(4), 11-23.
- Ashworth, P. (2003). Conceptual foundations of qualitative psychology. In J.A. Smith (Ed), *Qualitative psychology: A practical guide to methods* (pp. 4-25). London, UK: Sage Publications Ltd.
- Atkinson, P., Coffey, A., & Delamont, S. (2003). *Key themes in qualitative research: Continues and changes*. New York, NY: Altamira Press.
- Barker, C., Pistrang, N., & Elliott, R. (2002). *Research methods in clinical psychology: An introduction for students and practitioners (2<sup>nd</sup> ed.)*. Chichester, UK: John Wiley & Sons, Ltd.
- Barker, S., Lavender, T., & Morant, N. (2001). Client and family narratives on schizophrenia. *Journal of Mental Health*, 10(2), 199-212.

- Baxter, J., & Eyles, J. (1997). Evaluating qualitative research in social geography: establishing 'rigour' in interview analysis. *Transactions of the Institute of British Geographers*, 22, 505-525.
- Bellack, A. S. (2006). Scientific and consumer models of recovery in schizophrenia: concordance, contrasts and implications. *Schizophrenia Bulletin*, 32(3), 432-442.
- Bentall, R. P. (2003). *Madness Explained. Psychosis and human nature*. London, UK: Penguin Books.
- Bentall, R. P., Jackson, H., & Pilgrim, D. (1988). Abandoning the concept of schizophrenia: Some implications of validity arguments for psychological research in psychotic phenomena. *British Journal of Clinical Psychology*, 27, 303-324.
- Bertelsen, M., Jeppesen, P., Petersen, L., Thorup, A., Ohlenschloeger, J., Le Quach., et al. (2008). Five-year follow-up of a randomised multicentre trial of intensive early intervention vs standard treatment for patients with a first episode of psychotic illness: The Opus trial. *Archives of General Psychiatry*, 65(7), 762-771.
- Bhaskar, R. (1978). *A Realist Theory of Science*, Hassocks: Harvester Press.
- Birchwood, M. (2000). The critical period for early intervention. In M. Birchwood, D. Fowler & C. Jackson (Eds.). *Early intervention in psychosis* (pp. 28–63). Chichester: John Wiley & Sons.
- Birchwood, M., & Tarrier, N. (1994). *The psychological management of schizophrenia*. Chichester, UK: Wiley.



- Birchwood, M., Todd, P., & Jackson. (1998). Early intervention in psychosis: The critical period hypothesis. *British Journal of Psychiatry*, 172(33), 53-59.
- Blackman, L. (2001). *Hearing voices: Embodiment and experience*. London, UK: Free Association Books.
- Borneo, A. (2008). *Your choice: Results from the Your treatment, Your choice survey: final report*. Retrieved January 11, 2009 from [www.rethink.org](http://www.rethink.org)
- British Psychological Society Report. (2000). *Recent Advances in Understanding Mental Illness and Psychotic Experience*. Leicester, UK: British Psychological Society. Retrieved January 12, 2008 from [www.bps.org.uk](http://www.bps.org.uk)
- Butler, G. (2006). The value of formulation: A question for debate. *Clinical Psychology Forum*, 160, 9-12.
- Chadwick, P.K. (1997). Recovery from psychosis learning more from patients. *Journal of mental health*, 6, 577-588.
- Chadwick, P., Sambrooke, S., Rasch, R., & Davies, E. (2000). Challenging the omnipotence of voices: Group cognitive behavioural therapy for voices. *Behaviour Research and Therapy*, 38, 993–1003.
- Chandra, A., & Minkovitz, C. S. (2006). Stigma starts early: Gender differences in teen willingness to use mental health services. *Journal of Adolescent Health*, 38, 754.e1-754.e8.
- Charmaz, K. (2001). Qualitative interviewing and grounded theory analysis. In J. Gubrium., & J. Holstein (Eds.), *Handbook of interview research: Context and method* (pp. 675-694). London, UK: Sage Publications Ltd.

- Charmaz, K. (2008). Grounded theory. In J. A. Smith (Eds.), *Qualitative Psychology: A Practical guide to research methods* (pp. 81-110). London, UK: Sage Publications Ltd.
- Chen E.Y.H. (1999). Early intervention in schizophrenia patients – rationale for its implementation and practice. *Hong Kong Medical Journal*, 5, 57–62.
- Cho, J., & Trent, A. (2006). Validity in qualitative research revisited. *Qualitative Research*, 6, 319-340.
- Coffey, M., & Hewitt, J. (2008). ‘You don’t talk about the voices’: voice hearers and community mental health nurses talk about responding to voice hearing experiences. *Journal of Clinical Nursing*, 1591-1600.
- Conrad, P. (1987). The experience of illness: Recent and new directions. *Research in the Sociology of Health Care*, 6, 1-31.
- Corrigan, P.W. (2000). Mental health stigma as social attribution: Implications for research methods and attitude change. *Clinical Psychology- Science and Practice*, 7, 48 – 67.
- Corrigan, P.W., & Penn, D.L. (1999). Lessons from social psychology on discrediting psychiatric stigma. *American Psychologist*, 54, 765 – 776.
- Corrigan, P. W., River, P. L., Lundin, R. K., Penn, D. L., Uphoff-Wasowski, K., Campion, J. et al. (2001). Three strategies for changing attributions about severe mental illness. *Schizophrenia Bulletin*, 27(2), 187-195.
- Craig, T.K.J., Garety, P., Power, P., Rahaman, N., Colbert, S., Fornells-Ambrojo, M., et al. (2004). The Lambeth Early Onset (LEO) Team: randomised controlled trial of the effectiveness of specialised care for early psychosis. *British Medical Journal*, 329, 1067-1069.

- Creswell, J. W. (2002). *Educational research: Planning, conducting, and evaluating quantitative and qualitative approaches to research*. Upper Saddle River, NJ: Merrill/Pearson Education.
- Creswell, J. W. (2003). *Research design: Quantitative, qualitative, and mixed methods approaches* (2nd ed.). Thousand Oaks, CA: Sage.
- Cresswell, J.W., Fetters, M.D., & Ivankova, N V. (2004). Designing a mixed methods study in primary care. *Annals of Family Medicine*, 2, 7-12.
- Cullberg, J. (2006). *Psychoses: An integrative perspective*. East Sussex, UK: Routledge.
- Danermark, B., Ekstrom, M., Jakobsen, L., Karlsson, J.C. (2002). *Explaining Society: Critical realism in the social sciences*. London: UK, Routledge.
- Davidson, L. (1992). Developing an empirical–phenomenological approach to schizophrenia research. *Journal of Phenomenological Psychology*, 23(1), 3–15.
- Davidson, L. (2003). *Living outside mental illness: Qualitative studies of recovery in schizophrenia*. New York, NY: University Press.
- Davidson, L., & Stayner, D. (1997). Loss, loneliness, and the desire for love: perspectives on the social lives of people with schizophrenia. *Psychiatric Rehabilitation Journal*, 20(3), 3–12.
- Davidson, L., & Strauss, J. S. (1992). Sense of self in recovery from severe mental illness. *British Journal of Medical Psychology*, 65, 131-145.
- Department of Health. (1999). *A National Service Framework for Mental Health*, Department of Health, London: England. Retrieved December 11, 2007, from [www.dh.gov.uk](http://www.dh.gov.uk)

- Department of Health. (2000). *The NHS plan: A plan for investment: A plan for reform*, Department of Health, London: England. Retrieved December 12, 2007, from [www.dh.gov.uk](http://www.dh.gov.uk)
- Department of Health. (2001). *The Mental Health Policy Implementation Guide*, Department of Health, London. Retrieved December 11, 2007, from [www.dh.gov.uk](http://www.dh.gov.uk)
- Department of Health. (2005). *Research governance framework for health and social care (2<sup>nd</sup> ed.)*, Department of Health. London: England. Retrieved December 11, 2007, from [www.dh.gov.uk](http://www.dh.gov.uk)
- Denzin, N. K. (1995). Symbolic Interactionism. In J. A. Smith., R. Harre., & L. Van Langenhove (Eds.). *Rethinking psychology* (pp. 43-58). London, UK: Sage Publications Ltd.
- Denzin, N. K., & Lincoln, Y. S. (2003). Introduction: The discipline and practice of qualitative research. In N. K. Denzin, & Y. S. Lincoln (Eds.). *Collecting and interpreting qualitative materials (2<sup>nd</sup> ed.)* (pp. 1-45). London, UK: Sage Publications, Inc.
- Denzin, N.K., & Lincoln, Y.S. (2005). *The sage handbook of qualitative research. (3<sup>rd</sup> ed.)*. London, UK: Sage Publications.
- Dinos, S., Stevens, S., Serafty, M., Weich, S., & King, M. (2004). Stigma: the feelings and experiences of 46 people with mental illness: Qualitative study. *British Journal of Psychiatry*, 184, 176-181.
- Double, D. (1990). What would Adolf Meyer have thought about the neo-Kraepelinian approach? *Psychiatric Bulletin*, 1, 471-474.
- Early Psychosis Prevention and Intervention Centre (EPPIC). (2006). *What is psychosis? Information Sheet*. Retrieved January 15, 2008, from

- Edwards , J., & McGorry, P. D. (2002). *Implementing early intervention in psychosis: a guide to establishing early intervention in psychosis services*. London, UK: Martin Dunitz Ltd.
- Elliott, R., Fischer, C. T., & Rennie D. L. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.
- Emanuel, E. J., Wendler, D., & Grady, C. (2000). What makes clinical research ethical? *Journal of the American Medical Association*, 283, 2701-2711.
- Farina, A. (1998). Stigma. In: K.T. Mueser, & N. Tarrier (Eds.), *Handbook of social functioning in schizophrenia* (pp. 247 – 289). Needham Heights, MA: Allyn & Bacon.
- Fernandez, C. V., Kodish, E., & Weijer, C. (2003). Informing study participants of research results: An ethical imperative. *Ethics and Human Research*, 25(3), 12-19.
- Foucault, M. (2006). *History of madness*. (J. Murphy, & J. Khalfa, Trans.). London, UK: Routledge. (1972).
- Garety, P., Craig, T.K.J., & Dunn, G. (2006). Specialised care for early psychosis: symptoms, social functioning and patient satisfaction. Randomised controlled trial. *British Journal of Psychiatry*, 188, 37-45.
- Georgaca, E. (2004). Reality and discourse: A critical analysis of the category of delusions. *British Journal of Medical Psychology*, 73(2), 227–242.
- Giorgio, A., & Giorgio, B. (2008). Phenomenology. In J.A. Smith (Ed.), *Qualitative psychology: A practical guide to methods* (2<sup>nd</sup> ed) (pp. 51-80). London, UK: Sage Publications Ltd.

- Glaser, B.G. (1992). *Emergence vs. Forcing: Basics of grounded theory analysis*. Mill Valley, CA; Sociological Press.
- Glaser, B.G. & Strauss, A.L. (1967). *The discovery of grounded theory: Strategies for qualitative research*. New York, NY: Aldine
- Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*. London, UK: Sage Publications.
- Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. In N. K. Denzin., Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 105-117). Thousand Oaks, CA: Sage Publications.
- Hanson, W.E., Cresswell, J.W., Cresswell, J.D., Plano Clark, V.L., & Petska, K.S. (2005). Mixed Methods Research Designs in Counselling Psychology. *Journal of Counselling Psychology*, 52, 224-235.
- Harrop, C., & Trower, P. (2001). Why does schizophrenia develop at late adolescence? *Clinical Psychology Review*, 21(2), 241–266.
- Hatfield, A. B. (1989). Patients' accounts of stress and coping in schizophrenia. *Hospital and Community Psychiatry*, 40, 1141-1145.
- Hayward, P., & Bright, J.A. (1997). Stigma and mental illness: A review and critique. *Journal of Mental Health*, 6(4), 345 – 354.
- Heidegger, M. (1962). *Being and time* (J. Macquarrie & E. Robinson, trans.). Oxford, UK: Blackwell Publishing Ltd.
- Henwood, K., & Pigeon, N. (1992) Qualitative research and psychological theorizing. *British Journal of Psychology*, 83, 97-111.
- Hirschfeld, R., Smith, J., Trower, P., & Griffin, C. (2005). What do psychotic experiences mean for young men? A qualitative investigation.

- Psychology and Psychotherapy: Theory, Research and Practice*, 78, 249-270.
- Hollway, W. (2001). The psycho-social subject in evidence-based practice. *Journal of Social Work Practice*, 15, 9–22.
- Husserl, E. (1969). *Ideas: General introduction to pure phenomenology* (W. R. Boyce Gibson, trans.). London, UK: Allen & Unwin.
- Ingleby, D. (Ed.) *Critical Psychiatry: The politics of mental health*. Harmondsworth: Knopf Doubleday Publishing.
- James, A. (2001). *Raising our voices: An account of the hearing voices movement*. Gloucester, UK: Handsell Publishing.
- Johannessen JO, McGlashan TH, Larsen TK, Horneland, M., Joa, I., Mardal, S. et al. (2001). Early detection strategies for untreated first-episode psychosis. *Schizophrenia Research*, 51, 39–46.
- Jones, S., Hughes, S., & Ormrod, J. (2001). A group evaluation of a hearing voices group. *Clinical Psychology Forum*, 8, 35–38.
- Jorgensen, P., Nordentoft, M., Abel, M.B., Gouliaev, G., Jeppesen, P., Kassow, P. (2000). Early detection and assertive community treatment of young psychotics: the Opus Study Rationale and design of the trial. *Social Psychiatry and Psychiatric Epidemiology*, 35, 283–7.
- Judge, A. M., Estroff, S. E., Perkins, D. O., & Penn, D. L. (2008). Recognising and responding to early psychosis: A qualitative analysis of individual narratives. *Psychiatric Services*, 59(1), 96-99.
- Kingdon, D. G., & Turkington, D. (1994). *Cognitive-behavioural therapy of schizophrenia*. New York, NY: Guilford Publications.

- Knight, M. T. D., Wykes, T., & Hayward, P. (2003). 'People don't understand': An investigation of stigma in schizophrenia using Interpretative Phenomenological Analysis (IPA). *Journal of Mental Health*, 12(3), 209-222.
- Koch, T., & Harrington, A. (1998). Reconceptualizing rigour: the case for reflexivity. *Journal of Advanced Nursing*, 28(4), 882-890.
- Kuipers, K., Holloway, F., Rabe-Hesketh, S., Tennakoon, L. (2004). An RCT of early intervention in psychosis: Croydon Outreach and Assertive Support Team (COAST). *Social Psychiatry and Psychiatric Epidemiology*, 39, 358–363.
- Larsen, J. A. (2007). Understanding a complex intervention: Person-centred ethnography in early psychosis. *Journal of Mental Health*, 16(6), 333-345.
- Larsen, T.K., Melle, I., Auestad, B., Friis, S., Haahr, U., Johannessen, J.O. et al. (2006). Early detection of first episode psychosis: The effect on 1 year outcome. *Schizophrenia Bulletin*, 32, 758-764.
- Lawler, S. (2002) Narrative in social research. In T. May (Eds.), *Qualitative research in action* (pp. 242-258). London, UK: Sage Publications Ltd.
- Lazare, A., Cohen, F., Jacobson, A.M., Williams, M.W., Mignone, R.J., & Zisook, S. (1972). The walk-in patient as a 'customer'. A key dimension in evaluation and treatment. *American Journal of Orthopsychiatry*, 42, 872-883.
- Le Vasseur, J. J. (2003). The problem of bracketing in phenomenology. *Qualitative Health Research*, 13(3), 408-420.
- Lincoln, Y.S., & Guba, E. G. (1985). *Naturalistic Inquiry*. London, UK: Sage Publications Ltd.



- Linley, P. A., & Joseph, S. (2003). Trauma and personal growth. *The Psychologist*, 16(3), 135.
- Lowe, M., Rappolt, S., Jaglal, S., & MacDonald, G. (2007). The role of reflection in implementing learning from continuing education in practice. *Journal of Continuing Education in the Health Professions*, 27(3), 143-148.
- Madill, A., Jordan, A., & Shirley, C. (2000). Objectivity and reliability in qualitative analysis: Realist, contextualist and radical constructionist epistemologies. *British Journal of Psychology*, 91, 1-20.
- Mann, C. E., & Himelein, M. J.(2004). Factors associated with stigmatization of persons with mental illness. *Psychiatric Services*, 55, 185-187.
- Marshall, M., Lewis, S., Lockwood, A., Drake, R., Jones, P., & Croudace, T. (2005). Association between duration of untreated psychosis and outcome in cohorts of first episode patients. *Archives of General Psychiatry*, 62, 975-983.
- Marshall, M., Lockwood, A., Lewis, S., & Fiander, M. (2004). Essential elements of an early intervention service for psychosis: the opinions of expert clinicians. *BMC Psychiatry*, 4(17). Retrieved February 8, 2008, from <http://www.biomedcentral.com/1471-244X/4/17>
- Mathison, J. (1989). 'Why triangulate?'. *Educational Researcher*, 17(2), 13-17.
- May, R. (2004). Making sense of psychotic experience and working towards recovery. In J. F. M. Gleeson., P. D. McGorry (Eds.), *Psychological Interventions in Early Psychosis: A Treatment Handbook* (pp. 245-260). Chichester, UK: John Wiley & Sons Ltd.
- Mays, N., & Pope, C. (2000). Qualitative research in health care: Assessing quality in qualitative research. *British Medical Journal*, 320, 50-52.

- McEvoy, P., & Richards, D. (2003). Critical realism: a way forward for evaluation research in nursing? *Journal of Advanced Nursing*, 43(4), 411-420.
- McGlashan, T.H., & Johannessen, J.O. (1996). Early detection and intervention with schizophrenia: rationale. *Schizophrenia Bulletin*, 22, 201–222.
- McGorry, P.D., & Jackson, H. J. (1999). *The Recognition and Management of Early Psychosis: A Preventive Approach*. Cambridge, UK: Cambridge University Press.
- McGorry, P.D., Yung, A. R., Phillips, L. J., Yuen, H.P., Francey, S., Cosgrave, E.M., et al (2002). Randomized controlled trial of interventions designed to reduce the risk of progression to first-episode psychosis in a clinical sample with sub-threshold symptoms. *Archives of General Psychiatry*, 59, 921-928.
- McGrath, J. J. (2005). Myths and plain truths about schizophrenia epidemiology- the NAPE lecture 2004. *Acta Psychiatrica Scandinavica*, 111, 4-11.
- McGrath, J., Saha, S., Welham, J., El Saadi, O., MacCauley, C., Chant, D. (2004). A systematic review of the incidence of schizophrenia: the distribution of rates and the influence of sex, urbanicity, migrant status and methodology. *BMC Medicine*, 2(13). Retrieved February 8, 2008, from <http://www.biomedcentral.com/1471-244X/4/17>
- McKenzie, L.H. (2006). Service-users and carers' experiences of a psychosis service. *Journal of Psychiatric and Mental Health Nursing*, 13, 636-640.
- Melle, I., Larsen, T.K., Haahr, U., Friis, S., Johannessen, J.O., Opjordsmoen, S., Simonsen, E. et al. (2004). Reducing the duration of untreated

psychosis in first episode psychosis: effects on clinical presentation.

*Archives of General Psychiatry*, 61, 143–150.

Mental Capacity Act of 2005, c.9 (2005), Retrieved December 9, 2008, from

[http://www.opsi.gov.uk/acts/acts2005/ukpga\\_20050009\\_en\\_1](http://www.opsi.gov.uk/acts/acts2005/ukpga_20050009_en_1)

Medical Research Council. (2000). A framework for development and

evaluation of RCT's for complex interventions to improve health. MRC:

Retrieved July 10, 2008, from [www.mrc.ac.uk](http://www.mrc.ac.uk)

Murray, M. (2008). Narrative psychology. In J. A. Smith (Eds.), *Qualitative*

*Psychology: A Practical guide to research methods* (pp. 111-132).

London, UK: Sage Publications Ltd.

National Institute for Health and Clinical Excellence. (2002). *Schizophrenia:*

*Core interventions in the treatment and management of schizophrenia in*

*primary and secondary care*. NICE: London. Retrieved December 12,

2007, from [www.nice.org.uk](http://www.nice.org.uk)

National Institute for Health and Clinical Excellence. (2009). *Schizophrenia:*

*Core interventions in the treatment and management of schizophrenia in*

*primary and secondary care (Update)*. NICE: London. Retrieved August

14, 2009, from [www.nice.org.uk](http://www.nice.org.uk)

Newton, E., Larkin, M., Melhuish, R., & Wykes, T. (2007). More than just a

place to talk: Young people's experiences of a group psychological

therapy as an early intervention for auditory hallucinations. *Psychology*

*and Psychotherapy: Theory, Research and Practice*, 80, 127-149.

Nordentoft, M., Jeppesen, P., Petersen, L., Thorup, A., Øhlenschläger, J.,

Christensen, T.O.et al (2004). Duration of untreated psychosis: results

from the OPUS trial. *Schizophrenia Research*, 70(Suppl 1):31.

- Norman, R. M. G., Malla, A. K., Verdi, M. B., Hassall, L. D., & Fazekas, C. (2004). Understanding delay in treatment for first-episode psychosis. *Psychological Medicine*, 34, 255-266.
- O'Leary, V. E., & Ickovics, J. R. (1995). Resilience and thriving in response to challenge: An opportunity for a paradigm shift in women's health. *Women's Health: Research on Gender, Behaviour and Policy*, 1, 121-125.
- O'Toole, M.S., Ohlsen, R.I., Taylor, T.M., Purvis, R., Walters, J., & Pilowsky, L.S. (2004). Treating first episode psychosis- The service-users' perspective: a focus group evaluation. *Journal of Psychiatric and Mental Health Nursing*, 11, 319-326.
- Patton, M.Q. (1990). *Qualitative evaluation and research methods* (2nd ed.). California, CA: Sage Publications Ltd.
- Pelosi, A. & Birchwood, M. (2003). Is early intervention for psychosis a waste of valuable resources? *British Journal of Psychiatry*, 182, 196-198.
- Perry, B. M., Taylor, D., & Shaw, S. K. (2007). "You've got to have a positive state of mind": An interpretative phenomenological analysis of hope and first episode psychosis. *Journal of Mental Health*, 16(6), 781-793.
- Petersen, L., Jeppesen, P., Thorup, A., Abel, M.B., Øhlenschläger, J., Christensen, T.O, et al. (2005). A randomised multicentre trial of integrated versus standard treatment for patients with a first episode of psychotic illness. *British Medical Journal*, 331,602–5.
- Pilgrim, D. (2007). The survival of psychiatric diagnosis. *Social Science and Medicine*, 65, 536- 547.

- Pilgrim, D., & Bentall, R. P. (1998). The medicalisation of misery: A critical realist analysis of the concept of depression. *Journal of Mental Health*, 8(3), 261–274.
- Potter, J., & Wetherell, M. (1987). *Discourse and social psychology: Beyond attitudes and behaviour*. London, UK Sage Publications Ltd.
- Reading, B., & Birchwood, M. (2005). Early intervention in psychosis: Rationale and evidence for effectiveness. *Disease Management and Health Outcomes*, 13(1), 53-63.
- Reissman, C. K. (1993). *Narrative analysis*. London, UK: Sage Publications Ltd.
- Ridgway, P. (2001). Restorying psychiatric disability: Learning from first person recovery narratives. *Psychiatric Rehabilitation Journal*, 24(4), 335-343.
- Rolfe, G. (2006). Validity, trustworthiness and rigour: quality and the idea of qualitative research. *Methodological Issues in Nursing Research*, 53(3), 304-310.
- Rolfe, G., Freshwater, D., & Jasper, M. (2001). *Critical Reflection for Nursing and the Helping Professions: a User's Guide*, Basingstoke, UK: Palgrave.
- Romme, M., & Escher, S. (2000). *Making sense of voices*. London: MIND Publications.
- Sackett, D.L., Rosenburg, W.M.C., Muir Gray, J.A., Haynes, R.B. & Richardson, W.S. (1996). Evidence based medicine. What it is and what it isn't. *British Medical Journal*, 312, 71-72.

- Sainsbury Centre for Mental Health. (2003). *A window of opportunity: A practical guide for developing early intervention in psychosis services*. Briefing 23. Retrieved December 11, 2007, from [www.scmh.org.uk](http://www.scmh.org.uk)
- Sandelowski, M. (1993). Rigor or rigor mortis: the problem of rigor in qualitative research revisited. *Advances in Nursing Science*, 16(2), 1-8.
- Schulze, B., M. C. Angermeyer. (2003). Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals. *Social Science & Medicine*, 56, 299-312.
- Seidel, J., & Kelle, U. (1995). 'Different functions of coding in the analysis of textual data'. In U. Kelle (Ed.), *Computer-aided qualitative data analysis: theory, methods and practice* (pp.52-61). London, UK: Sage Publications Ltd.
- Sheitman, B. & Lieberman, J.A. (1998). The natural history and pathophysiology of treatment resistant schizophrenia. *Journal of Psychiatric Research*, 32,143-150.
- Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, 11, 261- 271.
- Smith, J.A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative research in psychology*, 1, 39-54. Retrieved December 10, 2007, from [www.qualresearchpsych.com](http://www.qualresearchpsych.com)
- Smith, J. A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray, K. Chamberlain (Eds),

- Qualitative health psychology: Theories and methods* (pp. 218- 240).  
London, UK: Sage Publications Ltd.
- Smith, J.A. & Osborn, M. (2003). Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative psychology: A practical guide to methods* (pp. 51-80). London, UK: Sage Publications Ltd.
- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J.A. Smith (Ed.), *Qualitative psychology: A practical guide to methods* (2<sup>nd</sup> ed) (pp. 51-80). London, UK: Sage Publications Ltd.
- Staniszewska, S., & Ahmed, L. (1999). The concepts of expectation and satisfaction: do they capture the way patients evaluate their care? *Journal of Advanced Nursing*, 29(2), 364-372.
- Stanley, K., Lewis, O., & Abraham, F. (1986). *Positive and negative syndrome scale (PANSS) rating manual*. New York, NY: MSCRU.
- Szaz, T. S. (1961). The use of naming and the origin of the myth of mental illness. *American Psychologist*, 16, 59-65.
- Taylor T., O'Toole M., Ohlsen R.I., Jones H.M., Purvis R.G., Szmukler G. et al. (2002). Quality of life, wellbeing, side effects and compliance with quetiapine in the treatment of first episode psychosis. *Schizophrenia Research* 53, 161.
- Theuma, M., Read, J., Moskowitz, A. & Stewart, A. (2007). Evaluation of a New Zealand early intervention service for psychosis. *New Zealand Journal of Psychology*, 36, 136-145.
- Thompson, K. N., McGorry, P. D., & Harrigan, S. M. (2003). Recovery style and outcome in first-episode psychosis. *Schizophrenia Research*, 62, 31-36.

- Uvcok, A., Polat, A., Cakir, S., & Genc, S. (2006). One year outcome in first episode schizophrenia: Predictors of relapse. *European Archives of Psychiatry and Clinical Neuroscience*, 256, 37-43.
- van Deventer, J. P. (2007). Ethical considerations during human centred overt and covert research. *Quality and Quantity*, 43, 45-57.
- Walters, A.J. (1995). The phenomenological movement: implications for nursing research. *Journal of Advanced Nursing*, 22, 791-799.
- Warner, R. (1994). *Recovery from schizophrenia: Psychiatry and political economy*. (2<sup>nd</sup> Ed). London, UK: Routledge and Kegan Paul.
- Warner, R. (2005). Problems with early and very early intervention in psychosis. *British Journal of psychiatry*, 187, s104-s107.
- Willig, C. (2001). *Introducing qualitative research in psychology: Adventures in theory and method*. Buckingham, Philadelphia: Open University Press.
- Willig, C. (2008). *Introducing qualitative research in psychology: Adventures in theory and method* (2<sup>nd</sup> ed.). Buckingham, Philadelphia: Open University Press.
- Wing, J., Beevor, A., Curtis, R., Park, S., Hadden, S., & Burns, A. (1998). Health of the Nation Outcome Scale (HoNOS): Research and development. *British Journal of Psychiatry*, 172, 11-18.
- Wolff, N. (2000). Using Randomized Controlled Trials to Evaluate Socially Complex Services: Problems, Challenges and Recommendations. *Journal of Mental Health Policy and Economics*, 3, 97-109.
- Woodward, C., & Joseph, S. (2003). Positive change processed and post-traumatic growth in people who have experienced childhood abuse:



- Understanding vehicles of change. *Psychology, Psychotherapy: Theory, Research and Practice*, 76, 267-283.
- World Health Organization. (2007). *International Statistical Classification of Diseases and Related Health Problems - 10th Revision - Third Edition* (Online Edition). Retrieved on May 25, 2008, from <http://www.who.int/classifications/apps/icd/icd10online>
- Wykes, T., Parr, A., & Landau, S. (1999). Group treatment of auditory hallucinations. Exploratory study of effectiveness. *British Journal of Psychiatry*, 175, 180–185.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15, 215-228.
- Yardley, L. (2008). Demonstrating validity in qualitative psychology. In J.A. Smith (Ed.), *Qualitative psychology: A practical guide to methods* (2<sup>nd</sup> ed) (pp. 235-252). London, UK: Sage Publications Ltd.
- Young, S. L., & Ensing, D. S. (1999). Exploring recovery from the perspectives of people with psychiatric disabilities. *Psychiatric Rehabilitation Journal*, 22(3), 219-231.

## Appendices

### Appendix A: Notes for Contributors

Psychology and Psychotherapy: Theory, Research and Practice: (formerly The British Journal of Medical Psychology) is an international scientific journal with a focus on the psychological aspects of mental health difficulties and well-being; and psychological problems and their psychological treatments. We welcome submissions from mental health professionals and researchers from all relevant professional backgrounds. The Journal welcomes submissions of original high quality empirical research and rigorous theoretical papers of any theoretical provenance provided they have a bearing upon vulnerability to, adjustment to, assessment of, and recovery (assisted or otherwise) from psychological disorders. Submission of systematic reviews and other research reports which support evidence-based practice are also welcomed, as are relevant high quality analogue studies. The Journal thus aims to promote theoretical and research developments in the understanding of cognitive and emotional factors in psychological disorders, interpersonal attitudes, behaviour and relationships, and psychological therapies (including both process and outcome research) where mental health is concerned. Clinical or case studies will not normally be considered except where they illustrate particularly unusual forms of psychopathology or innovative forms of therapy and meet scientific criteria through appropriate use of single case experimental designs.

#### 1. Circulation

The circulation of the Journal is worldwide. Papers are invited and encouraged from authors throughout the world.

#### 2. Length

Papers should normally be no more than 5000 words, although the Editor retains discretion to publish papers beyond this length in cases where the clear and concise expression of the scientific content requires greater length.

#### 3. Submission and reviewing


All manuscripts must be submitted via our [online peer review system](#). The Journal operates a policy of anonymous peer review.

#### 4. Manuscript requirements

- Contributions must be typed in double spacing with wide margins. All sheets must be numbered.
- Tables should be typed in double spacing, each on a separate page with a self-explanatory title. Tables should be comprehensible without reference to the text. They should be placed at the end of the manuscript with their approximate locations indicated in the text.
- Figures can be included at the end of the document or attached as separate files, carefully labelled in initial capital/lower case lettering with symbols in a form consistent with text use. Unnecessary background patterns, lines and shading should be avoided. Captions should be listed

on a separate sheet. The resolution of digital images must be at least 300 dpi.

- For articles containing original scientific research, a structured abstract of up to 250 words should be included with the headings: Objectives, Design, Methods, results, Conclusions. Review articles should use these headings: Purpose, Methods, Results, Conclusions. For further details please see the document below:

 [Psychology and Psychotherapy: Theory, Research and Practice - Structured Abstract Information](#)

- For reference citations, please use APA style. Particular care should be taken to ensure that references are accurate and complete. Give all journal titles in full.
- SI units must be used for all measurements, rounded off to practical values if appropriate, with the imperial equivalent in parentheses.
- In normal circumstances, effect size should be incorporated.
- Authors are requested to avoid the use of sexist language.
- Authors are responsible for acquiring written permission to publish lengthy quotations, illustrations, etc. for which they do not own copyright.

For guidelines on editorial style, please consult the [APA Publication Manual](#) published by the American Psychological Association.

## **5. Brief reports**

These should be limited to 1000 words and may include research studies and theoretical, critical or review comments whose essential contribution can be made briefly. A summary of not more than 50 words should be provided.

## **6. Publication ethics**

All submissions should follow the ethical submission guidelines outlined in the documents below:

 [Ethical Publishing Principles – A Guideline for Authors](#)

 [Code of Ethics and Conduct \(2006\)](#)

## **7. Supplementary data**

Supplementary data too extensive for publication may be deposited with the [British Library Document Supply Centre](#). Such material includes numerical data, computer programs, fuller details of case studies and experimental techniques. The material should be submitted to the Editor together with the article, for simultaneous refereeing.

## **8. Copyright**

On acceptance of a paper submitted to a journal, authors will be requested to sign an appropriate assignment of copyright form. To find out more, please see our [Copyright Information for Authors](#).

## Structured abstracts

Psychology and Psychotherapy: Theory, Research and Practice

Authors should note that all papers submitted to the Psychology and Psychotherapy: Theory, Research and Practice must include structured abstracts. Papers will not be considered for publication unless they have a structured abstract in the correct format.

Articles containing original scientific research should include a structured abstract with the following headings and information:

**Objectives** State the primary objectives of the paper and the major hypothesis tested (if appropriate).

**Design** Describe the design of the study and describe the principal reasoning for the procedures adopted.

**Methods** State the procedures used, including the selection and numbers of participants, the interventions or experimental manipulations, and the primary outcome measures.

**Results** State the main results of the study. Numerical data may be included but should be kept to a minimum.

**Conclusions** State the conclusions that can be drawn from the data provided and their clinical implications (if appropriate).

## Appendix B: Participant Information Sheet



### PARTICIPANT INFORMATION SHEET

#### Study Title

Service-users' Experiences of an Early Intervention in Psychosis Service.

#### Introduction

I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully. You may also wish to talk to others about the study.

Part 1 tells you about the purpose of this study and what will happen to you if you decide to take part.

Part 2 gives you more detailed information about how the study will be conducted.

If there is anything that is not clear, or if you would like more information, please ask. Please take time to decide whether or not you wish to take part.

#### PART 1

##### Purpose of the study

Early Intervention in Psychosis (EIP) services are fairly new in this country. Therefore, it is good to know how people who are linked into the service feel and try and understand their experiences. This research is looking to discover more about your perceptions of how you came into contact with the service and the experience of the service you have received.

The information gathered would help EIP services to identify positive and negative aspects of the early intervention approach. The information could be used to inform other EIP services and impact on the way in which future services are designed. Finally, the information gathered will also contribute to a national debate about the value of the EIP approach. To date no published research has been found which uses interviews to gain information about service-users' experiences of an EIP approach and its impact on their experience of psychosis. In addition, this study is being undertaken as thesis for part of a Doctorate in Clinical Psychology.

### **Why have I been invited?**

You have been chosen to participate in this research as you have been receiving a service from (NHS Trust name) Trust Early Intervention in Psychosis (EIP) service, for more than 2 years. Therefore, you are considered to be able to provide valuable information about your experiences of the service you have been receiving.

You were identified by an EIP team member from the EIP service database which stores details of all service-users. In total there will be 8 people who will take part in this study. All participants will be identified and approached in the same way.

### **Do I have to take part?**

It is up to you to decide whether or not take part in this study. The study will be described in detail in this information sheet which your Care co-ordinator will go through with you. You will then be given a copy of the information sheet. If you decide to take part you will sign a consent form, to show you have agreed to take part.

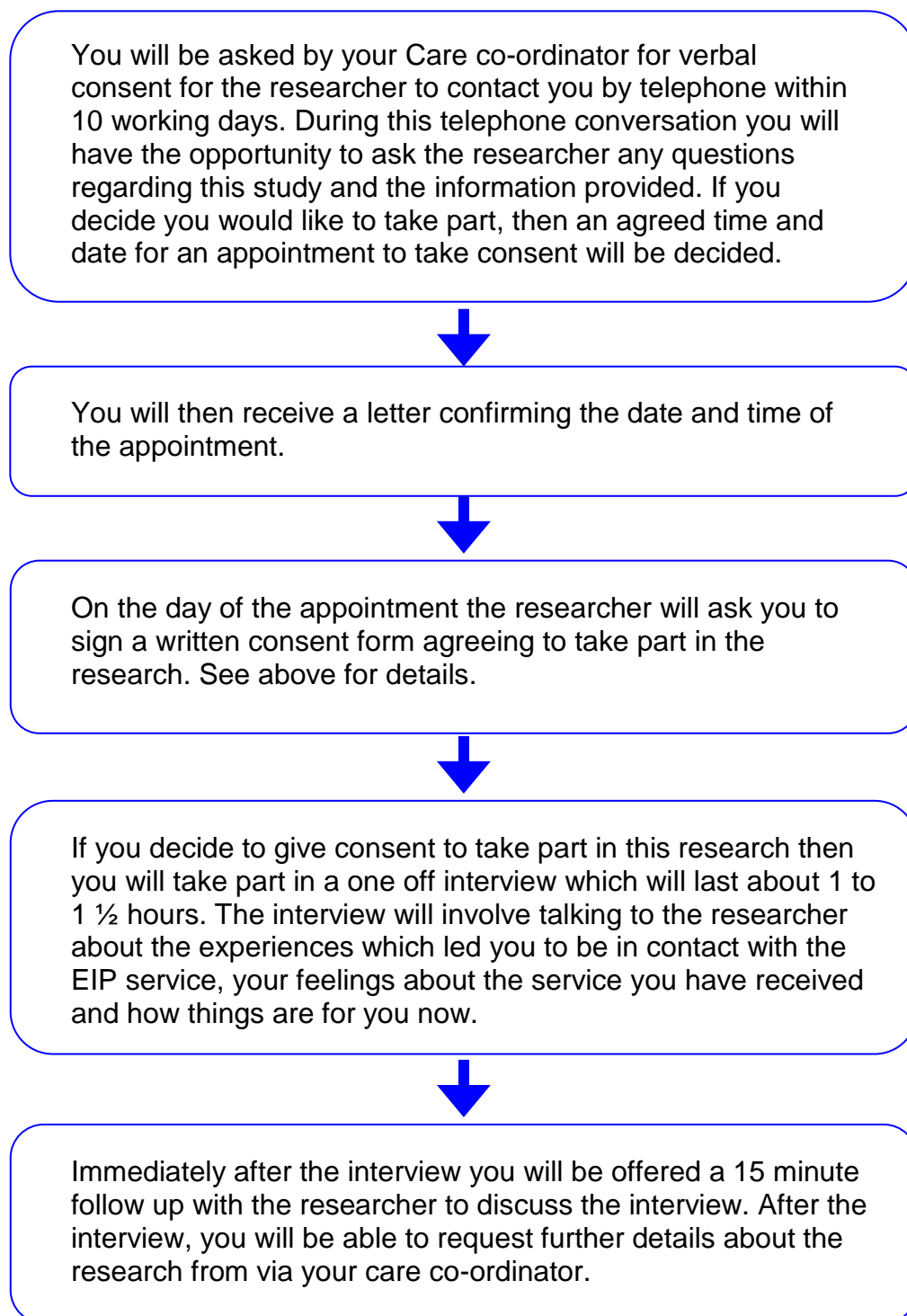
You are free to withdraw from the research at anytime without giving a reason. It is important to understand that this research is independent of the EIP service. Therefore, any information gathered during the interview, or choosing not to take part will have no impact on the service you receive.

### **What will happen to me if I take part?**

If you decide after reading this information sheet you are interested in taking part in this research, the following steps shown in Summary Flow Cart 1 would be taken.

When providing written consent before taking part, you will be asked to consent for the following things to happen:

- To take part in a one off interview with the researcher.
- Agree to the interview being tape recorded and transcribed (typed up word for word) and for all identifiable information to be disguised and anonymised, so that the interview remains confidential.
- For the researcher to use anonymised direct quotations in the write up of the research.
- For the researcher to gather specific background information about your time in the service from your care coordinator.



[Summary Flow Chart 1](#)

## **Expenses**

The interviews will be carried out at a time and place which is convenient to you. Therefore, if it is necessary for you to travel to and from the interview, all reasonable travel expenses will be reimbursed.

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

As a participant you will be required to attend a one off interview lasting about 1 to 1 ½ hours, which would be held at an agreed time and place. During the interview you will be asked open questions about your feelings towards being linked into an EIP service and the service you have received.

### **What are the possible disadvantages and risks of taking part?**

There are no known risks of taking part in this study. Interviews will cover issues you will be familiar with discussing, throughout your time in the EIP service. However, as the interview involves talking about your experiences of being linked to services, it is possible that you could find some aspects of the interview upsetting.

Immediately after the interview you will have an optional 15 minutes with the researcher to discuss the interview and its content. Following the interview you will be able to request a follow up appointment with the EIP service Clinical Psychologist to discuss any issues arising from the interview. In addition, if you have any other concerns about the interview then telephone contact can be made with Care co-ordinators who will offer you ongoing support.

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

Taking part in this study offers you the opportunity to express your feelings about the EIP service you have received and how it has impacted on you. In addition, the information you provide could be used to inform other EIP services and alter the way in which services are designed in the future.

### **What happens when the research study stops?**

When you have finished participating in the interview, you will continue to receive a service from the EIP team. You will be able to request further details regarding the research via your Care co-ordinator. Details on how you will receive information about the results of the study are outlined in the question 'What will happen to the results of the research study?'

*If the information in Part 1 has interested you and you are considering participating in this research, please read the additional information in Part 2 before making any decision.*

## **PART 2**

### **What will happen if I don't want to carry on with the study?**



You are free to withdraw from the research at anytime without giving a reason. It is important to understand that this research is independent of the EIP service. Therefore any information gathered during the interview, or choosing not to take part will have no impact on the service you receive.

If you decide you no longer want to take part in this study, then no information gathered about you would be used in the write up of the research. However, information will be stored in line with University regulations. See 'Will my taking part in this study be kept confidential?' for more details.

### **What if there is a problem? / How to make a complaint**

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do their best to answer you questions See 'Further information and contact details' for more information. If you remain unhappy and wish to complain formally, you can do this through the NHS complaints procedure. Details can be obtained through your EIP team. Although the likelihood of harm is very low this research is sponsored and insured by (NHS Trust name) indemnity scheme which may arrange compensation.

### **Will my taking part in this study be kept confidential?**

When taking part in the interview, you will give written consent for the interview to be tape recorded. Following the interview all tape recordings will be transcribed (typed up word for word) and transcripts will not contain any identifying information (including details about you and other persons mentioned during the interview, i.e. staff or family member's names). Direct quotes may be used in the write up of this study, however, they will be anonymised and you will not be identifiable.

Each transcript and tape will be allocated a participant number. A list of names and corresponding participant numbers will be kept separately from the tapes and transcripts, to maintain strict confidentiality. Following the end of the research, tape recordings, transcriptions and other data will be stored in a locked cabinet in a University of Nottingham building, which is locked and alarmed at night. They will be labelled confidential and dated and will be stored for 7 years and then destroyed, in line with University Research Code of Conduct.

During the interview, all information will be kept confidential. Confidentiality would only need to be broken if the researcher considered anything you have said to be a sign that you are at risk to yourself or someone else or if there are any child protection issues. However, the researcher would always try and discuss this with you before talking to anyone else.

### **Involvement of the General Practitioner (GP)**

It is not necessary for your GP to be notified of your involvement in this study.

## **What will happen to the results of the research study?**

The transcripts for your interview will be analysed by the researcher. In addition, the anonymised transcripts (names and details removed) will be looked at by other researchers, who are also employed by (NHS Trust Name) or the University of Nottingham. This is to ensure the research is of a high quality.

The results of the study are intended to be written up as part of a Doctorate in Clinical Psychology thesis and published in a scientific or academic Journal. Although anonymised quotations might be used in the write up of the report, you will not be identified in the publication. A copy of this thesis will be available in the University of Nottingham Library. Following the write up of the research, all participants will receive a summary of the research report and main findings. A small summary of the research will also appear in the EIP service newsletter.

## **Who is organising and funding the research?**

This research is forming part of a Doctorate in Clinical Psychology qualification and is sponsored by (NHS Trust Name).

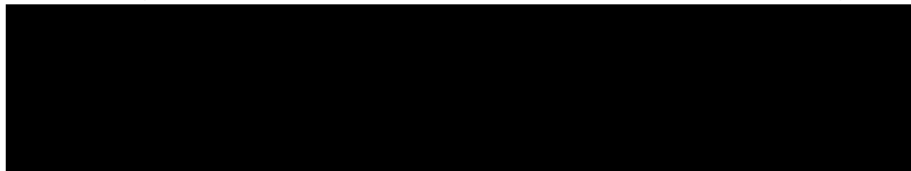
## **Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Leicestershire, Northamptonshire and Rutland Research Ethics Committee.

## **Further information and contact details**

### **1. Specific information about this research project**

If you like more information about this research project, or have any concerns please feel free to contact the main researcher Kate Harris, Trainee Clinical Psychologist, or Dr Roshan das Nair, Consultant Psychologist at:



### **2. Advice as to whether you should participate**

You might want to talk to other people about whether you should participate in this research, such as family or friends. You may also want to talk to your care coordinator or another member of the EIP team.

### **3. Who they should approach if you are unhappy with the research See the question on “If there is a problem/ how to make a complaint.”**

## Appendix C: Consent Form



Patient Identification Number for this interview: \_\_\_\_\_

### **CONSENT FORM**

**Title of Project:** Service-users' Experiences of an Early Intervention in Psychosis Service.

**Name of Researcher:** Katy Harris

Please tick box

- |  |                          |
|--|--------------------------|
| 1. I confirm that I have read and understood the information sheet dated 01.09.08 (Version 1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. | <input type="checkbox"/> |
| 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without the service I receive from the EIP team being affected.  | <input type="checkbox"/> |
| 3. I agree to my interview being tape recorded and then transcribed with all identifiable information being disguised and anonymised.  | <input type="checkbox"/> |
| 4. I agree to the use of anonymised direct quotations being used in the write up of this research.   | <input type="checkbox"/> |
| 5. I have read the demographic and service information sheet and I agree for the researcher to gather this information about myself, from my Care Coordinator.   | <input type="checkbox"/> |
| 6. I agree to take part in this study.   | <input type="checkbox"/> |

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

When completed, 1 copy for participant, 1 for researcher's file.

## Appendix D: Full NHS Research Ethical Approval



### **National Research Ethics Service**

**Leicestershire, Northamptonshire & Rutland Research Ethics Committee 1**

1 Standard Court  
Park Row  
Nottingham  
NG1 6GN

Telephone: 0115 8839428  
Facsimile: 0115 9123300

18 November 2008

Miss Katy Harris  
Trainee Clinical Psychologist



Dear Miss Harris

**Full title of study:** Service Users' Experiences of an Early Intervention in Psychosis Service.  
**REC reference number:** 08/H0406/194

The Research Ethics Committee reviewed the above application at the meeting held on 07 November 2008. Thank you for attending to discuss the study.

#### **Ethical opinion**

In discussion, the Committee noted the following ethical issues.

- The Committee asked what the role of the care co-ordinator will be in selecting patients. You explained that your supervisor, who is a clinical psychologist, will give you a list of patients who have been in the service for at least two years, which will only be identified by initials. You will then ask the care co-ordinator to approach suitable patients and ask them for permission to make contact. The care co-ordinator will also be able to advise if any patients are known to be unsuitable for a home visit. The supervisor has access to the database as part of her clinical role and is allowed to access the patient data.
- The Committee asked what the normal length of time a patient is involved in the service is. You explained that it is a standard three year programme. If ongoing care is needed after that the patient would be referred to another service.
- The Committee recommended that consent forms should be stored separately from the demographic questionnaires as the consent forms are identifiable, possibly by the supervisor.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

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

The Committee agreed that all sites in this study should be exempt from site-specific assessment (SSA). There is no need to submit the Site-Specific Information Form to any

This Research Ethics Committee is an advisory committee to East Midlands Strategic Health Authority.  
The National Research Ethics Service (NRES) represents the NRES Directorate within the  
National Patient Safety Agency and Research Ethics Committees in England.

Research Ethics Committee. The favourable opinion for the study applies to all sites involved in the research.

#### Conditions of the favourable opinion

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

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

Management permission at NHS sites ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Peer Review		10 October 2008
Protocol	1	01 September 2008
Investigator CV		01 September 2008
Application	AB/133046/1	19 September 2008
Participant Consent Form	1	01 September 2008
Participant Information Sheet		01 September 2008
Questionnaire: Demographic & Service Information Sheet	1	01 September 2008
Interview Schedules/Topic Guides	1	01 September 2008
Investigator CV		
Investigator CV		

#### Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

#### After ethical review

Now that you have completed the application process please visit the National Research Ethics Website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

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

- Notifying substantial amendments
- Progress and safety reports
- Notifying the end of the study

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

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

08/H0406/194

Please quote this number on all correspondence

With the Committee's best wishes for the success of this project

Yours sincerely



**Chair / Committee Coordinator**

Email:



Enclosures:

*List of names and professions of members who were present at the meeting and those who submitted written comments  
"After ethical review – guidance for researchers" SL-AR2 for other studies*

Copy to:





Please keep this letter with you during the course of your research to confirm that you have Director's approval to conduct research in the areas where your research is taking place. If you have any concerns they can contact the RMG department on 0115 951 5000 or via email at [rmg@nhs.uk](mailto:rmg@nhs.uk).



NHS Trust

Yours sincerely

Trust research study ref: AMH/03/12/08  
(please quote in all correspondence)

3<sup>rd</sup> December 2008

Miss Katy Harris  
Trainee Clinical Psychologist

Dear Miss Harris

I am writing to confirm that the following study is authorised to take place within our Trust:

**Title:** Service Users' Experiences of an Early Intervention in Psychosis Service

**Directorate(s):** AMH City  
AMH County

**Start Date:** 1<sup>st</sup> October '08 **End Date:** 1<sup>st</sup> December '10

**Outline:** To explore service users experiences of early intervention in psychosis approach. To interview 8-10 participants who have been receiving the service for more than 2 years.

We wish you well with your work. In accordance with the Research Governance framework, The Trust RMG Department follows up such work to assess its impact and influence on practice and policy. You will receive a brief progress report form to complete six months after the start of your study which will provide you with the opportunity to let us know of any problems you may be having. We will also ask you for some information at the end of your study.

RMG Approval Letter/v2/20.11.2007

Please keep this letter with you during the course of your research to confirm that you have Directorate and RMG Dept. approval, to gain access to the areas where your research is taking place. If you or others have concerns they can contact the RMG department on [REDACTED] or mobile [REDACTED] or by email to [REDACTED]

Yours sincerely

[REDACTED]

[REDACTED]

[REDACTED] Trust RMG Department

1<sup>st</sup> December 2006

Ms Katy Harris  
Trainee Clinical Psychologist  
Nottinghamshire Healthcare NHS Trust  
I-WHO, University of Nottingham  
International House, 2 Floor  
Jubilee Campus, Wollaton Road  
Nottingham  
NG8 1BB

Dear Miss Harris

I am writing to confirm that the following work is authorised by  
[REDACTED] our Trust:

[REDACTED] User's Experience [REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]



## **Appendix E: Semi- Structured Interview Schedule**

1. Tell me about the experiences that led you to be involved with the Early Intervention service.

- *What sense did you make of what was happening?*

2. Tell me about what your first contact / first few contacts with the Early Intervention team was like?

- *What was it like meeting with the team for the first time?*

3. Tell me about how things are for you now?

- *Where do you feel you are now?*

- *How do you feel about the future?*

4. What do you think has influenced where you are now?

- *What has contributed towards the ways things are for you now?*

5. Tell me about what it has been like to be in contact with this service?

-*How has it felt receiving mental health service from this team?*

-*What has it meant to you to be in contact with the service?*

Follow-up question- Is there anything else you would like to say about your experiences or anything that I have not asked that you would like to talk about?

### Prompts

Can you tell me more about that?

What sense did you make of that?

What was that like?

What did/ does that mean for you?

What meaning did that have for you?

How did you experience that?

How did you feel about that?

## Appendix F: Extracts from Reflective Research Diary

### Extract 1

*I wanted to reflect on some of my own assumptions and feelings prior to starting my interviews. I have previously worked in an EIP service, during my first year training placement. I really enjoyed my placement, for many reasons. I had a fantastic supervisor, the team was great to work with and I really enjoyed the client group. I felt quite positive about the EIP model of working, but I recognise that this is only my personal view, which may very well differ to the views of the service-users. I guess that is what made me pursue this research in the first place. I am also very interested in service-users views and I guess I'm an advocate of service-user inclusion, such as in recruitment etc.... During my time in the service I also had experience of service-users not engaging with the service and it made me realise the service can't be for everyone. So what is it that people don't want? Are there negative aspects to EIP services that I wasn't able to fully understand during my time?*

*Right so thinking about my assumptions! I assume that participants will have their own meanings for their experiences and I would imagine those will vary from person to person. I guess I also assume people will want to talk about these experiences and I guess those who participate will want to talk, but what about those who don't take part. I guess there could also be people who don't want to think or talk about their experiences.*

*What about my feelings about psychosis? After working with this client group, I feel that they are a very misunderstood group, who are often portrayed negatively in the media and by the general public. My view of psychosis is a non- medicalised view, that psychosis must have some relevance to life situations, past and present and not simply some chemical imbalance. So many of my client hallucinations had real connections to their lives, once you took the time to think about it. I don't believe the experiences are random or insignificant, quite the opposite.*

*I also think that psychosis does not have to be life long. I guess recovery from psychosis is what ever you define it as. For me recovery could mean learning to live with symptoms, in a way that they are not distressing to the person. Some clients in the EIP service actually wanted to experience their voices, as they often found comfort in them.*

### Extract 2

**Reflection following interview with participant 1:** *I have just finished my first interview and wanted to reflect on how it went. I think that overall he seemed comfortable and seemed able to really take on board my questions and then interpret them in his own way. He spoke about lots of things I wasn't expecting, which was really interesting.*

*Overall, I felt that he attributed a lot of his personal progress and positive experiences to the actions of the EIP service and had a lot of praise for the service as a whole. This did make me wonder whether this had anything to do with me recruiting participants via the service and Care co-ordinators and whether this had any priming effect on him generating positive views and experiences. However, he did spend time discussing negative experiences of the service and some of his criticisms and this was without prompting from myself.*

*I think that when he did start to discuss negative experiences of being in contact with the EIP service and the impact on him emotionally, I tried to explore this further within the interview, as the descriptions he gave were very interesting and complex and warranted further exploration.*

*At one point in the interview he was talking about his experience of psychology involvement, which he had experienced very positively. However, he then started asking me about my job as a psychologist, which I guess made me worry he might affect his views. I think that in the transcript it will be quite evident that I tried to deflect the conversation away from myself and my role as a psychologist, back towards his views of his own experiences.*

## Appendix G: Extracts from Audit-Trail

### Extract from analysed transcript for participant 8

Initial notes	Line	Transcript extract	Emerging themes
Not normal Shame of EIP  Shame of psychosis Different from depression	252 253 254 255 256 257 258 259 260 261 262 263	P (Participant)- The experiences were very abnormal, but I'm still really ashamed of erm... of sort of being in EI, EIP, err... because its, the name is really sort of... its early intervention in psychosis, so to me it means... they were intervening early in my psychosis and I had psychosis, so I didn't like that. I mean depression's fine with me, but having psychosis isn't. K (Interviewer): Right so there's something about that label, that's different? P- Yeah, yeah. K- Can you tell me a little bit more about that and sort of the name it has and why you're ashamed?	Shame- EIP service name  Shame- psychosis/label  Comparison to other diagnoses
View of psychosis Shame of psychosis	264 265 266 267 268	P- Erm it just means, to me it means that it's something whacky and totally erm... serious and... well... I'm just ashamed of it really, really ashamed to have... like psychotic depression as sort of a label and also I've been reading up stuff on the internet as well and they say things like "oh it could lead to this and that, yer know if you've experienced psychosis, then you've got like three years where its like a critical time period for developing stuff like schizophrenia or things like that.	Shame of psychosis label  Own judgements and fears of psychosis label
Fears of what it might lead to	269 270 271 272		

Trying to be free of services	273 274 275 276	And its linked with all that, that kind of erm... and the fact that I have to take medication, cus, I, I was trying to wean off the antidepressants (K-ummm) and I thought that that would be it with services and then this came along and yer know (5 second pause and shrugs shoulders).	Psychosis- in the way of plans to be free
Psychosis in the way of plans	277 278 279 280 281 282 283	K- Ummm, you said that you didn't want to take, you were quite adamant you didn't want to take the medication and then you felt a little bit like it was being forced on you and (P-I did) what made you eventually decide to take it?	
Care co-ordinator talking about consequences/ influencing	284 285 286 287 288 289	P- Erm, it was something I think Emily said and erm, she said that " you've got this course at Uni and yer know, you've got your boyfriend at the time erm... yer know to live for I suppose, erm, yer know and you've got nothing to lose by trying it, trialling the erm medication (K-right) for a period"... and I guess I, I, wasn't that far gone I guess and I, I, I did think for a long long time I was resistant for quite a long time, until yer know, I just kind of broke down, I thought that was, either I just jump off a bridge and just end it all, or I try this one last avenue (K-right) repugnant as it was.	Taking medication- worn down
Initial resistance worn down	290 291 292	K- Is that because you felt like it wasn't getting any better?	Limited choices
Limited choices- suicide or medication- medication better of the two	293 294 295 296 297 298	P- yeah, it wasn't getting any better, had, yer know, no one else to turn to, but services and... I thought well " do the smart thing (refers to self) yer know, try it, at least try it before yer know... jumping off a bridge or something." So...	
No improvement No one to turn to- except services	299 300 301 302 303	K- It sounds a bit like you felt that were the only two options, take the meds or jump off a bridge?	Services were only other option

	304	P- Yeah, yeah.	
	305	K- Is that how it felt, they were the only options?	
	306	P- It did, it did. I mean I've heard now, there's stuff like	
	307	talking therapies now, that maybe could have helped, I	
Choices prescribed	308	don't' know, I don't know but, that's the route I was	Lack of choices offered
to her- no other	309	given, the choice I was given, so I had to take on of	by EIP
options offered	310	them.	
	311	K- And you were saying at the beginning you wish	
	312	you'd been given other choices?	
Own research-	313	P- Yeah, definitely, definitely, cus I know from sort of	
other options	314	researching on the internet, yer know, you know that	
available	315	there are other options out there for dealing with, yer	Other options available
Would have	316	know, symptoms like that (K-ummm) so... yeah, would	
preferred other	317	have appreciated it if they'd offered something else	
options	318	other than medication, instead of just coming round	
	319	and persuading you very strongly... yer know, "we	Forced choice
EIP persuading her	320	really recommend, you, really, really, really do".	
to take medication	321	K- Yeah, what was that like with somebody being so	
	322	sort of, like you said really strongly pushing that on	
Fear of	323	you?	
consequences of	324	P- Scary because, I'd been on section before and I	
not taking	325	didn't want to go down that route again, so yer know	
medication	326	that was shameful in its self, being on section (K-being	Shame of previous
	327	on section) and being in hospital. I, I didn't want to go	experiences- fear of
Shame of being	328	down that route and I was just scared, very scared.	repetition
sectioned.	329	K- Yeah, were you scared, do you mean if you didn't	
Previous	330	do it?	
experiences	331	P- Yeah, progress to possibly being sectioned again or	
Fear	332	going (k-right) into hospital again, and it's awful (k-	Limited choices- harsh
	333	ummm) yer know, I could sort of imagine that would	consequences
Other outcome to	334	have happened if yer know I hadn't taken the meds.	

not taking medication	335 336 337	K- You said you'd been on section before, was that when you were depressed?	
Previous suicide attempts	338 339 340	P- Yeah when I was depressed and took an overdose... erm and then just wanted to leave hospital when I woke up because it hadn't worked and wanted to go back and try again and... obviously was sectioned for it.	Previous experiences resulting in fear
Fear	341 342 343	K- And that experience made you fearful?	
	344 345	P- Yeah, very fearful.	
Ongoing shame of service	346 347 348	K- How do you, you know you were saying you, you, felt ashamed about taking the meds and about being in this service, is that something you still feel now?	
Also they have helped	349 350	P- Yeah defiantly, I still feel very ashamed, erm, but at the same time, I feel that, people should sort of, not advertise it, but for want of a better word, advertise that these services do exist and... I'm not saying that I'm a convert, but I do think that they've helped me a lot (k-ummm) and I can look back now at the, at the time then I didn't think, I was just so ashamed and thought that nothing could help me but I'd just give it a go (k-ummm) but I've given it a go, it's helped, I'm still ashamed... but I know they've helped, so... I kind of like want people to know that this service exists (K-yeah) and sort of kind of wanted to support it really in any kind of way possible, cus its helped so much.	Ambivalence- Shame vs wanting people know/EIP helped
Wants people to know about services	351 352 353 354	K- You say sort of advertise it sort of like, do you mean the general public or?	Helping role of EIP
Hopelessness	355 356	P- No, to, to, to erm... healthcare people, so that they know that this service exists and yer know that can refer other needy people (K-ummmm) to the service, because it's... it's been good.	Wanting people to know about EIP
EIP helped	357		
Wants people to know about it	358 359 360 361		
Wants healthcare professionals to know- refer people	362 363 364 365		Increasing knowledge

People don't know about it- results in feelings of shame	366 367 368 369 370 371 372	K- Yeah, so you just wish it was more widely known about? P- Yeah because if it's not widely known about, it is a bit shameful, cus people go "so who's that person who comes around your house very two weeks" and you're like well she's with early intervention in psychosis, erm... "and what's that?" they don't know... yer know.	Shame and judgements of other people
Close others' and the general public- don't know about services	373 374 375 376 377 378 379	K- When you say they, who, who, what kind of people say that? P- Like friends and yer know and family and the public I suppose. K- Right, so people you see on a daily basis will ask why, why are those women coming round? P- Yeah.	Lack of understanding
Unknown Specialised not mainstream	380 381 382 383 384	K- Is that, wha, does that add to what makes it shameful for you, what makes you ashamed? P- Erm... a little, a little, the fact that its not known and it's this little... little... specialised service... and your sort of in this group and you're not in sort of the main stream I guess. It's the way I feel of it, it might very well be main stream but I, I feel as though its not, I feel as though its some kind of little special group that needs to be taken aside cus they need that extra remedial lesson type thing, like in school when you have to be taken out of class to go to remedial lesions.	EIP different- adds to feelings of shame and separation
Different to other mental health services	385 386 387	K- Yeah, so it feels really like you said, a little group in its self away form everything else around it.	
Different to other people with mental health problems	388 389 390	P- Yeah, it's the way I feel.	
Need more help 'special'	391 392	K- You said that's a little bit that adds to what you're ashamed about, what else do you think adds to what makes you feel ashamed?	
Comparison to school	393 394		
Shame	395 396		



Specialised= shame	397 398 399 400	P- I'm not sure really, I'm just ashamed to be part of... part of this special service really and I don't... yeah. K- So its' being ashamed of being part of the EIP service and people asking you about it and not knowing about it.	Shame of EIP
Different to community mental health teams CMHT- more known about and accepted- different to EIP	401 402 403 404 405 406 407 408 409 410	P- Yeah, yeah, where as if, you said that oh I just have a CPN that comes round cus she's part of a community team, cus everyone knows of community teams (k- right), but not a lot of people, yer know, know about EIP. K- So you think it would be more accepted then if you were part of a more general mental health team? P- Yeah, yeah (5 second pause).	EIP different and less known/ accepted
Positive view of current life situation	411 412 423 414 415 416 417 418	K- OK. The other thing I was interested in and it's sort of bringing you forward quite a lot and I was really interested in how things are for you now, how things are going for you at the moment? P- Erm... they're going really well, really, really well, yer know, I mean like, I mean I'm looking you in the eye and that's, think that's, yer know, wasn't possible before, erm... and I actually feel really appreciative, so it's a bit of err... contradiction really of feelings. I'm a bit in turmoil because obviously I'm ashamed, but I do appreciate what they've done and they've done a lot so. Cus I'm getting, i'm getting towards the end of being with EIP, I've been with them a long time now... erm, so... its been good, I'm looking forward to sort of... in a good way, sort of ending and closure of this sort of chapter in my life.	Change in symptoms and self
Change in self Contradiction- shame and appreciation Recognition of EIP impact	419 420 421 422 423 424 425	K- So you're feeling quite good about the end of the	Ambivalence about EIP ashamed vs appreciative
Ending with EIP- closure-positive	426 427		Positive view of ending

view of ending	428	time?	
	429	P- I am, I am yeah.	
	430	K- Can you tell me a little bit about anything else that's	
	431	about how things are for you now, what's going on for	
	432	you now?	
	433	P- Erm... well, I'm gona start a new job on Monday	
Starting a job-	434	err... yeah I got married whilst being in services, in	Changes in life
marriage	435	EIP, so, worked through that, I was nervous and sort of	
Role of EIP in	436	wreaked before that (laughs), so... I, I've been through	EIP support
aspects of life	437	a lot with sort of EIP propping me up really, so that's	
	438	good.	
	439	K- Can you tell me a little about your job, cus I don't	
	440	know what you're actually going to do?	
	441	P- I'm, I'm gona be a (names job role and hospital).	
	442	K- Right, what is that, is that a ward?	
	443	P- Its err... rehabilitation, inpatient rehabilitation unit,	
Anxieties about	444	so, yeah, I'm so, err, nervous about starting it, so I	
new job	445	guess its good that I've still got Emily I suppose, cus, I	Ambivalence about EIP
Please to have	446	guess I've become dependant which is something	involvement ending
EIP- care co-	447	which is also a bit... erm, operand to me, erm... sort of	
ordinator- support	448	her coming every two weeks and being able to sound	
Feeling of	449	off stuff and sort of talk about it, but... I am a bit excited	
dependence/	450	about starting work and a bit nervous as well.	
excitment	451	K- Are you already trained as a nurse then?	
Ambivalence-	452	P- Yeah I qualified in march, erm, so I've got my	
	453	graduation coming up in July erm... that will be really	
	454	good, cap and gown (laughs).	
	455	K- The full works.	
	456	P- Yeah, photographs.	
	457	K- That will be great.	
	458	P- Yeah.	

Identifying with other people with mental health problems	459	K- When you say rehabilitation, what are people in rehabilitation for?	Identifying with others shared experience
	460		
	461	P- Its inpatient mental health unit.	
	462	K- Right, Ok.	
	463	P- So	
	464	K- How are you feeling about working sort of with people who are being rehabilitated from mental health problems?	
	465		
	466	P- Quite good, because... it sounds a bit strange but I do see myself having, well being one of those people, if I hadn't sort of recovered I guess... so it feels good to be able to help them as well, cus I feel part of them erm.. sort of a... yer know... I'm like you type thing and I can help you now. So it feels quite good, in a good way.	
	467		
	468		
Positive comparison to others	469		Positive comparisons
Wanting and feeling able to help others	470	K- So like, you understand things?	Wanting to help others
	471	P- yeah, I can understand what they're going through yer know, I, I've got the T-shirt to prove that I'm, I've been there and done that.	
In apposition to help- shared experience	472	K- Ummm	Support of others
	473	P- Yeah, so its, its, I'm looking forward to it, yeah.	
	474	K- You said then that you obviously feel that you could be them if you hadn't recovered, is that how you view then, that you've recovered?	
	475	P- Yeah, if I hadn't, if I hadn't got my loving husband, if I hadn't got Emily erm... if I hadn't got Dr Smith, I guess, id be one of those... poor people in a... possibly be one of those people in a rehabilitation unit or homeless, yer know, I could see that happening yer know.	
	476	K- Right, yeah. You say, cus obviously you use the	
Role of others- family, EIP	477		What could have been
Comparions to what could have been without support	478		
	479		
	480		
	481		
	482		
	483		
	484		
	485		
	486		
	487		
	488		
	489		

View of recovery	490	word recovered, I'm, I'm just interested what that word means for you, what does recovered mean for you?	
	491		
	492	P- To me it means that erm... I'm learning to live with my symptoms and with having to take medication, erm and being able to deal with it, cus I was so, I was very rebellious in my early days against medication and the whole system really (K-right) erm it was, escaping from wards and things like that erm... and going to the GP and going "right that's it I'm not taking anymore of these tables" and chucking them at him, things like that and I think I've become wise and that's, to me what recovery, what recovery means.	View of recovery
Living with symptoms- medication	493		
	494		
Coping	495		
Comparison to previous self	496		Acceptance of symptoms
	497		
	498		
Change in self	499		
	500		
	501		
Acceptance of symptoms/self	502	K- yeah.	
	503	P- Sort of living with my symptoms and dealing with it, accepting it.	
	504		
	505	K- Do you still get sort of things, do you still get similar experiences to what you had then?	
Symptoms are blips- medication positive role	506	P- Sometimes, I get these blips, which is what Emily calls, them, little sort of blips that happen, and my amour she calls the medication and she goes "there's little chinks in your armour" and that's how I view it now as well, I've got chinks in my amour, because not all your body ever can be protected by armour, there's gona be weak spots and there's gona be times when you sort of slip and have a bit of wobble.(k-ummmm)	
	507	I've had a couple of wobbles, a few wobbles, shall we say (k-ummm) erm... which are scary, cus you think oh its happening again... but yer know fortunately they've not been lasting that long and I think that's what.	
	508		
View of care co-ordinator influencing her own view	509	K- Do you, what do you sort of do if you have, or you sense that you're having a blip? Or do you notice it?	Acceptance of symptoms/hard times
EIP supporting acceptance	510		
	511		
Acceptance of hard times- still scared though	512		
	513		
	514		
	515		
	516		
	517		
	518		
	519		
	520		

Describing way in which notice symptoms/ change in self	521 522 523 524 525 526	P- I do, I have blips of sort of un-realism sort of happening (K-right) erm... where the whole world feels unreal, different somehow (K-right) almost like it's a set, like a movie set (K-right) erm... and I'm, I'm the only one that's sort of... the normal person from a, from the normal world, that this world isn't the right world, its sort of a different one (K-right, OK) but it looks the same (K-ummm) but its not right, and there's a definite feeling of it being not right.	Noticing symptoms
Feeling of world being different	527 528 529 530 531	K- And is that just a feeling, it doesn't, like you said it doesn't look different?	
Feelings of an unreal world	532 533 534 535 536 537	P- It doesn't look different at all, all people, its like a movie set basically, that you're on, somehow fake (k-ummm, yeah). K- So do you notice when you're starting to have that feeling?	
Still happens- but not worried	538 539	P- Yeah, cus it lasts quite a while (k-ummm) but not enough to, not long enough to get very worried about it. That's why my, my anti-psychotic doses have been sort of rising and sort of (indicated with finger pointing down).	
Change in medications	540 541 542	K- Yeah, depending.	Acceptance- less worried
Comparison to old self- rebellious against medication	543 544 545	P- Yeah, I've still got that rebellious streak where I want to lower the dose and com off it, erm... but, I'm... I suppose I smart enough to realise that I actually need them, I've got things to lose now, yer know, I want to start a family at some point, erm and I want to stay well for that.	
Feelings of needing medication- not wanting things to go wrong	546 547 548 549 550 551	K- So there's sort of things, there's lots more now than there ever was affecting the decisions you make. P- Definitely.	Comparison with old self
			Change in self

Partnership working with EIP	552	K- How has it been, sort of you said your dose goes up and down quite a lot, how much of a, erm, how much have you influenced how your medications fluctuated? P- Oh they've been great actually... partnership working basically, erm... with my psychiatrist, erm and Emily, we sort of always, now.... Yer know, we've, we always chat about things before changing the dose and sort of, I agree, I will agree, it wont be done sort of... pushing me into now, where as before, it used to be right, yer know, "I think you should raise the dose and I think we'll do that" but where as now more "what do you think, yer know, do you think you should raise the dose a bit" and I'll be like ummm, yer know, umm well yer know. K- When do you think that changed then? P- I don't know it happened quite, erm... quite insidiously (k-ummm) yer know, erm... I don't know precisely when yer know when it changed, but, I guess when I became more accepting or services and dealing with the fact that I am, I'm not... I guess, not normal is not the word... erm... I've got the, an illness, I guess erm and I accep...ted that and I guess when I accepted that, that was when... it changed, to become sort of a partnership working (k-ummm), because before it would, I never accepted it, I was always rebellious, erm... you know hated services (k-ummm) hated that I was ill, didn't think it would help, yer know, but I accept it now, so I guess when I accepted it that was when it became different.	Change in involvement in intervention decisions  Control and agency
	553		
	554		
	555		
	556		
	557		
	558		
	559		
	560		
	561		
Agency and control over decisions	562		Acceptance of services/interventions
	563		
	564		
	565		
	566		
	567		
	568		
	569		
	570		
	571		
Comparison to forceful approach/ lack of control	572	K- When do you think that changed then? P- I don't know it happened quite, erm... quite insidiously (k-ummm) yer know, erm... I don't know precisely when yer know when it changed, but, I guess when I became more accepting or services and dealing with the fact that I am, I'm not... I guess, not normal is not the word... erm... I've got the, an illness, I guess erm and I accep...ted that and I guess when I accepted that, that was when... it changed, to become sort of a partnership working (k-ummm), because before it would, I never accepted it, I was always rebellious, erm... you know hated services (k-ummm) hated that I was ill, didn't think it would help, yer know, but I accept it now, so I guess when I accepted it that was when it became different.	Comparison to old self
	573		
	574		
	575		
	576		
	577		
	578		
	579		
	580		
	581		
Not knowing when changed	582	K- When do you think that changed then? P- I don't know it happened quite, erm... quite insidiously (k-ummm) yer know, erm... I don't know precisely when yer know when it changed, but, I guess when I became more accepting or services and dealing with the fact that I am, I'm not... I guess, not normal is not the word... erm... I've got the, an illness, I guess erm and I accep...ted that and I guess when I accepted that, that was when... it changed, to become sort of a partnership working (k-ummm), because before it would, I never accepted it, I was always rebellious, erm... you know hated services (k-ummm) hated that I was ill, didn't think it would help, yer know, but I accept it now, so I guess when I accepted it that was when it became different.	Acceptance of services/interventions
	583		
	584		
	585		
	586		
	587		
	588		
	589		
	590		
	591		
Acceptance of psychosis and service	592	K- When do you think that changed then? P- I don't know it happened quite, erm... quite insidiously (k-ummm) yer know, erm... I don't know precisely when yer know when it changed, but, I guess when I became more accepting or services and dealing with the fact that I am, I'm not... I guess, not normal is not the word... erm... I've got the, an illness, I guess erm and I accep...ted that and I guess when I accepted that, that was when... it changed, to become sort of a partnership working (k-ummm), because before it would, I never accepted it, I was always rebellious, erm... you know hated services (k-ummm) hated that I was ill, didn't think it would help, yer know, but I accept it now, so I guess when I accepted it that was when it became different.	Comparison to old self
	593		
	594		
	595		
	596		
	597		
	598		
	599		
	600		
	601		
Illness medical view	602	K- When do you think that changed then? P- I don't know it happened quite, erm... quite insidiously (k-ummm) yer know, erm... I don't know precisely when yer know when it changed, but, I guess when I became more accepting or services and dealing with the fact that I am, I'm not... I guess, not normal is not the word... erm... I've got the, an illness, I guess erm and I accep...ted that and I guess when I accepted that, that was when... it changed, to become sort of a partnership working (k-ummm), because before it would, I never accepted it, I was always rebellious, erm... you know hated services (k-ummm) hated that I was ill, didn't think it would help, yer know, but I accept it now, so I guess when I accepted it that was when it became different.	Acceptance of services/interventions
	603		
	604		
	605		
	606		
	607		
	608		
	609		
	610		
	611		
Change in self- less rebellious	612	K- When do you think that changed then? P- I don't know it happened quite, erm... quite insidiously (k-ummm) yer know, erm... I don't know precisely when yer know when it changed, but, I guess when I became more accepting or services and dealing with the fact that I am, I'm not... I guess, not normal is not the word... erm... I've got the, an illness, I guess erm and I accep...ted that and I guess when I accepted that, that was when... it changed, to become sort of a partnership working (k-ummm), because before it would, I never accepted it, I was always rebellious, erm... you know hated services (k-ummm) hated that I was ill, didn't think it would help, yer know, but I accept it now, so I guess when I accepted it that was when it became different.	Comparison to old self
	613		
	614		
	615		
	616		
	617		
	618		
	619		
	620		
	621		
Acceptance of self- impact on views of receiving services	622	K- When do you think that changed then? P- I don't know it happened quite, erm... quite insidiously (k-ummm) yer know, erm... I don't know precisely when yer know when it changed, but, I guess when I became more accepting or services and dealing with the fact that I am, I'm not... I guess, not normal is not the word... erm... I've got the, an illness, I guess erm and I accep...ted that and I guess when I accepted that, that was when... it changed, to become sort of a partnership working (k-ummm), because before it would, I never accepted it, I was always rebellious, erm... you know hated services (k-ummm) hated that I was ill, didn't think it would help, yer know, but I accept it now, so I guess when I accepted it that was when it became different.	Acceptance of services/interventions
	623		
	624		
	625		
	626		
	627		
	628		
	629		
	630		
	631		
Increase in control- following acceptance of self	632	K- When do you think that changed then? P- I don't know it happened quite, erm... quite insidiously (k-ummm) yer know, erm... I don't know precisely when yer know when it changed, but, I guess when I became more accepting or services and dealing with the fact that I am, I'm not... I guess, not normal is not the word... erm... I've got the, an illness, I guess erm and I accep...ted that and I guess when I accepted that, that was when... it changed, to become sort of a partnership working (k-ummm), because before it would, I never accepted it, I was always rebellious, erm... you know hated services (k-ummm) hated that I was ill, didn't think it would help, yer know, but I accept it now, so I guess when I accepted it that was when it became different.	Comparison to old self
	633		
	634		
	635		
	636		
	637		
	638		
	639		
	640		
	641		

## **All themes emerging from Participant 8**

Emotional impact

Not knowing who to talk to about experiences

Escalation of symptoms

Social impact of symptoms

Unable to cope/ coping

Upset

Social withdrawal

Shame and judgements of other people

Change in views and beliefs

Unable to talk to others

Reluctance to take medication

Ambivalence about medication- helped vs. disliking taking them

Ambivalence about contact with EIP- Pleased to have EIP vs. reluctance

Anxieties about the future

Positive view of the future

Initial contacts daunting

Confronting experiences

Scared

Alone

Ambivalence- trust vs mistrust

Reassurance- reduce stigma

Normalising- reduce stigma

Comparison to other diagnoses

No one understands

Own judgements and fears of psychosis label

EIP different- adding to feelings of shame and separation

Regular contact with EIP

Shame- EIP service name

Shame- psychosis/label

Ambivalence- Shame vs wanting people know/ EIP helped

Limited choices

Services were only other option

Lack of choices offered by EIP

Other options available

Wanting people to know about EIP

Fear of judgement from others

Forced choice

Limited choices- harsh consequences

Psychosis- in the way of plans to be free

Taking medication- worn down

Shame of previous experiences- fear of repetition

Ambivalence about EIP ashamed vs. appreciative

Lack of understanding

Increasing people's knowledge

Change in symptoms and self

Ambivalence EIP involvement ending- closure vs anxiety about independence

Identifying with others shared experience

Wanting to help others

What could have been?



EIP support/ helping role

View of recovery

Comparison with old self

Change in involvement in intervention decisions

Acceptance of symptoms

Acceptance of hard times

Noticing symptoms

Acceptance- less worried

Change in view of the problem

Self blame/ pressure to stay well

Other people's openness about mental health problems

Other people's acceptance

Changes in life

Positive comparisons to others

Support of others

Control and agency in decisions

Acceptance of services/interventions

Change in cultural self beliefs

Wanting to experience peer group support

## Clustering of emerging themes from Participant 8

### **‘Stigma’**

#### ***Sub- theme: Shame***

Shame- EIP service name

Shame- psychosis/label

Comparison to other diagnoses

Own judgements and fears of psychosis label

Shame of previous experiences- fear of repetition

EIP different- adding to feelings of shame and separation

#### ***Sub-theme: Others’ judgements***

Shame and judgements of other people

Fear of judgement from others

Lack of understanding

Not knowing who to talk to about experiences

No one understands

Unable to talk to others

#### ***Sub-theme: Overcoming stigma***

Wanting people to know about EIP

Increasing people’s knowledge

Reassurance- reduce stigma

Other people’s openness about mental health problems

Other people’s acceptance

---

## ***‘Choice and agency’***

### **Sub-theme: Limited options**

Taking medication- worn down

Limited choices

Services were only other option

Lack of choices offered by EIP

Other options available

Forced choice

Limited choices- harsh consequences

### **Sub-theme: Increase in involvement**

Change in involvement in intervention decisions

Control and agency in decisions

Acceptance of services/interventions

-----

## ***‘Recovery’***

### **Sub-theme: Support from others**

EIP support/ helping role

Support of others- family

Regular contact with EIP

EIP- Normalising

### **Sub-theme: Identifying with others**

Identifying with others shared experience

Positive comparisons to others

Wanting to help others

Wanting to experience peer group support

**Sub-theme: Acceptance**

View of recovery

Acceptance of symptoms

Acceptance of hard times

Noticing symptoms

Acceptance- less worried

Change in symptoms and self

Unable to cope/ coping

What could have been?

Change in views and beliefs

Comparison with old self

Change in view of the problem

-----

**‘Ambivalence’**

**Sub-theme: EIP services**

Initial contacts daunting

Confronting experiences

Ambivalence- trust vs. mistrust

Ambivalence- Shame vs. wanting people know/ EIP helped

Ambivalence about EIP ashamed vs. appreciative

Ambivalence about contact with EIP- Pleased to have EIP vs. reluctance

**Sub-theme: Medication**

Ambivalence about medication- helped vs. disliking taking them

Reluctance to take medication

**Sub-theme: Exiting the service**

Ambivalence EIP involvement ending- closure vs anxiety about independence

Anxieties about the future

Positive view of the future

---

***'Impact of psychosis'*****Sub-theme: Social and emotional**

Emotional impact

Escalation of symptoms

Social impact of symptoms

Upset

Social withdrawal

Scared

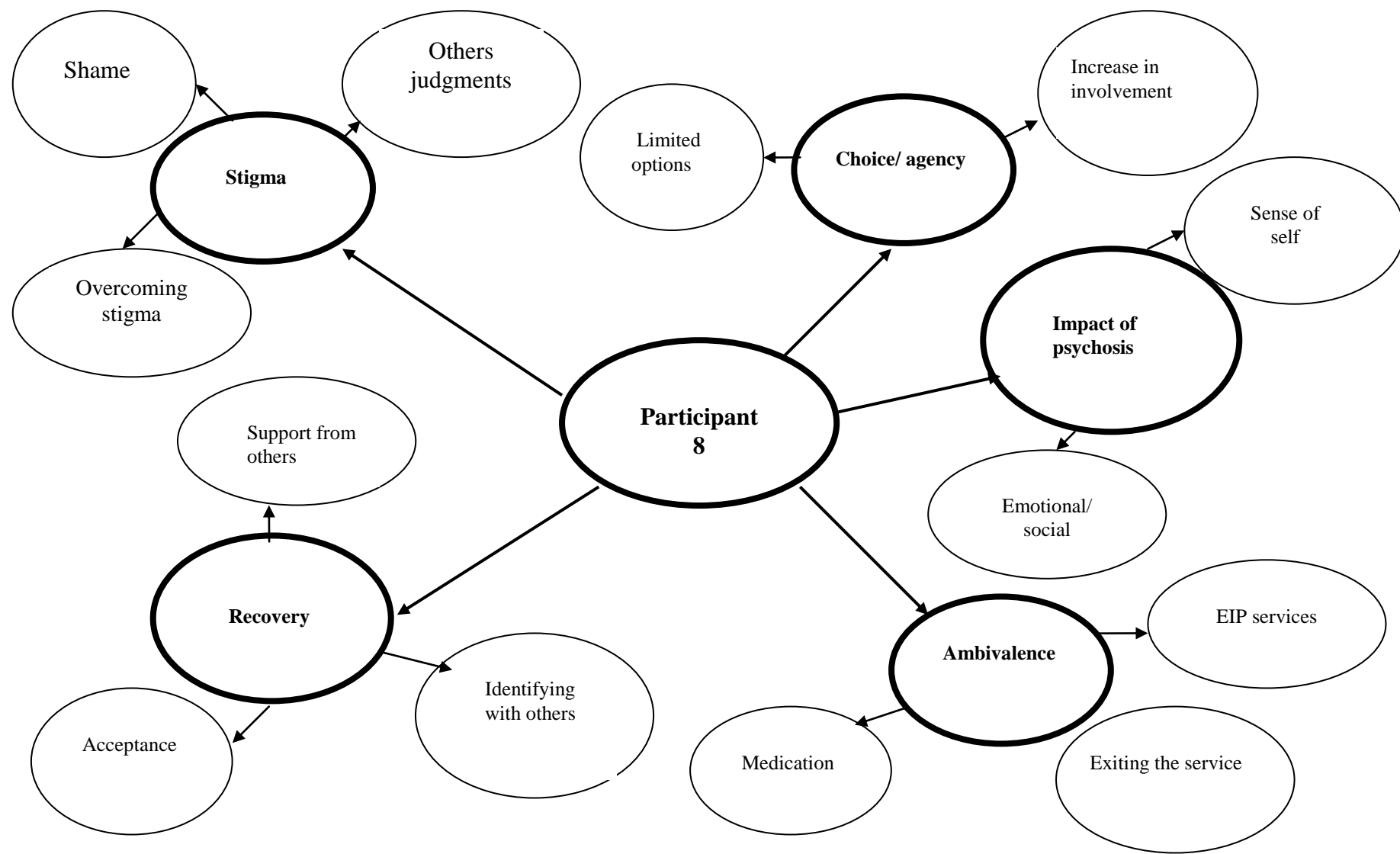
Alone

**Sub-theme: Sense of self**

Change in cultural / self beliefs

Psychosis- in the way of plans to be free

Self blame/ pressure to stay well



## Supporting verbatim extracts

### Extract from reflective diary

*Earlier today I was thinking about my table of themes from participant 8. One of the emerging themes was recovery and her talking about accepting her symptoms and her experiences of psychosis and being able to live with them. This made me think about the impact of my own assumptions about recovery from psychosis on this theme emerging, as it represents one of my own views about psychosis. This then made me want to check again whether or not this was grounded within the actual words spoken by the participant. So went back over the transcript and checked this. Was pleased to see that this theme was quite richly described by her in several places and also that she specifically used the words “recovered” and “accepting it” without being prompted by myself in anyway.*

These are just some examples of the extracts which illustrate the theme ‘Recovery’ identified in participant 8 interview.

### **Acceptance**

Interviewer (K)- Right, yeah. You say, cus obviously you use the word recovered, I’m, I’m just interested what that word means for you, what does recovered mean for you?

Participant (P) -To me it means that erm... I’m learning to live with my symptoms and with having to take medication, erm and being able to deal with it, cus I was so, I was very rebellious in my early days against medication and the whole system really (K-right) erm it was, escaping from wards and things like that erm... and going to the GP and going “right that’s it I’m not taking anymore of these tables” and chucking them at him, things like that and I think I’ve become wise and that’s, to me what recovery, what recovery means.  
K- yeah.

P- Sort of living with my symptoms and dealing with it, accepting it.

K- Do you still get sort of things; do you still get similar experiences to what you had then?

P- Sometimes, I get these blips, which is what Emily calls, them, little sort of blips that happen, and my armour she calls the medication and she goes “there’s little chinks in your armour” and that’s how I view it now

as well, I've got chinks in my armour, because not all your body ever can be protected by armour, there's gona be weak spots and there's gona be times when you sort of slip and have a bit of wobble.(k-ummmm) I've had a couple of wobbles, a few wobbles, shall we say (k-ummm) erm... which are scary, cus you think oh its happening again... but yer know fortunately they've not been lasting that long and I think that's what.

-----

P- I do lately, now become more and more open to sort of talking about it, which is probably why I'm, I'm talking to you about it (K-yeah), before I would never have (K-right) and I wouldn't speak to James about anything, but I am now sort of becoming more, getting to grips with it...

-----

P- I do, I have blips of sort of un-realism sort of happening (K-right) erm... where the whole world feels unreal, different somehow (K-right) almost like it's a set, like a movie set (K-right) erm... and I'm, I'm the only one that's sort of... the normal person from a, from the normal world, that this world isn't the right world, its sort of a different one (K-right, OK) but it looks the same (K-ummm) but its not right, and there's a definite feeling of it being not right.

K- And is that just a feeling, it doesn't, like you said it doesn't look different?

P- It doesn't look different at all, all people, its like a movie set basically, that you're on, somehow fake (k-ummm, yeah).

K- So do you notice when you're starting to have that feeling?

P- Yeah, cus it lasts quite a while (k-ummm) but not enough to, not long enough to get very worried about it.

### ***Identifying with others***

K- How are you feeling about working sort of with people who are being rehabilitated from mental health problems?

P- Quite good, because... it sounds a bit strange but I do see myself having, well being one of those people, if



I hadn't sort of recovered I guess... so it feels good to be able to help them as well, cus I feel part of them erm.. sort of a... yer know... I'm like you type thing and I can help you now. So it feels quite good, in a good way.

K- So like, you understand things?

P- yeah, I can understand what they're going through yer know, I, I've got the T-shirt to prove that I'm, I've been there and done that.

-----  
P- Yeah... alone yeah, to me, its just, its just Emily and Dr Smith working together and then its me and I'm alone in the service, obviously Emily says, you know I do see other patients so I know other patients exist, but maybe... I don't know maybe suggesting that there's a group that can get together, or something like that, or along those lines, you know maybe just so that you are in contact with other people in the actual same service (K-yeah) and... I don't know go out for a cup of coffee or something and make it a coffee evening or some forum maybe or... I don't know something to put you in touch with other people that are in the same position.

K- What meaning do you think that would have for you to be other people from the same service?

P- It would, it would be great I think, erm, it would mean that I'm not alone, erm... cus all you have contact with is the professionals (K-yeah) erm... but you know that there must be other people in the service as well, but it doesn't feel like it, so maybe, if they did something like that (K-yeah).

K- Yeah, that sounds like something that would make you feel less on you own, and like you said it must be strange, cus obviously you hear about other service-users and you're aware they must be there, but you never actually have any contact with them.

P- Yeah and I'm sure I must not be the only one who feels this way, I'm sure there must be other people that are, or even if it was an internet forum at least it was some kind of, some thing you can trade sort of stories and you know get to know somebody else who's been through the same things as you.

K- How do you think that would make you feel sort of sharing you know people sharing their stories of what they've been through?

P- I think it would be good, I think it would help me come to term and understand mine and understand theirs and the gist of it that you know, I wouldn't feel so alone and that's all that, you know it doesn't have to be serious it doesn't have to be in-depth or anything you know.

### ***Support from others***

P- Yeah, if I hadn't, if I hadn't got my loving husband, if I hadn't got Emily erm... if I hadn't got Dr Smith, I guess, id be one of those... poor people in a... possibly be one of those people in a rehabilitation unit or homeless, yer know, I could see that happening yer know.

-----

P- Erm... well, I'm gona start a new job on Monday err... yeah I got married whilst being in services, in EIP, so, worked through that, I was nervous and sort of wrecked before that (laughs), so... I, I've been through a lot with sort of EIP propping me up really, so that's good.

-----

P- It sort of, James's really supportive erm... you know, its just being in love I guess and having someone that understands you and someone to confide in you know.

-----

P- Yeah, well they said that yer know, your not alone, erm... its just, its psychotic symptoms erm... and... we've sort of heard of symptoms like this before (K-right) and err... your not alone...

-----

P- I felt a little relieved, I felt a little relieved that I wasn't alone and that they'd seen it before basically and they didn't seem to sort of veer back and go "god you no,

that sounds totally out of, yer know, ridiculous” and everything, they, they were quite calm about it and erm... basically said, you’re not alone and that, that, those words just made me feel a lot of relief (K-yeah).

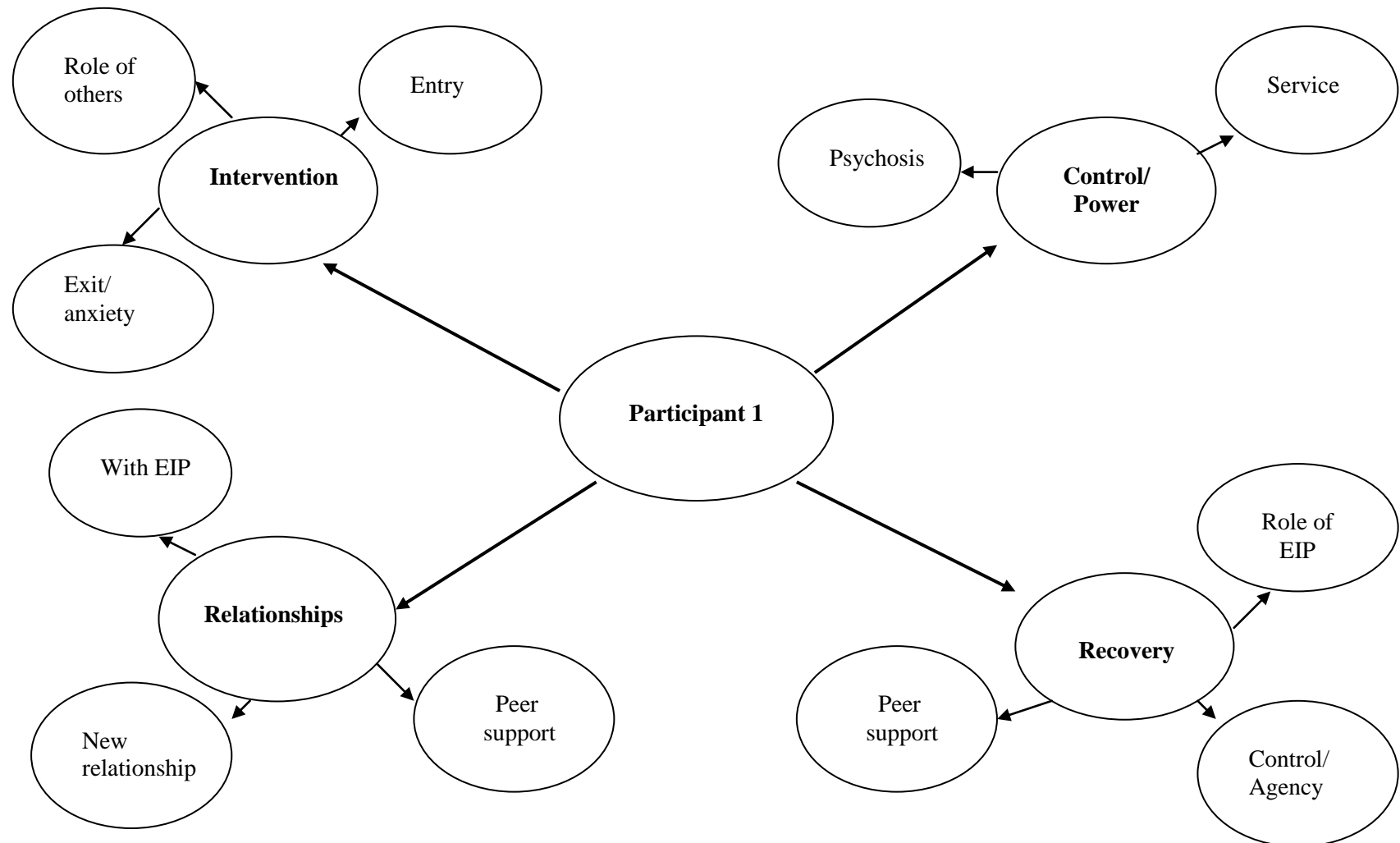
K- And you hadn’t heard that before? That was the first time you’d spoken to somebody?

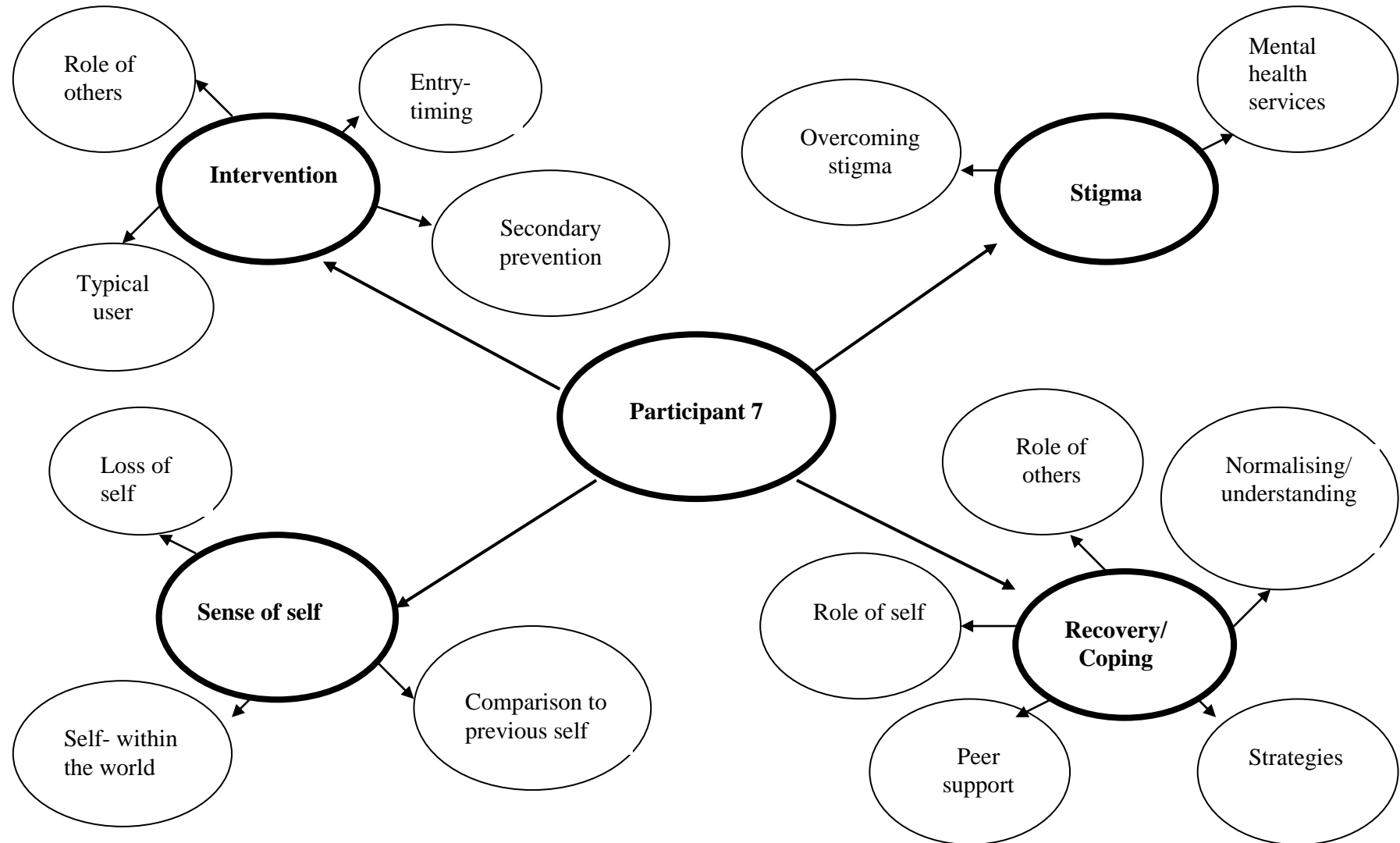
P-No, cus the only, the first time I had sort of confided was to Dr Smith and, you know, she being a psychiatrist and didn’t really expect her to reel back in horror even, so she didn’t but I did get the impression she was bit perplexed by it as well.

K- Right

P- But the EIP nurses weren’t, they were jus, they were wonderful.

## Two examples of master theme lists from other participants





## Appendix H: Demographic and Service Information Sheet

Participant number\_\_\_\_\_

Age\_\_\_\_\_ Gender\_\_\_\_\_

### Ethnicity (please circle)

White British   White Irish   White Other

Indian   Pakistani   Bangladeshi   Other Asian

Black Caribbean   Black African   Black Other   Chinese   Other

White Black Caribbean   White Black African   White and Asian   Other Mixed

### Marital Status (please circle)

Married   Cohabiting   Single   Separated   Divorced   Widowed

### Employment status (please circle)

Employed   Self employed   Volunteer work   Unemployed   Student

Length of time in EIP service\_\_\_\_\_ City or County Team\_\_\_\_\_

EIP Psychiatrist   Y   N

Any hospital admissions   Y   N   if 'yes' please state how many \_\_\_\_\_

### Service Specific Questions

During their time in the EIP service, has the participant ever had involvement either directly or indirectly (supervision or consultancy) from any of the following:

Clinical Psychology	Y	N
Occupational Therapy/ Vocational	Y	N
Dual Diagnosis Team	Y	N
Crisis Team	Y	N

During their time in the EIP service, has the participant ever had a change of Care Co-ordinator?

Y N

If 'yes' please state how many Care Co-ordinators the participant has had in total \_\_\_\_\_

During their time in the EIP service, has the participant ever attended any service led groups?

Y N

If 'yes' please specify \_\_\_\_\_

## Appendix I: Procedural Summary Flow Diagram

