

**From Referral to Discharge: The Experiences of Engaging with and
Moving on from Early Intervention Services**

A thesis submitted to The University of Manchester for the degree of Doctor of Clinical
Psychology in the Faculty of Biology, Medicine, and Health

2018

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Total Word Count (excluding tables, figures, references and appendices): 15,364

Declaration

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Acknowledgements

I would like to thank my supervisors Dr Sandra Bucci, Dr Katherine Berry and Dr Joanna Brooks for their continued support, guidance and wisdom throughout all stages of this project. I would like to thank the University of Manchester for supporting the design and implementation of my research and all staff within the Department of Clinical Psychology who offered help in forming links with services for recruitment. I would like to thank staff in all teams who helped me make contact with participants, in the face of numerous competing demands. I would also like to thank my family, friends, and fellow Clinical Psychology trainees who have provided much support, encouragement and relief in times of panic. My biggest thanks go to the participants who agreed to take part in the study and shared their stories with me. Their optimism, resilience and strength was inspirational and will not be forgotten.

Thesis Abstract

This thesis forms part of the examination for the Doctor of Clinical Psychology (ClinPsyD) in the Faculty of Biology, Medicine and Health (School of Health Sciences) at The University of Manchester.

Paper one is a meta-synthesis of qualitative literature exploring the views of service users and carers/family members regarding their experiences of engaging with EIS. Following a standardised approach, four databases were searched and a sample of 14 papers were identified. Using an inductive thematic analysis (ITA) approach, within a critical realist epistemological framework, three main themes were identified: the importance of a personal relationship with an EIS staff member, the impact of this relationship and the consideration of life after EIS. The results highlighted the importance of service users and/or carers/family members building and maintaining a strong therapeutic bond with at least one member of EIS staff.

Paper two is a qualitative study investigating service users' experiences of transitioning from EIS. Semi-structured interviews were completed with 15 participants who had either been discharged to primary care or to Community Mental Health Teams (CMHTs) and analysed, again using ITA, adopting a critical realist stance. Analysis identified five main themes: feeling ready for discharge, relationships and trust, planning for discharge, expectations of future care and the safety net of early intervention. The results and discussions offer practical implications and recommendations for services.

Paper three provides a critical reflection of the research process. It includes reflections on the methodological approaches used, strengths, limitations and implications of the findings for research and clinical practice.

Paper 1

Service User and Carer Experiences of Engaging with Early Intervention Services: A Meta-Synthesis Review

This paper has been prepared for submission to *Psychosis*. Author guidelines can be found in Appendix 1. Some changes have been made to aid readability, for example, tables included in the main text. The word count has been moderately extended for this version to add additional context in places.

**Service User and Carer Experiences of Engaging with Early Intervention
Services: A Meta-Synthesis Review**

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The University of Manchester

Word count

Main body: 5266

Reference list: 1593

Tables & figures: 951

Abstract

The provision and implementation of Early Intervention for psychosis Services (EIS) has received increasing attention over recent years, particularly in the UK, in light of the publication of the 'Implementing the Early Intervention in Psychosis Access and Waiting Time Standard' (2016). Within this document, the potential implications of not treating distressing psychosis are explored from a service user point of view and a wider socio-economic perspective, and conclusions are drawn regarding the importance of EIS.

Therefore, as maximising engagement with EIS is of clinical and economic importance, exploring the experiences of those who access the services is vital. Although research has been conducted exploring the experiences of engaging with EIS from both a service user and carer/family member point of view, to date, the data has not been collated to generate a new understanding. This paper presents a meta-synthesis of qualitative findings from such studies. Aims of this study were: (1) to review and synthesise qualitative findings relating to the experiences of service users and/or carers/family members engaging with EIS; and (2) highlight the implications of findings for applied practice.

Following a standardised approach, four databases were searched and a sample of 14 papers were identified. Using an inductive thematic analysis (ITA) approach, within a critical realist epistemological framework, three main themes were identified: the importance of a personal relationship with an EIS staff member, the impact of this relationship and the consideration of life after EIS. The results highlighted the importance of service users and/or carers/family members building and maintaining a strong therapeutic bond with at least one member of EIS staff. Results are discussed in terms of implications for practice and recommendations for future research.

Keywords: *Early Intervention, psychosis, experiences, qualitative, meta-synthesis*

1. Introduction

Early Intervention Services (EIS) are community based multi-disciplinary services that are offered worldwide to provide treatment and support to individuals experiencing a first episode of psychosis (FEP; Marshall & Rathbone, 2011). Engagement with EIS typically lasts for three years and support is often of a more intensive nature than other secondary care services, taking a more assertive outreach approach, which, if appropriate, can extend to family members and carers (Marshall & Rathbone, 2011). Engaging with EIS results in better clinical outcomes than standard care alone (Bird et al., 2010), including fewer subsequent inpatient admissions (Craig et al., 2004), improved social functioning (Knapp, Patel, Curran et al., 2013) and reduced symptomatology (Revier, Reininghaus, Dutta et al., 2015). When support is extended to family members, relapse rates have been shown to reduce by as much as 40% (Knapp, Andrew, McDaid et al., 2014). As important as this is from a service user point view, this also has significant economic implications. In the UK, it is estimated untreated psychosis costs the economy over £11 billion per year when taking into account factors such as reduced employment and state spending on crisis management or inpatient services (The Schizophrenia Commission, 2012). Over a 10-year period, EIS investment focussing on early detection and intervention would save £15 for every £1 spent (Knapp, Andrew, McDaid et al., 2014), demonstrating the importance of effective commissioning and provision of such services.

Given the short and long-term benefits of engaging with EIS from both a personal and economic point of view, much research has focussed on the routes to accessing services and the experiences of seeking help for early psychosis (Anderson, Fuhrer & Malla, 2013; Bechard-Evans et al., 2007). There has, however, been comparatively less research investigating the subjective experiences of service users and family members experience of services, once they access services. This is important, because on-going engagement and

willingness to engage with services has been shown to be a major factor in the recovery process (Lecomte et al., 2008) and sustaining both the personal and economic benefits of EIS involvement. Additionally, the benefits of exploring the experiences of those who access mental health services to aid evaluation and further development, as opposed to looking at them from a purely economic or academic viewpoint, are numerous. In broad terms, the process of exploring individuals' experiences via qualitative research provides rich, meaningful data, which can be interpreted in further detail and incorporated with existing or emerging theory (Seidman, 2006). With regards to mental health services, the practice of involving service user and carers' views in the provision and assessment of services provides the opportunity to learn from 'experts by experience' (Law & Morisson, 2014), thereby potentially reducing marginalisation and systematic disempowerment for those involved (Ennis & Wykes, 2013). Although there have been some qualitative studies exploring the experiences of service users and carers engaging with EIS, there are no published papers that have collated these findings into a single review, evaluated the relative strength of papers, and distilled the key clinical findings within each paper. This meta-synthesis was conducted to address this need. The aims of this meta-synthesis were to: (1) review and synthesise qualitative findings relating to the experiences of service users and/or carers/family members engaging with EIS (engagement was defined for this review as the process of accessing and working collaboratively with EIS staff); and (2) highlight the implications of findings for applied practice.

2. Method

Meta-synthesis is an interpretative approach to collating and synthesising existing qualitative data, with the aim of establishing a coherent new interpretation of the findings

(Paterson & Canam, 2001; Zimmer et al, 2006). An explicit systematic approach of identifying and assessing the quality of potential papers, followed by analysis of the data and synthesis, was employed with the aim of gaining an understanding of the experiences of service users and/or their family members in accessing Early Intervention Services for psychosis.

2.1. Search Strategy

As outlined in figure 1, in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher et al., 2009), the initial search for published papers utilised four databases: PsycInfo, Cinahl, Embase and Medline. In order to be considered for inclusion, all papers were required to be qualitative study journal articles, published in English. As EIS teams have been established in relatively recent years, there were no limits on year of publication. Search terms used were: (Early Intervention Service*) OR (First episode*) AND ((Psychotic) OR (Psychosis) OR (Schizophren*) OR (Bipolar)) AND ((Satisfaction*) OR (Opinion*) OR (Attitude*) OR (View*) OR (Experience*) OR (Perception*) OR (Evaluati*) OR (Value*) OR (Perspective*). Additionally, reference lists of retrieved papers were searched for additional relevant papers. Once identified, papers were initially reviewed by title, abstract and then full article. Papers were eligible if they met the following criteria: i) examined service user and/or family member opinions on the experience of being registered with an EIS; ii) used a qualitative method design; iii) separated the views and experiences of service users and family members rather than collating them; and iv) published in English language. Papers that also included other opinions (e.g. staff members) were deemed fit for inclusion, provided they separated these views from service user and/or family member views. This led to a final sample of 14 studies.

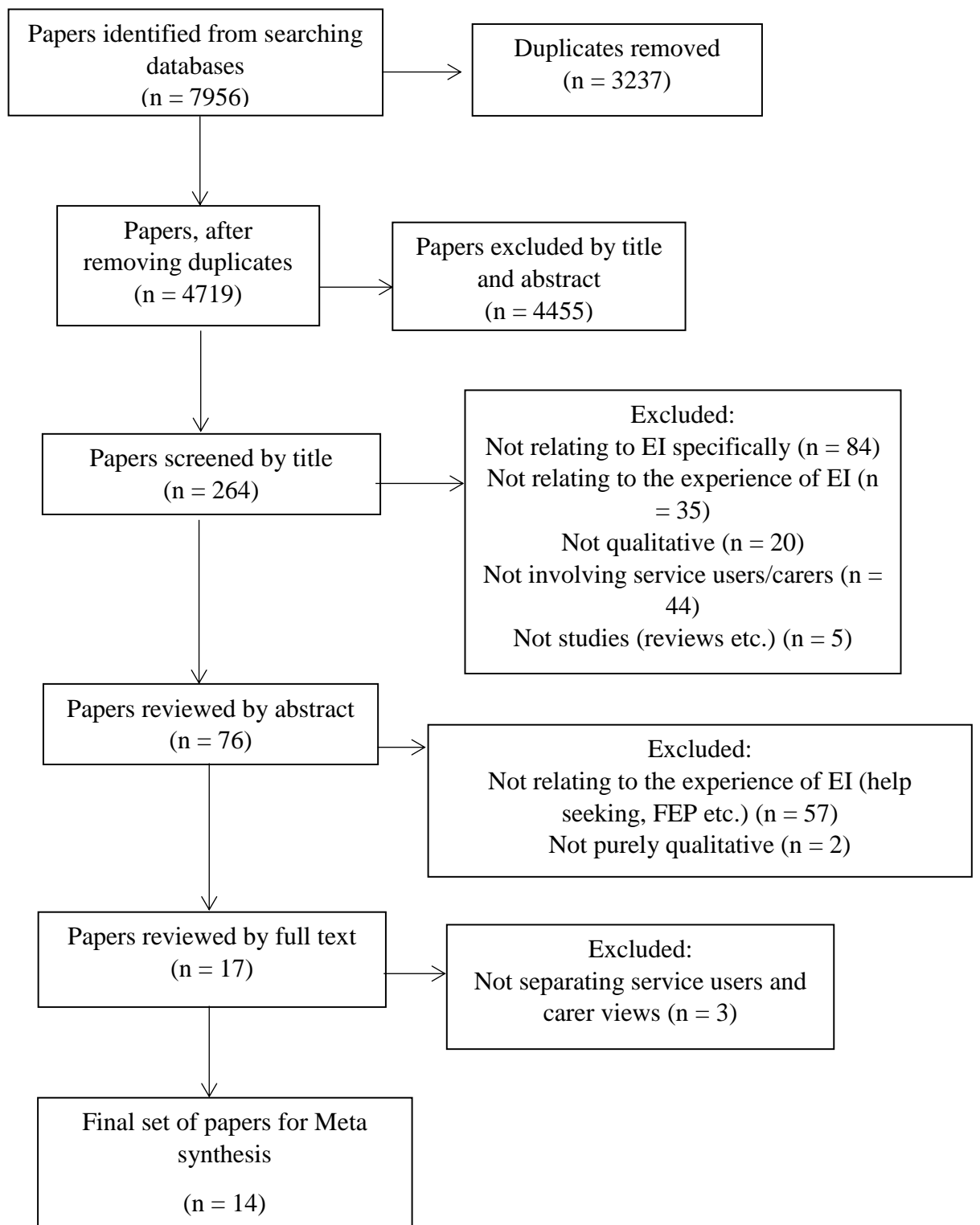


Figure 1: The screening process for studies to be included in the review

2.2. Quality appraisal

Study quality was assessed using the Critical Appraisal Skills Programme (CASP, 2013), comprised of 10 items, assessing the relevance and credibility of the papers. Adopting the principle suggested by Duggleby et al. (2010), each item was assigned a score, with '3' indicating fully addressed, '2' denoting partially addressed and '1' barely addressed. Scoring was completed by the first author and cross-referenced with another researcher to reach a consensus, enabling discussion regarding difference in opinions. The appraisal was undertaken to ensure that appropriate weight was placed on findings in papers that were rated a better quality to increase overall validity of the review. Although one of the main observations of the review highlighted that very few papers referred to researchers' reflexivity or ethical considerations beyond seeking informed consent and ethical approval, only one paper scored below 20/30 (Sin, 2012), suggesting a general high quality of papers.

2.3. Data extraction and synthesis

The selected papers were read, re-read and key information from the studies was recorded (see Table 1). In accordance with the principles of meta-synthesis and in line with previous examples of meta-synthesis of qualitative studies (Bayliss et al, 2014), data were extracted from each paper from the original data presented (first order constructs) and the authors' analysis of their primary qualitative data (second order constructs). Using a thematic approach (Braun and Clarke, 2006) from a critical realist perspective (Fletcher, 2016), the first author then grouped these constructs into emergent core themes. Following discussion of these within the research team, including consideration of how each paper identified contributed to each emergent core theme, an iterative process of further analysis was undertaken by the first author. The aim of this process was to develop a cohesive,

synthesised understanding of the data, going beyond the reported findings in each individual paper (Malpass et al., 2009) and led to emergent themes being further grouped into final higher-order themes. This allowed for the aforementioned synthesis of data from papers adopting differing epistemological standpoints. These final themes were again reviewed and agreed by the research team. These final themes are considered third order constructs and allow for further reflection on how these synthesised findings sit within the wider literature and might extend beyond the original papers. Following this, the first author returned to the data and checked that themes identified sufficiently reflected the data and that other themes had not been overlooked, ensuring findings were data-driven and substantiated.

3. Results

3.1. Overview

Fourteen papers were deemed eligible for inclusion in the review. Nine studies were conducted in the UK, three in Australia, one in Denmark and one USA. Six utilised Interpretive Phenomenological Analysis (IPA), five used a form of thematic analysis, three grounded theory. Participant numbers ranged from 7-80 (mean=24). Eight papers interviewed service users only; five interviewed carers/family members and one interviewed both.

As illustrated in table 1, the studies utilised a variety of theoretical frameworks and methods of analysis, including Interpretative Phenomenological Analysis (IPA) and Grounded Theory. It has been argued that synthesising research holding different epistemological viewpoints is problematic, due to the inherent differing concepts and underlying principles (Sandelowski, Docherty & Emden, 1997). In contrast, Finfgeld

(2003) contend that synthesising multiple approaches can be a productive process, leading to a richer, 'truer' understanding. This was the standpoint taken for this review; as such, papers were not excluded on the basis of their epistemological viewpoints in this review.

Table 1: Summary of the papers included in the review

Study	Participants	Aim	Data analysis	Setting	Results and themes	Quality Appraisal Score
O'Toole et al. (2004) (UK)	3 focus groups, made up of FEP SU's (n=12)	Explore SUs' experiences of an FEP intervention service	IPA	1 EIS in UK (location not specified)	EIS as a 'very different experience' – importance of 1:1 relationships. Increased engagement with society and motivation. 'Human' approach as a key component of recovery. Flexibility as a positive	21
Penny et al. (2009) (UK)	6 families – no SU involvement in interviews (n=11)	To explore the treatment experiences of families of Pakistani origin accessing an EIS	IPA	1 EIS in UK (location not specified)	Theme of loss – EIS overly optimistic; social aspect of psychosis; carers valuing the relationship between key workers & SUs; diverging understandings of illness and recovery	22

McCann et al. (2011) (Australia)	Primary caregivers of individuals accessing an FEP service (n=20)	Describing primary caregivers' experiences of young adults accessing FEP services	IPA	FEP service, Melbourne, Australia	GP as a source of referral to EIS; barriers encountered when trying to access EIS – thresholds of 'illness', insufficient services; carers' knowledge, experience & assertiveness enhancing access – increased knowledge matching increased confidence	27
McCann et al, (2011a) (Australia)	Primary caregivers of individuals accessing an FEP service (n=20)	Exploring caregivers' satisfaction with clinicians' response to them as informal carers of YP with FEP	IPA	FEP service, Melbourne, Australia	Clinicians being approachable as strong positive – accessible & supportive, responsive to carers' needs, knowledgeable & facilitating; some carers feeling undervalued – not being taken seriously & issues re: confidentiality	24

Harris et al. (2012) (UK)	SUs who had been with EI >2 years (n=8)	1. Explore SUs' perspectives of being in contact with and EIS 2. Explore how being in EI has impacted view of psychosis & current life experiences	IPA	1 EIS in UK (location not specified)	Experiences of stigma (self, others & of services); importance of relationships, especially with care co-ordinator, but also, peers; understanding experiences of psychosis necessary to move forward with recovery; sense of agency over psychosis – control vs powerless; impact on sense of self, both individually and within wider world	28
Lester et al. (2011) (UK)	SUs who had left EI (n=21)	Explore SU view on EIS and Primary Care	Constructivist Grounded-Theory	5 geographically diverse sites in UK	EI seen as 'gold standard'; value of good relationship with key workers (trust, good interpersonal skills); barriers and facilitators of transition; underutilisation of primary care	25
Lester et al. (2012) (UK)	SUs – 1 st interview < 6 months	Exploring the views over time of young people referred to	Constructivist Grounded-Theory	As part of wider UK EDEN	Importance of relationship with key workers – EIS seen as youth friendly and matching needs. Flexible approach helpful; EIS helping	20

	of engaging (n=63), 2 nd > 12 months (n=36)	EI, especially the importance of relationships		project	with understanding of psychosis; visits too frequent for some, especially when combined with change of workers; some feeling overinvolvement reinforcing illness stigma; value of family support and them gaining an understanding of psychosis; changing self- identity – EIS workers seen as important allies	
Sin et al. (2012) (UK)	Siblings of individuals accessing EIS (n=31)	Understanding the experiences & service needs of siblings of individuals with FEP	‘Responsive- reader and framework methods’	2 EIS in South-East England	Siblings seeing themselves as important in liaising with services, despite EIS having limited resources for them; diverse emotional responses; impact of psychosis on relationships; coping strategies & resilience; siblings’ needs often overlooked when compared with carers, need for more information and respite	19

Stewart (2012) (UK)	Young people engaged with EIS (n=30)	Exploring the factors contributing to engagement with EIS	Grounded Theory	1 EIS in UK (location not specified)	Relationships with key-worker key	26
Van Schalkwyk et al. (2015) (USA)	SUs (n=11)	Exploring participants' narratives of early treatment experience	Inductive Thematic Analysis	STEP (EIS), Connecticu t, USA	Importance of feeling listened to and understood. Understanding of illness as very important factor	18
Jansen et al. (2015) (Denmark)	SUs (n=10)	Examine SU experience of moving between early psychosis detection team (TOP) and a	Social constructivist Thematic Analysis	OPUS (EIS) Denmark	Stigma & fear of systems as a barrier to help seeking; impact of trauma on psychosis; importance of significant others; experiencing EIS as safe and trusting the teams, building strong alliances; the relief of receiving a diagnosis and chance to talk	28

		specialised psychosis service (OPUS)			about difficulties and gain insight/understanding	
Lavis et al. (2015) (UK)	Carers (n=80)	Exploring the impact of EIS for FEP on carers' experiences	Constructivist thematic Analysis	Part of wider EDEN project	EI helping with caring responsibilities, providing information and alleviating distress. Value of plain language; carers feeling listened to; conflicts with EI re: confidentiality and not feeling taken seriously; some reports of EIS not helping with emotional impact in carers; lack of knowledge re: support for carers	22
Tindall et al. (2015) (Australia)	Service users accessing EIS (n=7)	Exploring factors influencing engagement with case managers	IPA	EIS, Australia (not specified)	EIS instilling initial hope for recovery; relationship with keyworker as key facilitator – being knowledgeable re: psychosis, maintaining confidentiality, taking an active interest in SU, warm, sensitive and flexible	24

					approach; change in care manager seen as negative – need for consistent relationships	
Allard et al. (2016) (UK)	Carers (n=16) SUs (n=16)	Exploring service users' and carers' views on EIS	Thematic Analysis, adopting a phenomenological analytical approach	UK. Part of wider EDEN project	Carers: retrospective accounts of desperation, relief at engagement, EIS offering hope & optimism Service Users: relationship with key worker helping with insight, understanding illness more important than long-term goals	22

EIS – Early Intervention Service; SU – Service User; IPA – Interpretive Phenomenological Analysis; FEP – First Episode Psychosis

3.2. Findings

Analysis of the data revealed three main themes: the importance of a personal relationship with an EIS staff member, the impact of this relationship and the consideration of life after EIS.

3.2.1. The importance of a personal relationship with an EIS staff member

The vast majority of studies explicitly described the nature of the relationship that both service users and carers formed with EIS staff. In most studies, this was narrowed down to the relationship with a specific member of staff, typically a key-worker. The value of a ‘real’ relationship with at least one EIS staff member was evident throughout most studies and underpinned most accounts of engaging with EIS. A ‘real’ relationship was described as one in which service users and carers felt staff members took a genuine, person-centred interest in their holistic well-being, ultimately seeing them as more than ‘just a patient’ or ‘just a carer’. More specifically, across the papers, several factors were identified as necessary in ensuring this relationship was experienced as ‘real’. These included EIS staff adopting a calm, warm and approachable style of interaction (McCann et al., 2011; Lester et al., 2012; Jansen et al., 2015), using ‘plain’ language so as to avoid a sense of hierarchy (Lavis et al., 2015; McCann et al., 2011;), ensuring the service user and/or carer felt listened to and taken seriously by adopting a non-judgemental stance (O’Toole et al., 2004; McCann et al., 2011; McCann et al., 2011a; Stewart, 2012; Tindell et al., 2015; Jansen et al., 2015; Van Schalkwyk et al., 2015) and not dismissing or overlooking any concerns (Jansen et al., 2015; Van Schalkwyk et al., 2015). Additionally, where staff were perceived as being prepared to work flexibly both in terms of the immediate practicalities of working together (e.g. discussing location and frequency of meetings) and more longitudinally (such as negotiating medication changes or psychosocial interventions), this was seen as

beneficial in helping to create an equal, two-way relationship (O'Toole et al., 2004; Stewart, 2012; Tindell et al., 2015).

The combination of these identified factors appeared to aid both parties in experiencing the relationship as a genuine, 'human' one, free of typical clinical boundaries. This 'human' element was something that Stewart (2012) and Jansen et al. (2015) expanded upon and described as the main impetus for continued engagement with the service, in part due to the difference of this relationship when compared to other mental health staff and services, which were often seen as more distant and removed:

... [EIS staff member], she's very human, you know. She didn't put up a wall between what's professional and private, so she's herself, whereas often with [previous] psychiatrists and nurses, it's like hitting your head against a brick wall... (Participant in Stewart, 2012).

Furthermore, an individualised, human relationship with EIS staff was identified by service users and authors as an integral component of recovery, underpinning the prime importance of the establishment and maintenance of this unique therapeutic bond, more so than any specific psychosocial or pharmaceutical intervention:

I see her every two weeks. I don't know what I would do without her...

(Participant in Lester et al., 2011).

Their [service users'] naming of particular nurses as their key point of contact was also symbolic of the treatment as being primarily relationship-based and highly individualized... (O'Toole et al., 2004).

Support for the importance of this genuine two-way relationship was found in papers that reported the impact of changes or disruptions in care on service users, which included feeling engagement with EIS was over-bearing (Lester et al., 2011) and increased

reluctance and scepticism in opening up to new members of staff (Tindell et al., 2015), suggesting that a constant, caring relationship would prevent such feelings and promote meaningful, continuing engagement. Additionally, even if the relationship was constant, findings reported in McCann et al. (2011) suggest that experiencing staff who adopt a superior, stigmatising approach led to participants feeling excluded, isolated, and ultimately, more reluctant to engage with EIS. This further supports the importance of a genuine, two-way, human relationship.

3.2.2. The impact of the relationship with an EIS staff member

As outlined in Theme 1, a stable, genuine relationship with EIS staff appeared to be the cornerstone on which future progress under EIS was built upon. Exploring this further and examining the direct impact of this relationship on recovery yielded three sub-themes: an increased sense of agency; improved quality of interactions with others; and an improved sense of identity.

3.2.2.1. Sense of agency

A positive working relationship with EIS appeared to have a direct impact on the reported level of agency individuals felt they had with regards to their mental health difficulties. Agency here refers to the degree to which individuals felt they had ‘control’ over their problems, or ability to deal with related issues. Harris et al. (2011) explicitly link the development of a good rapport with EIS with an increased sense of mastery and control over the symptoms and impact of psychosis, while O’Toole et al (2004), Jansen et al. (2015) and Tindell et al. (2015) discussed the empowering nature of gaining a sense of control over one’s psychosis as a result of engaging with EIS and building therapeutic relationships. This increased sense of agency was viewed as a highly valued by-product of engagement for many service users:

...even if I do hear voices, I know that it's not actually people talking, I know it's actually just going off in my own brain... I'm able to think, I can challenge it myself... Jane (EIS Psychologist) helped with that... when I do hear the voices, I go straight to my list that I got off Jane and it works... (Participant in Harris et al, 2011).

This suggests that the presence of a wiser other figure that service users trusted allowed for the gradual internalisation of the methods and techniques EIS staff employed to help manage their difficulties, meaning they were gradually able to utilise such techniques without the help of EIS.

Engagement with EIS also had an impact upon the extent to which carers felt they themselves had agency, or at least some degree of control, over their responses to their loved ones' difficulties. For many, the experience of having a positive relationship with staff and subsequently receiving psychoeducation enabled many carers to feel better able to support their family member and respond accordingly to acute episodes (McCann et al., 2011; Sin et al., 2012; Lavis et al., 2015):

They've all been fantastic [clinicians] in including us when they could, in treating... [son's name] and explaining everything to us. There's some very good information and fact sheets put out [by clinicians] and that's all very supportive of us and enables us to provide that information to friends of...[son], to let them understand what's going on...

(Participant in McCann et al., 2011).

This process appears to be less dependent on internalising information, as in service users' experiences, and rather more based on the acquisition and subsequent application of practical advice and information, on a much more pragmatic basis. This arguably reflects

the different needs of service users and carers, with the former requiring a deeper sense of agency in order to cope with the phenomenological experience of psychosis, and the latter needing a sense of mastery over the everyday, practical impact of psychosis.

3.2.2.2. Interactions with others & relationships outside of EIS

As with the process of internalising a sense of agency, many papers note that through forming a secure, stable bond with EIS staff, service users gained a framework of a positive relationship that they could take forward into other relationships, such as with family members (Lester et al., 2011; Allard et al., 2016) or future mental health services (Harris et al., 2011; Stewart 2012). Such findings would suggest that the introduction of a positive relationship in the safe, managed environment of EIS provided service users with the confidence to explore similar experiences in other areas of their lives:

...I'm more willing to say, 'This is what I'm experiencing,' without feeling ashamed or seeing it as a weakness. I was scared about her [mother] getting worried and things like that. But she's been great (Participant in Lester et al., 2011).

It also seemed that their [service users'] positive relationships with [EIS] staff prevented negative beliefs about initial treatment from generalizing across all staff relationships and defining future treatment experiences... (Stewart, 2012).

Similar experiences were reported by carers and/or family members, who reported seeing the benefits of the client-staff relationship:

He [participant's son] seems happier since he's been seeing someone on a regular basis and he seems more able to talk to us now. He's opening up and talking about things, you know, like how he feels, what's happening in his life. I think that the EIS

have made him feel that it's okay to talk and to say how you feel about things, you know... (Participant in Allard et al. (2016).

This was also noted in Penny, Newton & Larkin (2009), in which, although many family members felt there were aspects of the service they were dissatisfied with, the value of their loved one having a genuine relationship with a key-worker was held in high esteem. It can therefore be postulated that the formation of a trusting connection with an external party (EIS) provided a much-needed 'breathing space' for both sides of the service user-carer relationship. With this breathing space, both were able to gradually work on establishing positive bonds with each other again, with the burden of managing the difficulties associated with psychosis eased by the introduction of another source of support that was involved enough to have a positive impact, but removed enough so as not to interfere with the dynamics of the familial relationship.

3.2.2.3. Improved sense of identity

Another benefit of service users establishing a positive bond with at least one EIS staff member was that for many, it appeared to aid in reframing their sense of identity, from feeling essentially flawed or damaged, to being increasingly accepting and compassionate towards their difficulties (Harris et al., 2011; Lester et al., 2012; Stewart, 2012). This suggests that for many, the space to talk freely about their problems with someone they could trust and receive useful information from helped service users, in essence, to rewrite their personal narrative, thereby no longer seeing themselves as fundamentally 'broken', but rather a multi-faceted individual who happened to be dealing with mental health difficulties:

I know my [EIS staff member] wants us to believe that we can get through this... I quickly got from that I'm not the problem, the problem is the problem...

(Participant in Stewart, 2012).

Of the papers, only O'Toole et al. (2004) explored this development further, postulating that although receiving practical help such as psychoeducation is important, a much more latent process may be involved in this internalisation, with service users strongly identifying with services and their ethos, integrating it into their newly formed, post-psychosis, identity:

The main observation is that participants strongly identified with the team, its philosophy and goals... participants seemed to have taken on the identity of the team as their own...

(O'Toole et al, 2004).

This was not universally reported, however, as for a smaller number of service users, this reframing, and indeed involvement with EIS in general, was not such a positive experience and only served to reinforce their perception of themselves as different from others:

I used to be a normal person you know... you feel so alone, and you feel jealous of normal people (Participant in Lester et al., 2011).

Engagement with EIS also appeared to have a positive impact on many service users' sense of identity within the context of wider society. Many studies refer to the social isolation experienced by service users prior to involvement with EIS; subsequently, a number also report that through engaging with EIS, individuals were increasingly able to integrate themselves back into society and view themselves as a member of a wider community, whether this was amongst peers (Stewart, 2012; van Schalkwyk et al., 2015) or within society in a broader sense (O'Toole et al., 2004; Lester et al., 2012; Tindell et al. 2015).

EIS facilitated peer groups were identified as helpful in achieving this, serving to further reduce social isolation and providing opportunities to disprove negative beliefs about the self, such as being alone in their difficulties (Harris et al., 2011; Stewart, 2012; Lester et al., 2012). In addition to this, the practical support offered by EIS in gaining life skills and helping with issues such as employment was also seen as important in helping service users feel a sense of identity within wider society, again suggesting that the gradual internalisation of the help and support provided by a ‘wiser other’ enabled lasting change that could be taken beyond EIS involvement (Tindell et al., 2015; van Schalkwyk et al., 2015).

3.2.3. Life after EIS

Building upon the process of taking the support and advice beyond engagement with EIS, a third overarching theme emerged from the data around consideration of life after EIS. This included two sub-themes: the hope of living a ‘normal’ life, and hopes and fears post-discharge.

3.2.3.1. Living a ‘normal’ life

A common goal for recovery identified by service users was the hope of achieving some degree of ‘normality’ in life, which could be sustained after leaving services. This goal was highly valued and was seen as more important than specific, more measurable goals, such as symptom reduction (Harris et al., 2011; Tindell et al., 2015; Lester et al., 2012; O’Toole et al., 2004). Although this sense of normality is highly subjective and overlaps with the sub-themes of improved agency and identity, it particularly highlights the acquisition of very practical ‘skills’ that can be applied to everyday situations into the ongoing recovery process, again something that cannot be easily operationalised or quantified:

The first clinician... he was cool. He really knew what I was going through when I was trying to find work, the struggle about it. Getting up, getting your clothes on, going to interviews, coming back home, doing follow-ups... He really sounded like he could actually relate to what it was I was going through. And he gave me advice on how to talk to girls, how to fix a car, simple things (Participant in van Schalkwyk et al., 2015).

That is not to say symptom reduction and continued stability was not seen as important to service users, and many did state this to be a positive experience of recovery (O'Toole et al., 2004; Lester et al., 2011; Harris et al., 2011; van Schalkwyk et al., 2015). However, in the main, the reintegration into society and increased efficacy in dealing with 'everyday' difficulties was valued as more important.

Many carers also reported similar findings. When discussing the recovery process, many carers saw the process of their loved one gaining confidence and increased engagement with wider communities as a priority, more so than symptom reduction or medication management (Penny et al., 2009; Allard et al., 2016):

I want him to have good company, because that's like medication (Participant in Penny et al., 2009).

3.2.3.2. Hopes and fears for the future

Although some papers report initial scepticism from service users during the early stages of engagement (Stanbridge et al., 2003), once a good relationship was established (as in Theme 1), many report a subsequent sense of relief and optimism for the future (Stewart et al., 2012; Lester et al., 2012; Jansen et al., 2015):

They encourage me to be interested in things and to think that I have a future. I thought my life was coming to an end and they kind of encourage me to see that there is life after psychosis... (Participant in Lester et al., 2012).

This was also reported in carers' recollections of EIS involvement. Allard et al. (2016) report that many carers felt an immediate sense of relief once they felt services were able to offer support and share the burden of care, something also reported in McCann et al. (2011) and Lavis et al. (2015):

...when they rang and said that they were going to take her (carer's daughter) on and, you know, I can't remember what happened after that, it was just such a relief...

(Participant in Allard et al., 2016).

In several instances, however, the optimism carers experienced gradually wore off and one paper reported carers expressing their concerns that EIS may have been overly optimistic in their initial appraisals and plans for engagement (Penny et al., 2009). Additionally, Lavis et al. (2015) reported that although carers saw the recovery of their loved one as more important than their own needs, over time, some frustrations grew that their own emotional needs were not considered by EIS. This was echoed in McCann et al. (2011) and also in Sin et al. (2012), which explored the views of siblings of individuals accessing EIS. These authors found that, like a significant minority of carers reported in other papers, though they self-identified as a cog within the mechanism of recovery alongside EIS, they felt there were insufficient resources to cope with both the enduring practical implications of caring for a loved one experiencing psychosis, and their own emotional responses. This suggests that although initial relief and optimism instilled by EIS involvement may be a highly valued component of services, the lack of continued emotional and practical support

for carers or family members result in reduced optimism for their own futures, post-EIS, even if the service users themselves still hold an optimistic view of their chances of being able to lead a sustained ‘normal’ life.

4. Discussion

The importance of a strong relationship with EIS staff was the most prominent theme throughout the papers reviewed and permeated subsequent themes. The quality of this relationship appeared to be the single most important factor in determining whether the experience of accessing EIS was a positive or negative one, for both service users and carers. This is in line with existing research that has highlighted the similarities between the nature of relationships built with mental health services and attachment bonds (Bucci et al., 2014), in that inconsistent or sub-optimal relationships are often associated with increased scepticism and reluctance to engage with mental health services (Catty et al., 2012), while a strong therapeutic bond can be linked to increased positive outcomes in service users (Lambert & Barley, 2001). More specifically, such findings have been reported when investigating relationships with EIS, in that forming an avoidant or insecure attachment with staff predicted reduced engagement with EIS (Gumley et al., 2014), whereas a secure, trusting bond was linked with increased trust and engagement (Mallinckrodt, 2010; Laugharne, Priebe & McCabe, 2011).

When considering this relational bond, many of the findings in this review suggest that through interacting with a trusted member of staff, who was perceived as knowledgeable and emotionally available, service users were able to learn and gradually internalise received advice and support, to the extent that they were eventually able to manage their difficulties independently. This is akin to the concept of ‘scaffolding’ (Fernandez, Wegerif,

Mercer & Drummond, 2002), a process at the core of the Zone of Proximal Development (ZPD) theory. ZPD can be applied to learning in an educational sense (Hedegaard, 2005), but also with regards to emotional and cognitive development (Ryle & Kerr, 2003) and postulates that an individual learns how to complete a task (such as how to cope with auditory hallucinations in this instance) through interaction and increased co-facilitation with a trusted, more proficient other, until they eventually become independently skilful (Kozulin, 2003). This is important when considering that in the papers reviewed, many service users identified their primary goals as ones that would require such a process of internalising received wisdom, including learning ways to cope with distressing aspects of psychosis. Importantly, and in line with ZPD, these are achievements that would hopefully continue post-discharge when the EIS worker was no longer available to help. As this is a relational process, building a strong, genuine rapport is essential.

That carers also reported finding support in the relationships they themselves formed with EIS demonstrates the importance of developing a good rapport beyond the service user-staff dynamic. Previous literature has outlined the impact caring for a loved one experiencing psychosis can have on carers or family members, including increased isolation, stress, decline in social functioning and increased economic difficulties (Awad & Voruganti, 2012). Once carers and wider family networks have engaged with services, however, research has indicated this can have a significant impact on their confidence in being able to offer help to their loved one and reduce the burden of care they had experienced prior to engagement (Awad & Voruganti, 2012), both of which were reported in the findings of this review. What was also acknowledged, however, was that although carers and family members valued EIS intervention, especially at first point of contact, a number often felt that as engagement progressed, their emotional well-being was not

sufficiently considered. This concurs with findings that family interventions may help the support systems around an individual experiencing psychosis with regards to practical matters, yet may not necessarily reduce caregiving distress (Szmuckler, Kuipers, Joyce, et al., 2003).

4.1. Clinical Implications

In accordance with existing research and theory, findings from this review suggest that one of the most valued aspects of engaging with EIS is the development and maintenance of a positive therapeutic bond with at least one member of staff. This is of clinical significance when placed alongside findings that difficulties in trusting others and forming new relationships are common in the experience of psychosis (Berry & Drake, 2010) and is of further importance when considering that the benefits of this can extend to service users' support networks and families. The focus of EIS initially should be directed towards initial engagement once an individual is referred to EIS, with effort placed on creating a genuine, two-way relationship to devise an individualised care plan that places at the heart of it the service users' hopes for recovery. Once achieved, the maintenance of this bond is integral in enabling continued engagement and extending this to wider support networks, including carers and family members. If involving members of the wider support network, caution must be exerted in setting expectations too high; though the introduction of extra support may instil confidence and optimism initially, the emotional needs of all parties must be considered as engagement continues (Bucci et al., 2014).

4.2. Limitations and Future Research

There are several limitations to consider. As meta-synthesis is still an emerging practice, there is not yet an established gold standard for the searching and synthesising of qualitative findings (Thomas & Harden, 2008); it is possible that a number of eligible papers were not identified and included. Papers that were included, however, were thoroughly read and references were hand-checked, thereby minimising the likelihood of this and reducing the chance potentially important findings or themes were missed. Another inherent limitation with synthesising qualitative data is that this is, in effect, synthesising others' findings. There is a possibility, therefore, that data omitted by the authors of the papers reviewed may have altered the findings of this review; however, the fact that there were similar findings across many of the papers again reduces this likelihood. More specifically, the majority of the studies reviewed were conducted in UK or Australia, and only one study specifically examined the experiences of an ethnic minority sample (Penny et al., 2009). This, therefore, reduces the transferability of many of the findings, particularly considering the varying structures of many nations' healthcare systems. Future research could consider exploring views and experiences of important but currently underrepresented groups so that their viewpoints are heard too. Additionally, due to practical limitations, it was not possible to search 'grey' literature, that is, papers that are not yet published. This is another consideration for future research.

REFERENCES

- Allard, J., Lancaster, S., Clayton, S., Amos, T., & Birchwood, M. (2016). Carers' and service users' experiences of early intervention in psychosis services: Implications for care partnerships. *Early Intervention in Psychiatry*, (June 2010), 1–7.
doi.org/10.1111/eip.12309
- Anderson, K. K., Fuhrer, R., & Malla, A. K. (2013). “There are too many steps before you get to where you need to be”: Help-seeking by patients with first-episode psychosis. *Journal of Mental Health*, 22(4), 384-395.
doi:10.3109/09638237.2012.705922
- Awad, A. G., & Voruganti, L. N. (2008). The burden of schizophrenia on caregivers. *Pharmacoeconomics*, 26(2), 149-162. doi:10.2165/00019053-200826020-00005
- Bechard-Evans, L., Schmitz, N., Abadi, S., Joober, R., King, S., & Malla, A. (2007). Determinants of help-seeking and system related components of delay in the treatment of first-episode psychosis. *Schizophrenia research*, 96(1), 206-214.
doi:10.1016/j.schres.2007.07.017
- Bennion, A. E., Shaw, R. L., & Gibson, J. M. (2012). What do we know about the experience of age related macular degeneration? A systematic review and meta-synthesis of qualitative research. *Social science & medicine*, 75(6), 976-985.
doi:10.1016/j.socscimed.2012.04.023

Berry, K., & Drake, R. (2010). Attachment theory in psychiatric rehabilitation: informing clinical practice. *Advances in psychiatric treatment*, 16(4), 308-315.

doi:10.1192/apt.bp.109.006809

Bird, V., Premkumar, P., Kendall, T., Whittington, C., Mitchell, J., & Kuipers, E. (2010). Early intervention services, cognitive-behavioural therapy and family intervention in early psychosis: systematic review. *The British Journal of Psychiatry*, 197(5), 350-356. doi:10.1192/bjp.bp.109.074526

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101doi: 10.1191/F1478088706qp063oa

Bucci, S., Roberts, N. H., Danquah, A. N., & Berry, K. (2015). Using attachment theory to inform the design and delivery of mental health services: A systematic review of the literature. *Psychology and Psychotherapy: Theory, Research and Practice*, 88(1), 1-20. doi:10.1111/papt.12029

Catty J, White S, Koletsi M, Becker T, Fioritti A, Kalkan R, Lauber C, Lissouba P, Rössler W, Tomov T, van Busschbach JT, Wiersma D, Burns T, (2012). Therapeutic relationships in vocational rehabilitation: predicting good relationships for people with psychosis. *Psychiatry Res.* 187(1-2) 68-73.
doi:10.1016/j.psychres.2010.10.018. PMID: 21094532.

Craig, T. K., Garety, P., Power, P., Rahaman, N., Colbert, S., Fornells-Ambrojo, M., & Dunn, G. (2004). The Lambeth Early Onset (LEO) Team: randomised controlled trial of the effectiveness of specialised care for early psychosis. *Bmj*, 329(7474), 1067. doi:10.1136/bmj.38246.594873.7C

Critical Appraisal Skills Programme (2018). CASP Qualitative Checklist. [online]
Available at: <http://casp-uk.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-Download.pdf> Accessed: 18/11/2017

Daniels, H. (Ed.). (2005). *An introduction to Vygotsky*. Psychology Press.

Duggleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C., & Williams, A. (2010). Metasynthesis of the hope experience of family caregivers of persons with chronic illness. *Qualitative Health Research*, 20(2), 14-158.
DOI:10.1177/1049732309358329

Ennis, L., & Wykes, T. (2013). Impact of patient involvement in mental health research: longitudinal study. *The British Journal of Psychiatry*, 203(5), 381-386.
doi:10.1192/bjp.bp.112.119818

Fernández, M., Wegerif, R., Mercer, N., & Rojas-Drummond, S. (2001). Re-conceptualizing "scaffolding" and the zone of proximal development in the context of symmetrical collaborative learning. *The journal of classroom interaction*, 40-54.

- Finfgeld, D. L. (2003). Metasynthesis: The state of the art—so far. *Qualitative health research*, 13(7), 893-904. doi:10.1177/1049732303253462
- Fletcher, A. J. (2017). Applying critical realism in qualitative research: methodology meets method. *International Journal of Social Research Methodology*, 20(2), 181-194. doi:10.1080/13645579.2016.1144401
- Gumley, A. I., Taylor, H. E. F., Schwannauer, M., & MacBeth, A. (2014). A systematic review of attachment and psychosis: measurement, construct validity and outcomes. *Acta Psychiatrica Scandinavica*, 129(4), 257-274. doi:10.1111/acps.12172
- Gurung, D., Upadhyaya, N., Magar, J., Giri, N. P., Hanlon, C., & Jordans, M. J. (2017). Service user and care giver involvement in mental health system strengthening in Nepal: a qualitative study on barriers and facilitating factors. *International journal of mental health systems*, 11(1), 30. doi:10.1186/s13033-017-0139-1
- Harris, K., Collinson, C., & das Nair, R. (2012). Service-users' experiences of an early intervention in psychosis service: An interpretative phenomenological analysis. *Psychology and Psychotherapy-Theory Research and Practice*, 85(4), 456–469. doi:10.1111/j.2044-8341.2011.02043.x
- Jansen, J. E., Pedersen, M. B., Hastrup, L. H., Haahr, U. H., & Simonsen, E. (2018). Important first encounter: Service user experience of pathways to care and early

detection in first-episode psychosis. *Early intervention in psychiatry*, 12(2), 169-176.

Knapp, M., Patel, A., Curran, C., Latimer, E., Catty, J., Becker, T., & Rössler, W. (2013). Supported employment: Cost-effectiveness across six european sites. *World Psychiatry*, 12(1), 60-68. doi:10.1002/wps.20017

Knapp, M., Andrew, A., McDaid, D., Iemmi, V., McCrone, P., Park, A. L., & Shepherd, G. (2014). Investing in recovery: making the business case for effective interventions for people with schizophrenia and psychosis. Accessed: <http://eprints.lse.ac.uk/56773/>

Kozulin, A. (Ed.). (2003). *Vygotsky's educational theory in cultural context*. Cambridge University Press.

Lambert, M. J., & Barley, D. E. (2001). Research summary on the therapeutic relationship and psychotherapy outcome. *Psychotherapy: Theory, research, practice, training*, 38(4), 357. doi:10.1016/j.tree.2016.11.005

Laugharne, R., Priebe, S., McCabe, R., Garland, N., & Clifford, D. (2012). Trust, choice and power in mental health care: Experiences of patients with psychosis. *International Journal of Social Psychiatry*, 58(5), 496-504. doi:10.1177/0020764011408658

- Lavis, A., Lester, H., Everard, L., Freemantle, N., Amos, T., Fowler, D., ... Birchwood, M. (2015). Layers of listening: Qualitative analysis of the impact of early intervention services for first-episode psychosis on carers' experiences. *British Journal of Psychiatry*, 207(2), 135–142. doi.org/10.1192/bjp.bp.114.146415
- Lecomte, T., Spidel, A., Leclerc, C., MacEwan, G. W., Greaves, C., & Bentall, R. P. (2008). Predictors and profiles of treatment non-adherence and engagement in services problems in early psychosis. *Schizophrenia Research*, 102(1), 295-302. doi:10.1016/j.schres.2008.01.024
- Lester, H., Khan, N., Jones, P., Marshall, M., Fowler, D., Amos, T., & Birchwood, M. (2012). Service users' views of moving on from early intervention services for psychosis: A longitudinal qualitative study in primary care. *British Journal of General Practice*, 62(596), e183–e190. Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=emed14&AN=364361587>
- Lester, H., Marshall, M., Jones, P., Fowler, D., Amos, T., Khan, N., & Birchwood, M. (2011). Views of young people in early intervention services for first-episode psychosis in England. *Psychiatric Services*, 62(8), 882–887. Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=psyc8&AN=2011-24795-004>

- Mallinckrodt, B. (2010). The psychotherapy relationship as attachment: Evidence and implications. *Journal of Social and Personal Relationships*, 27(2), 262-270.
doi:10.1177/0265407509360905
- Malpass, A., Shaw, A., Sharp, D., Walter, F., Feder, G., Ridd, M., & Kessler, D. (2009). “Medication career” or “moral career”? The two sides of managing antidepressants: a meta-ethnography of patients' experience of antidepressants. *Social science & medicine*, 68(1), 154-168. doi:10.1016/j.socscimed.2008.09.068
- Marshall, M., & Rathbone, J. (2011). Early intervention for psychosis. *Schizophrenia bulletin*, 37(6), 1111-1114. doi:10.1093/schbul/sbr110
- McCann, T. V., Lubman, D. I., & Clark, E. (2012). Primary caregivers' satisfaction with clinicians' response to them as informal carers of young people with first-episode psychosis: A qualitative study. *Journal of Clinical Nursing*, 21(1–2), 224–231.
Retrieved from
<http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=psyc9&AN=2011-28854-025>
- Mccann, T. V., Lubman, D. I., & Clark, E. (2011). First-time primary caregivers' experience accessing first-episode psychosis services. *Early Intervention in Psychiatry*, 5(2), 156–162. doi:10.1111/j.1751-7893.2010.00246.x

- Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & Prisma Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS medicine*, 6(7). doi:10.1371/journal.pmed.1000097
- 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(3), 319–326. doi:10.1111/j.1365-2850.2004.00730.x
- Paterson, B. L., & Canam, C. (2001). *Meta-study of qualitative health research: A practical guide to meta-analysis and meta-synthesis* (Vol. 3). Sage.
- Penny, E., Newton, E., & Larkin, M. (2009). Whispering on the water: British Pakistani families' experiences of support from an early intervention service for first-episode psychosis. *Journal of Cross-Cultural Psychology*, 40(6), 969–987. Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=psyc6&AN=2009-25102-006>
- Revier, C. J., Reininghaus, U., Dutta, R., Fearon, P., Murray, R. M., Doody, G. A., ... & Kravariti, E. (2015). Ten-year outcomes of first-episode psychoses in the MRC ÆSOP-10 study. *The Journal of nervous and mental disease*, 203(5), 379. doi:10.1097%2FNMD.0000000000000295
- Ryle, A., & Kerr, I. B. (2003). *Introducing cognitive analytic therapy: Principles and practice*. John Wiley & Sons.

Sandelowski, M., Docherty, S., & Emden, C. (1997). Focus on qualitative methods

Qualitative metasynthesis: issues and techniques. *Research in nursing and health*, 20, 365-372.

Schey, K. L., Luther, J. M., & Rose, K. L. (2016). HHS Public Access, 86(4), 1–21.

doi:10.1021/acscemneuro.5b00094.Serotonin

Schizophrenia Commission. (2012). The abandoned illness: a report from the

Schizophrenia Commission. *London: Rethink Mental Illness*

Seidman, I. (2013). Interviewing as qualitative research: A guide for researchers in

education and the social sciences. *Teachers college press*.

Sin, J., Moone, N., Harris, P., Scully, E., & Wellman, N. (2012). Understanding the

experiences and service needs of siblings of individuals with first-episode psychosis: A phenomenological study. *Early Intervention in Psychiatry*, 6(1), 53–59. doi:10.1111/j.1751-7893.2011.00300.x

Stewart, K. D. (2013). Factors contributing to engagement during the initial stages of

treatment for psychosis. *Qualitative Health Research*, 23(3), 336–347.

doi:10.1177/1049732312468337

Szmukler, G., Kuipers, E., Joyce, J., Harris, T., Leese, M., Maphosa, W., & Staples, E.

(2003). An exploratory randomised controlled trial of a support programme for

carers of patients with a psychosis. *Social psychiatry and psychiatric epidemiology*, 38(8), 411-418. doi:10.1007/s00127-003-0652-1

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC medical research methodology*, 8(1), 45. doi:10.1186/1471-2288-8-45

Thornicroft, G., & Tansella, M. (2005). Growing recognition of the importance of service user involvement in mental health service planning and evaluation. *Epidemiology and Psychiatric Sciences*, 14(1), 1-3. doi:10.1017/S1121189X00001858

Tindall, R., Francey, S., & Hamilton, B. (2015). Factors influencing engagement with case managers: Perspectives of young people with a diagnosis of first episode psychosis. *International Journal of Mental Health Nursing*, 24(4), 295–303. Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=psyc12&AN=2015-22383-001>

Yardley, L., & Bishop, F. (2008). Mixing qualitative and quantitative methods: A pragmatic approach. *The Sage handbook of qualitative research in psychology*, 352-370.

Zimmer, L. (2006). Qualitative meta-synthesis: a question of dialoguing with texts. *Journal of advanced nursing*, 53(3), 311-318. doi:10.1111/j.1365-2648.2006.03721.x

Paper 2

Moving on from Early Intervention: The Facilitators and Barriers of Transition

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Word count

Main body: 6272

Reference list: 975

Tables & figures: 100

Abstract

Early Intervention for psychosis Services (EIS) have been established worldwide and are offered to individuals experiencing a first episode of psychosis (FEP). Engagement with EIS typically lasts for three years, after which point, service users are either transferred to primary care (e.g. General Practitioner; GP) or Community Mental Health Teams (CMHT), according to perceived needs. Although NICE guidelines recommend this transfer of care should be arranged in conjunction with the receiving service, there exists little, if any, further practical guidance as to how this should actually be managed or implemented. This is of note, as the NHS Constitution (2015) pledges to ensure that any transition of care between any two services is as smooth as possible.

To date, only one small-scale study has examined service users' perspectives on the experience of transitioning from EIS (Lester et al, 2012). This study however solely focussed on transitioning to primary care. A further study (Woodward, 2017, in review) has explored EIS staff members' views on the discharge process. This current study aims to investigate the barriers and facilitators of transition from EIS to both primary and secondary care services from the perspectives of service users who have already been transitioned from EIS to other services.

Semi-structured interviews were completed with participants (n=15) who had either been discharged to primary care or to Community Mental Health Teams (CMHTs) and analysed using Interpretive Thematic Analysis, adopting a critical realist stance. Analysis identified five main themes: feeling ready for discharge, relationships and trust, planning for discharge, expectations of future care and the safety net of early intervention. The results and discussions offer practical implications and recommendations for services.

Keywords: *Early Intervention, Psychosis, Transition, Discharge, Qualitative Research*

1. Introduction

It is estimated that approximately 31.7 per 100,000 individuals in England will at some point in their lives experience psychosis (Kirkbride et al., 2012), with the vast majority of first episode of psychosis (FEP) occurring before the age of 35 (Kirkbride et al., 2006). The impact of this, upon both the individual and wider society, has been the focus of much research within recent years, much of it highlighting the negative effects of distressing psychosis if untreated. It is currently estimated, for instance, that individuals with severe and enduring mental health problems, such as psychosis, are up to five more times likely to require urgent hospital admission for physical health problems (NICE, 2016) and have an average life expectancy up to 20 years lower than the general population (Wahlbeck, Westman, Nordentoft, Gissler & Laursen, 2011). Additionally, there are often a range of implications for the families and support networks of the individual experiencing psychosis as they take on caring responsibilities amidst a highly emotive period (Tindell et al., 2015; Penny et al., 2016). Furthermore, financial costs are huge; a 2012 report estimated that psychosis costs the UK economy over £11 billion per year (The Schizophrenia Commission, 2012). The early phase of psychosis is, therefore, a critical period for early intervention and support so as to increase the likelihood of recovery and minimise the negative effects of distressing psychotic experiences.

Early Intervention for psychosis Services (EIS) have been established worldwide and are offered to individuals experiencing a first episode of psychosis (FEP). EIS in the UK operate within a multi-disciplinary framework, assigning a care co-ordinator to service users to devise an agreed individualised care plan, which can include a range of evidence-based psychosocial and pharmacological interventions ('Implementing the Early Intervention in Psychosis Access and Waiting Time Standard' 2016). Support is often of a more intensive nature than other secondary care services, adopting an assertive outreach

approach, which can extend to include family members and carers. Engagement with EIS typically lasts for three years, after which point, if the service user has responded well to intervention and has achieved a degree of stability, is discharged back to primary care services (e.g. General Practitioner; GP). If ongoing support is required, then care is transferred typically to another secondary service, such as a Community Mental Health Team (CMHT; NICE, 2014). Although the NICE guidelines for the prevention and management of psychosis and schizophrenia in adults (NICE, 2014) outline that this transfer of care should be arranged in conjunction with the receiving service, there exists little, if any, practical guidance as to how this should actually be managed or implemented. This is of clinical importance, as relapse following EIS input is not uncommon (Craig et al., 2004; Kam, Singh & Upthegrove, 2013), with some studies suggesting that gains made under EIS can be reversed in the three years following discharge (Bertelsen et al., 2008). The lack of clarification around what constitutes a ‘good’ transition from an EIS also has wider clinical implications, as the NHS Constitution (2015) pledges to ensure that any transition of care between any two services is as smooth as possible, placing service users and family members or carers at the heart of any decision making.

Although research exists exploring general transitions within mental health systems (Jones, Ahmed, Catty et al, 2009; Singh, Paul, Ford et al, 2010; Vigod et al, 2013), research into the specific transfer of care from an EIS is scarce. To our knowledge, only one small-scale study has examined service users’ perspectives on the experience of transitioning from EIS (Lester et al, 2012). Using semi-structured interviews and thematic analysis, three major themes emerged: EIS providing “gold standard” care, a standard that was not replicated in other services post-discharge; continuity of care was not always well established prior to discharge; while under the care of EIS, service users felt the need to use primary care resources significantly less. However, the study only focussed on transfer between EIS and

primary care services. In another study, while not focused on service users' experiences of transition, Woodward and colleagues (2018) explored EIS staff members' views and perceptions regarding the barriers and facilitators of transition for service users. Four themes were identified: the sense that service users remained 'stuck' in EIS due to lack of resources elsewhere; the challenges services face when trying to work across boundaries; the subjective sense of loss experienced when the therapeutic relationships comes to an end; and the importance of advance planning, which is seen as key in ultimately leading to service user empowerment. Building on the findings of these two studies, the aim of the current study is to use qualitative methods to investigate the barriers and facilitators of transition from EIS to both primary and secondary care services from the perspectives of service users who have already been transitioned from EIS to other services.

2. Method

2.1. Design

The current study used a qualitative design and used thematic analysis (Braun & Clarke, 2006) to analyse data from a critical realist perspective (Fletcher, 2017).

2.2. Sampling and Procedure

Once ethical approval was obtained, participants were recruited from EIS and CHMTs across the North-West of England, using convenience sampling. This involved contacting care co-ordinators and asking them to disseminate information to service users who met study eligibility. Following consent to contact, the researcher contacted participants to arrange the interview. Inclusion criteria were: (i) being previously registered with an EIS; (ii) having been discharged from the EIS within the previous 12 months; (iii) willingness to be audio-recorded; and (iv) the ability to speak fluent English. Twenty-one individuals expressed an interest in taking part in the study; two of these later declined due to

reluctance to be audio-recorded and three failed to respond after initial inquiry. This left a sample of 16 individuals who gave informed consent to be interviewed. At one interview, it was established that the participant was not fluent in English and unable to fully understand the questions and communicate responses. As a result, the participant was not deemed eligible to take part, leaving a total of 15 completed interviews.

Interviews were conducted in locations preferable to participants (own home or at service base), were digitally recorded and lasted between 16 and 50 minutes (mean: 30 minutes).

The topic guide was based on the research question, previous research (Lester, 2011; Singh et al, 2008) and service user and staff consultation, consisting of open-ended questions covering: (i) participants' experiences of EIS (e.g. *"What kind of impact did being in the service have on your life?"*); (ii) general views of the transition process (e.g. *"When did you find out you would be leaving EI?"*); (iii) perceptions of changes in care since discharge (e.g. *"What kinds of changes have you noticed since you left EI?"*); and (iv) opinions regarding helpful and unhelpful factors during the transition period (e.g. *"Was there anything that made the process easier for you?"*). As interviews proceeded, the topic guide was revised and altered to explore areas concerning new information that emerged during previous interviews. The topic of trusting staff in making decisions regarding discharge for instance, emerged during the early interviews so was interwoven into the revised topic guide. A reflective journal was kept during the interview process, with the researcher making notes regarding process issues that occurred during interviews to help further aid the coding process and preliminary analyses.

2.3. Data Analysis

Interviews were transcribed verbatim and subject to thematic analysis. Thematic analysis was the chosen method due to its flexible nature, facilitating explorative approach of the

data (Braun & Clarke, 2006). All transcripts were read and initially coded by the primary researcher, using NVivo software. Other members of the research team independently coded two transcripts, which were discussed in conjunction with the primary researcher's coding and reviewed for consensus. Where conflicting opinions arose, further discussion followed and, as required, the original recordings were returned to for further clarity. Subsequently, codes were grouped into themes and potential themes were reviewed by all members of the research team to ensure that they: (i) accurately reflected the data; (ii) were related to the research question; and (iii) were distinct enough so as not to be covering the same theoretical points as other themes. Following this initial grouping of data, the primary researcher further refined the themes to ensure they reflected the data. Once this was complete, the team again reviewed the themes and sub-themes.

2.4. Reflexivity

In qualitative analysis, reflexivity refers to the process of acknowledging the researchers' subjective experiences and how this may influence the process of analysing and interpreting data (Mosselson, 2010).

The first author is a Trainee Clinical Psychologist, who has previously worked in a community mental health multi-disciplinary setting, similar to one that many of the participants would have been discharged to. Additionally, the second and third authors are qualified Clinical Psychologists, who have experience of working with individuals with psychosis and researching the nature of attachments shared between service users and care co-ordinators. As such, the research team acknowledge that their shared knowledge and experiences may have had an impact upon interpretation of the data. For instance, their experiences of researching and developing therapeutic alliances with service users may have led to increased focus during analysis on the relational aspect of the discharge process

and may have overlooked, to some degree, the practical aspects of discharge. This however, was balanced to some degree by the inclusion of the fourth author, who was independent from the rest of the research team and held a non-clinical post. It was reasoned this added an element of objectivity to the analysis of the data. Additionally, the first author's experience of working alongside care co-ordinators who regularly received cases of transferred care from EIT was also reflected upon, should it cloud any judgement during the stages of analysis. It was acknowledged, for example, that there was a possibility that being aware of the pressures and demands placed upon care co-ordinators in CMHTs may have contributed to an expectation of service users to report feeling dissatisfied with the reduced level of care since leaving EIS.

Care was taken through supervision and the process of keeping a reflective journal to minimise the extent to which these experiences might dominate the analysis and ensured that the process of coding and formation of themes remained data-driven.

3. Results

3.1. Participant Characteristics

Participants were recruited from EIS and CMHTs within five NHS Trusts in the North West of England. Further information on the nature of the services and data relating to caseloads were not obtained at point of recruitment; however, the services covered predominantly urban populations and were multi-disciplinary in nature.

As illustrated in Table 1, most participants were male (n=13). Of the 15 participants, 10 had their care transferred to a CMHT while five were discharged back to Primary Care (i.e. GP, rather than a designated Mental Health team).

Table 1: Demographics of Participants

Participant Number	Gender	Time with EIS (years)	Service discharged to
01	Male	3	CMHT
02	Male	2.5	CMHT
03	Male	2	CMHT
04	Male	3	CMHT
05	Male	3	CMHT
06	Male	3	CMHT
07	Male	3	CMHT
08	Male	2.5	GP
09	Female	3	CMHT
10	Male	3	CMHT
12*	Male	3	GP
13	Male	3	GP
14	Male	2.5	GP
15	Male	2.5	GP
16	Female	3	CMHT

EIS – Early Intervention Service, CMHT – Community Mental Health Team, GP – General

Practitioner (Primary Care)

* – Participant 11 did not complete interview due to language barriers

3.2. Key Themes

Five key themes were developed from the data: Feeling Ready for Discharge, Relationships and Trust, Planning for Discharge, Expectations of Future Care and the Safety Net of Early Intervention. These themes are described below and broken down into further sub-themes.

3.2.1. Feeling Ready for Discharge

The subjective sense of readiness to be discharged from EIS was a prominent theme throughout most interviews, with participants' views of their own recovery and reduced need for the service largely determining whether they felt ready to leave the service or not. In the majority of instances in which participants reported they did feel ready to move on from EIS, this coincided with an acknowledgement of achieving both a degree of subjective recovery (e.g. reduction of symptoms or increased efficacy in dealing with difficulties independently) and importantly, re-integration into society independent of EIS (e.g. gaining employment, joining social networks). Achieving this stability and independence was subsequently linked with a reduced sense of need for EIS, to the extent that several participants described a desire that EIS' resources be diverted to others in greater need:

...it was going that anyway, d'you know what I mean? Cos... I don't think I needed them. I'd rather the help went to someone who did need it... [Participant 8].

It is worth noting that this sense of feeling 'ready' was not linked with any dissatisfaction of EIS. Rather, in the vast majority of interviews, participants were extremely grateful of the support from EIS. However, they felt that, to some degree, outgrown that level of care. As such, the timing and news of discharge was not a major source of distress for these individuals, as they were, as participant 3 described it, "*getting on with life*".

Comparatively, in cases where service users had achieved a level of stability but crucially had not reintegrated into society (i.e. developed a degree of independence from EIS) and remained somewhat reliant upon the service for support either emotionally or practically, the news of discharge resulted in feelings of sadness or distress:

... they genuinely seemed more like friends than NHS workers... you know. It has that... sting of sadness... [Participant 12].

... it's not good news, it's horrible... it's like someone telling you your family have been in a car crash or something, that's the best way to explain it. Really, that's how horrible a feeling it is... [Participant 6].

In many of these cases, discharge was not seen as a natural progression towards recovery, but rather as disappointing (if inevitable) and, in extreme cases, abandonment, even though others, such as family members, may have viewed the transition as a positive step:

I was just sort of relying on my girlfriend, my Dad... and a few others. And they were the ones that were going "you should be really happy about it"... they don't understand...if a driver knows how to change gears and a non-driver just got in a car, they don't know how to change gears, it's like telling him "you should know how to change gears, you've sat in the passenger seat!"... [Participant 6].

Additionally, the news of imminent discharge for many in this situation brought fears of relapse or deterioration of mental health to the surface:

I was scared. I was like "argh! I don't wanna get ill!" And then "what happens if this... and that..."... [Participant 16].

3.2.2. Relationships and Trust

The nature of the relationship participants had with EIS and particularly specific healthcare professionals largely determined their views on discharge, both in terms of trusting EIS's decisions and how they viewed the forming of future relationships.

3.2.2.1. Trusting EIS' decisions (and the Limits of this Trust)

A strong benefit of a positive consistent relationship with at least one member of staff within an EIS was that interviewees felt safe in the knowledge that someone in the team was aware of the relevant information about them, both personally and professionally. The nature of this bond helped participants feel secure in the professionals' ability to take an objective view of the correct decisions to be made regarding their future care, irrespective of any emotional subjective impact:

For me, at the time, mentally, it was like... they said I was going to be transitioning and I didn't ask any questions; I didn't say "who's it going to be?" or "when will it actually happen?" I just kind of said "right OK, I'm going to be transitioned" ...

[Participant 4].

This trust was evident, not just in cases in which participants were too busy "*getting on with life*" (Participant 3), but also in cases in which individuals were saddened to leave the service, but also saw discharge as inevitable:

I trusted them to know what they were doing, to do... what was best for me, even if I thought different... [Participant 12].

In contrast, there were a smaller number of participants who felt they did not have a good relationship with EI staff, either through interpersonal differences with individual members of staff or inconsistent contact:

...he [EI keyworker] wasn't the right guy... [Participant 10].

...it's just a shame that I didn't get the full level of care... due to staffing... [Participant 3].

These participants were subsequently more likely to report feeling mistrusting of professionals in managing the handover of their care. In some cases, this resulted in them either opting to try and take charge of discharge themselves, or allow other trusted parties, such as family members, to do so:

To be honest, no, no. Nothing really helped me... but that's how I wanted it, sort of do-it-yourself... [Participant 3].

3.2.2.2. Forming New Relationships

Whilst there is some overlap with the sub-theme of trusting EI's decisions, participants' attitudes towards forming new relationships with post-EI services were also largely based upon the experiences of their relationship with EIS. Those who had developed a safe and stable relationship with their EI workers, for instance, felt open and secure, if somewhat nervous, to forming new relationships:

...everyone was great on the day, on the day of the transition, everyone came round and it was made clear, "right, you're with us now" and she [EI CPN] was saying farewell and that was it really, so you know.. yeah it was OK. Luckily, it was nice and smooth... [Participant 4].

For participants who had felt a strong, dependent bond with their EI worker, however, the prospect of forming new relationships was met with reluctance, for fear of feeling abandoned again at some point in the future:

I'd already felt lost and I was just cracking on with this, then this letter comes through, I'm just like... "You know what? I can't be bothered putting myself through all that" ... [Participant 6].

Likewise, participants who reflected that their relationships with EI were negative (again, through inconsistent care or personal differences) also reported feeling wary of forming new relationships with another service. This appeared to be based on their negative experiences and the subsequent residual feeling of dissatisfaction towards mental health services in general, as best highlighted in the reflective journal entry for the interview with participant 10:

Participant appeared to be very guarded when discussing EI, describing it at one point as "three wasted years". Lots of non-verbal cues (e.g. sighing, dismissive hand gestures) when talking about specific relationships with key-worker and psychiatrists – reluctant to elaborate and became very quiet and solemn at this point. When discussing new relationship with CMHT, again very reluctant to elaborate, emphasising his wariness of new staff... [Interviewer, Reflective Journal, Interview 10].

3.2.3. Planning for Discharge

Planning for leaving EIS, which can be categorised as a catalogue of practical factors that helped participants feel supported leaving the service, was a theme that was prominent in most interviews.

3.2.3.1. Clear Information

The value of clear information, often in the form of ‘discharge packs’ or comprehensive summary letters was highlighted in several interviews, with emphasis placed on important contact details and a clear outline of future plans for care (e.g. remit of the following service, if applicable, or clear outlines of who to contact in case of emergency). Such clear information helped many interviewees feel prepared for the discharge and confident in plans made for future care:

Definitely [give a] discharge pack to everyone... that’s the key thing, coz it gives you a piece of paper where you can look at it if you know you’re getting into a bit of difficulty and “here’s your number to ring”. You know, the 24-hour psych nurse, the psychiatrist at the hospital...

[Participant 1].

In cases where participants felt like they had not received clear information, this coincided with feeling unclear about current or future plans for care (to the extent that a number of interviewees were unclear about what team they were *currently* under) and uncertainty with regards to who to contact for support:

“There’s a lack of information, I’m not a mind-reader... basically, they always concentrate on the current, the present tense. It would have been nice to have a look into the future and say “right OK, in the future, this is gonna happen, that’s gonna happen”... [Participant 2].

Additionally, preparatory information about the discharge itself was greatly valued by many service users, who were grateful of being reminded about it in advance, so that by the time it arrived, it did not come as a great shock to them. One participant detailed scheduled meetings, solely concerned with planning for eventual discharge at the halfway point of involvement (i.e. roughly 18 months into engagement) and six months prior to

discharge, as being extremely useful, and many others reported basic knowledge of a final meeting (i.e. the purpose of it and who would be attending) to be helpful:

...it was very helpful. Cos sometimes going to these appointments, you don't know what to expect. Cos you're thinking... you just walk in and then... and then there'd be all these different doctors! So he told me what doctors are going to be there...
[Participant 14].

3.2.3.2. Length of Handover Period

A significant number of interviewees reported that they felt the time between learning about discharge and actually leaving to be too short, resulting in them feeling destabilised and somewhat lost:

I knew you'd get discharged anyway, it was just like "woah"... it was a bit like pulling the rug from under you... [Participant 16].

Arguably unsurprisingly, this sense of the handover period being too short was noted among service users who were reluctant to leave EIS, yet of note, was also prominent among those who felt ready to leave the service (and in some cases, even stated they felt they could have been discharged earlier):

...because it was so sudden... I'd not had the sit down... "look, this is what's gonna happen, this is how it's gonna work"... there should be... a middle ground like a stepping stone, to say "look, this is how it's going to work" and just give people a bit more information about it, before they just chuck them into another service, because for me, luckily, I was alright, but for someone who's vulnerable, it might send them the opposite way... [Participant 3].

3.2.3.3. Familiarity

For those whose care was transitioned to another service (rather than back to primary care), familiarity of this receiving service was considered a positive. Familiarity here does not solely refer to being aware of the remit of the receiving team, but also being introduced to members of staff and the location of services. Interviewees who were aware of the procedures of contacting the new teams, where to find them and who to contact, felt confident in the new team with regards to their care:

They [CMHT] did ease me into the services and I did feel at home quite quickly...
[Participant 3].

This was largely achieved through meeting the new teams in a ‘handover meeting’, or through previous knowledge of building locations. Conversely, those who felt unfamiliar, or were not formally introduced to their receiving service, described frustration at having to navigate a novel system, or feeling that they once again have to explain their story ‘from scratch’ to staff who knew little or nothing about them.

They don't know me, and so I've got to start my story from scratch again. All that information that [EI CPN] knew, they don't know it... [Participant 16].

3.2.3.4. Reflecting on Progress

As outlined earlier, the process of leaving EIS had a significant emotional impact upon many participants, primarily due to the termination of their relationship with at least one EI worker. The acknowledgement of this and reflection of leaving EI in a wider sense was important for many participants. A number of interviewees reported that their EI worker reflecting on the progress they had made in terms of recovery, when linked with optimism for further progress post-EI, helped form a degree of closure, framing discharge as a positive step:

... it was helpful, yeah, because [EI CPN] outset... where I'd been when I started with the service and how I'd steadily progressed to being discharged from the service. She sat out where I'd been and also looked to the future and looked at EIS as being in the past in a way. You know, "you've graduated from EIS" ...

[Participant 1].

On a more practical level, the formal confirmation of the end of one's time with EI was something that was valued by a number of participants. Similarly, participants who did not receive this formal recognition reported feeling that it would have been beneficial:

...it kind of... petered out though... I don't think that I got a letter saying "we're stopped now; you're out". I think I would have liked some sort of confirmation saying "we're done... you're cut off now", you know? ... I don't think I got a letter or a phone call, or anything like that, saying "we're stopped"... I think that would have helped along the process a little...

[Participant 12].

3.2.4. Expectation of Future Care

The majority of interviewees reported experiencing a significant reduction in level of care since leaving EI, regardless of where their care was transferred. For those who felt sufficiently prepared (linking back to the 'readiness' theme), this change in level of care was expected and they reported feeling satisfied with this. In instances where this was not anticipated, however, this change in care came as a shock and was, for a number of individuals, distressing:

This... not speaking to no one and... having to go to A & E if you need help and all that... it's a joke... [Participant 7].

For some of these individuals, the shock of this reduction in care led to them retrospectively regretting leaving EIS, with participant 7 describing it as “*the worst mistake I’ve ever made in my life*”. For others, however, although this had come as a shock, their reported increased ability to deal with difficulties independently (again, linking back to the ‘readiness’ theme), meant that although initially it was daunting, the prospect of discharge was actually worse than the process of leaving EIS.

P: ...it was daunting, very daunting... but by the time I’d got round to it... it was more the thought of it, that was daunting, but the actual doing it was a walk in the park really... [Participant 3].

3.2.5. The Safety of Early Intervention

While interviewees were under the care of EIS, many of them described simply knowing that contact was easily available as a “crutch” (Participants 1 and 6) or “safety net” (Participants 13 and 16). This was evident in many of the participants who described feeling secure knowing EIS were there should they need it, yet reported rarely accessing the team. This notion of EIS acting as a safety net relates to distress at it being taken away (“*kicking the crutches away*” as both Participants 1 and 6 described it), as seen in many of the earlier themes.

What became evident through further analysis, however, was EIS continuing to act as a safety net *after* discharge for many of those individuals who were discharged back to Primary Care services. Many of the interviewees who reported feeling ready to leave EIS and were happy with their level of autonomy post-discharge still reported feeling some comfort in the (perceived) knowledge that, should they require it, they could approach EIS again for advice or support. For some, this had been made explicitly clear (i.e. they were told at point of discharge they could contact EIS again within a fixed period of time post-

discharge), yet for others, it was more based on instinct and, for want of a better word, hope:

I think if... in the back of me mind, if I ever really got stuck, I'd contact [EI CPN] again at the Early Intervention and she'd put someone in touch with me, I think...
[Participant 13].

4. Discussion

The aim of this study was to investigate the barriers and facilitators of transition to primary or secondary care services from service users' perspectives. Analysis of the data identified five main themes: 1) the subjective sense of feeling ready to leave EIS; 2) the impact of relationships and trust, with sub-themes of trusting EIS' decisions and forming new relationships; 3) preparing for discharge, with sub-themes of familiarity, clear information, reflecting on progress and length of handover period; 4) expectation of future care; and 5) the safety net of EIS. These themes and sub-themes do not exist completely independently, and there exist overlaps and relationships between the themes as illustrated in figure 1:

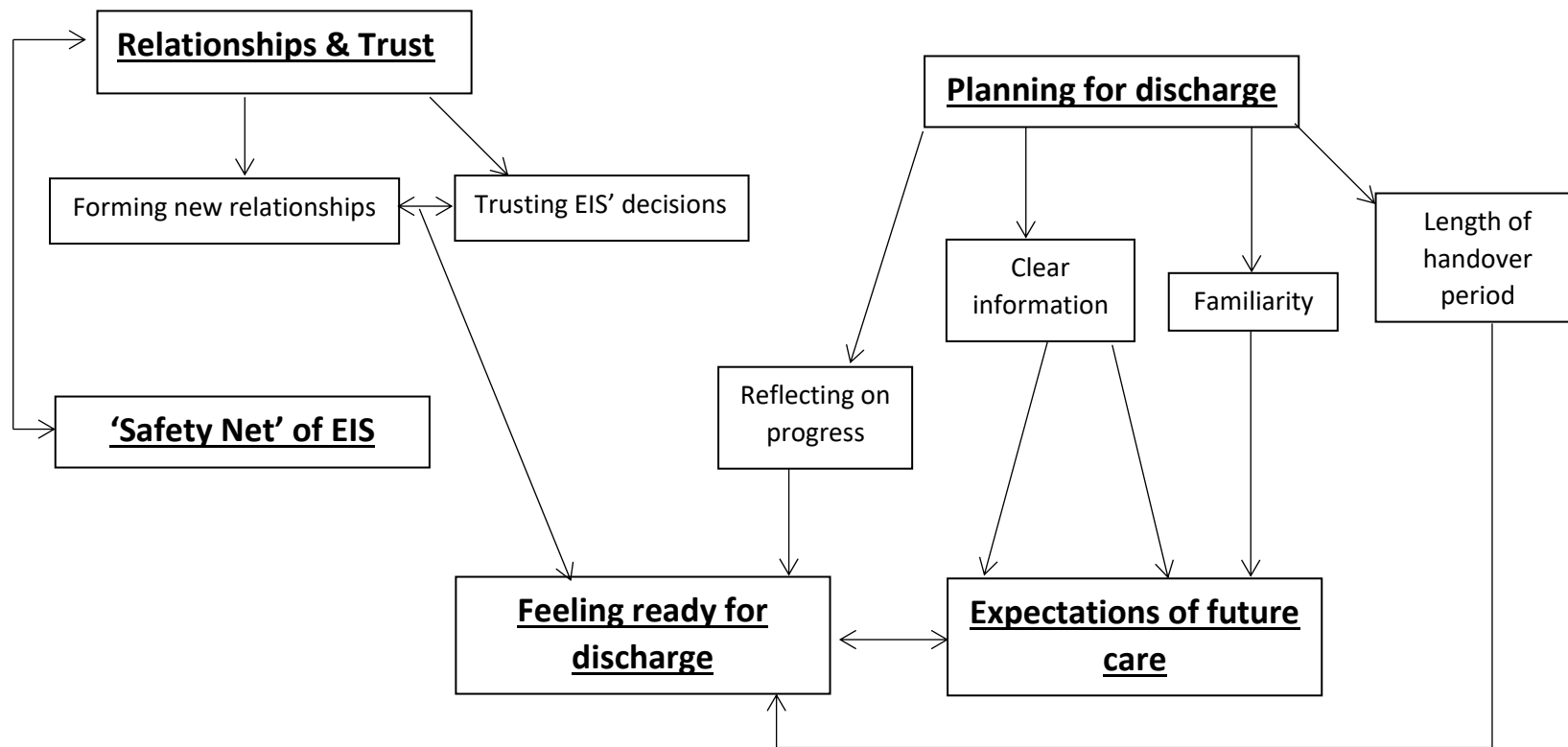


Figure 1: Thematic Map of the Results

The concept of 'readiness' as a quantifiable factor that can be measured pre-discharge has been investigated within adolescent services, with many physical health services attempting to design and implement disorder-specific 'readiness for discharge' rating scales (Schwartz et al., 2014). This is still an under researched area, however, and the notion of measuring readiness for transition as a generic, operationalised concept remains elusive. Rather, much literature has focussed on what the contributing factors towards this sense of readiness may be. As figure 1 illustrates, within this study, the sense of feeling 'ready' for discharge was central to the experience of transition, with several factors contributing to it. Of these factors, the quality and nature of the relationship between service user and EIS staff was integral. A good, stable relationship meant that service users were trusting of staff in making decisions regarding discharge and optimistic when considering forming new relationships. Conversely, a ruptured or overly dependent bond resulted in scepticism over the discharge decision and wariness of forming new relationships. This reflects previous research that has highlighted the resemblance of the relationship between mental health service users and staff to classic attachment relationships (Adshead, 1998; Bucci et al., 2014), in that insecure attachments are often associated with reduced engagement with mental health services (Tait et al., 2004; Catty et al., 2012), while a good therapeutic bond is linked with increased positive outcomes (Lambert & Barley, 2001). Additionally, and of note when considering the sub-theme of trust, a good therapeutic alliance and attachment has been observed to result in service users perceiving staff as stronger and wiser (Mallinckrodt, 2010). More specifically, research investigating the relationship between attachment styles and psychosis has drawn similar conclusions, with avoidant or insecure attachment styles associated with reduced engagement with EIS (Gumley et al., 2014) and a good 'personal' relationship linked to increased trust of EIS staff (Laugharne, Priebe & McCabe, 2011). In line with attachment

theories, a strong positive therapeutic attachment can act as a secure base for psychological exploration, with the knowledge there exists a safe haven, should any difficulties arise (Mallinckrodt, 2010, Bucci et al., 2014). This supports the theme identified in this study of EIS acting as a safety net, both prior to, and after, discharge.

This safety net theme overlaps with the overarching theme of relationships and trust and supports findings that a positive therapeutic relationship is a key factor in the process of being discharged from EIS (Lester et al., 2012) and moving between mental health services as a whole (Jones et al., 2009). Jones et al. (2009) state that at time of transition, a strong therapeutic bond is a valuable but fragile asset, that, if disrupted, can jeopardise the whole process and threaten continuity of care, which in itself has been identified as integral to not only the transitional process (Hovish et al., 2012), but recovery in general (Pitt et al., 2007). As difficulties in trusting others and forming new relationships are often components of the experience of psychosis (Berry & Drake, 2010), this is an element of transition that requires consideration.

That this bond is a valuable but fragile asset also highlights the importance of another central theme of this study: preparing service users for discharge. The importance of advanced planning was stressed in Woodward (2018) and is in line with an abundance of literature focussing on the transition between adolescent and adult services. The importance of clear information being relayed timely to service users, for instance, is highlighted by both the Social Care Institute for Excellence (SCIE) guidelines for supporting effective mental health service transitions for young people and the NICE guidelines for managing transition between inpatient and community-based mental health services.

The finding that many service users felt the length of handover process was too short also echoes studies which report a strong preference for a gradual, managed transition (Belling, McLaren & Paul, 2014; Broad et al., 2017). This approach allows for a less immediate severance of the established therapeutic bonds and also provides space for the service user to be gradually introduced to the new service and become familiar with the new settings and environment (Hovish et al., 2012), another sub-theme highlighted in this study. This familiarity helps build a sense of comfort and trust in the new service and reduces the impact of losing a well-established bond with the pre-discharge service (Hovish et al., 2012).

Another positive factor identified in preparing service users for discharge was EIS staff reflecting on progress made by the service user, particularly when framing this in the context of hope for the future. This supports theories that suggest a socially constructive, narrative or ‘Open Dialogue’ (OD) approach to managing psychosis can be helpful in reframing service users’ experiences and promoting hope for continued recovery, increased independence and social integration following transition from a highly involved service to one that offers a less intense levels of support (Holma & Aaltonen, 1997; France & Uhlin, 2003).

As illustrated in figure 1, many of the factors involved in preparing for discharge contribute to service users’ expectation of future care. The management of expectations following discharge has been reported as a vital element of the process of leaving inpatient care (Keogh, Callaghan & Higgins, 2015) and it has been found that unrealistic expectations of future care, or services failing to understand the expectations of services users, result in dissatisfaction and reduced engagement with the following service (Burton & Wright, 1980). Such findings are in line with several service user accounts in this current study; similarly, the frustration and fear of having to bring a new service ‘up-to-

date' with relevant information is mirrored in studies investigating transitions between services (Tuchman, Slap & Britto, 2008).

4.1. Clinical Implications

In line with existing research and theory, results of this study suggest that there are several practical steps that EIS and receiving services can take to facilitate a more optimal discharge and transition experience for service users. Ideally, the discharge process should be one that is gradual, allowing time for the service user to both process the news and gradually sever ties with keyworkers. Part of this severance can involve formally marking the end of involvement with the service and reflecting on progress made by the individual whilst under EIS, providing a sense of closure. Additionally, the importance of providing clear information, both about the process itself and the remit of the receiving service (if applicable) was highlighted. Practically, this can take the form of 'discharge packs' or letters containing the necessary information, or physically introducing service users to new staff and/or settings, helping form clear expectations regarding future support. On a wider scale, the role of a good therapeutic relationship is central in ensuring service users feel ready for discharge and in the actual transition experience itself. This bond is, therefore, something that should be established long before discharge, with precautions taken to reduce the amount of changes in care pre-discharge. It is acknowledged that changes of workers cannot always be predicted in advance, yet care should be taken to manage any ruptures in continuity of care. The strength of a good therapeutic bond meant that EIS continued to act as a safety net for many services users discharged back to primary care, yet it would clearly be over-ambitious to expect services to operate an open-door policy for previously discharged clients. Therefore, the possibility of EIS being able to offer 'signposting' advice post-discharge could be considered, should individuals feel the need to contact services, yet feel unsure about how to practically do this.

4.2. Limitations and Future Research

Due to the nature of recruitment, which relied upon staff to contact participants for consent for the researcher to make contact with a potential participant, the sample might not represent individuals who either did not experience a positive relationship with services or did not have a positive experience of discharge. It is possible that such individuals would no longer be in touch with staff and, as such, would not have been contactable for this study. Our findings might, therefore, be influenced by primarily positive accounts of discharge. Further research investigating the views of those who no longer engage or only have infrequent contact with mental health services would help reflect the wider population of those discharged from EIS. Of the sample, only two participants were female and only one was a member of an ethnic minority. This, therefore, raises the possibility that the results are weighted in favour of the experience of white males. Additionally, although the study encompassed five NHS Trusts, all were located in the North-West of England; views may not fully represent service users across other geographical locations, both in the UK and worldwide. Further research investigating the views of a more stratified sample would be useful in order to draw similarities and highlight differences with this current study, helping build up a fuller picture of the barriers and facilitators of transition from EIS. Efforts were made to ensure rigor within the analysis. However, we acknowledge that additional strategies such as member checking could have occurred. Time and resource constraints meant this was not possible. Furthermore, future research should explore the impact of positive and negative experiences of transition on long-term clinical outcomes.

REFERENCES

- Belling, R., McLaren, S., Paul, M., Ford, T., Kramer, T., Weaver, T., & Singh, S. P. (2014). The effect of organisational resources and eligibility issues on transition from child and adolescent to adult mental health services. *Journal of health services research & policy*, 19(3), 169-176. doi:10.1177/1355819614527439
- Berry, K., & Drake, R. (2010). Attachment theory in psychiatric rehabilitation: informing clinical practice. *Advances in psychiatric treatment*, 16(4), 308-315. doi:10.1192/apt.bp.109.006809
- Bertelsen, M., Jeppesen, P., Petersen, L., Thorup, A., Øhlenschläger, J., le Quach, P., ... & Nordentoft, M. (2008). Five-year follow-up of a randomized multicenter 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. doi:10.1001/archpsyc.65.7.762
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101. doi:10.1191/F1478088706qp063oa
- Bucci, S., Seymour-Hyde, A., Harris, A., & Berry, K. (2014). Client and therapist attachment styles and working alliance. *Clinical psychology & psychotherapy*, 23(2), 155-165. doi:10.1002/cpp.1944
- Burton, K. E., & Wright, V. (1980). The 'total solution' for total hip replacement surgery. *Journal of medical engineering & technology*, 4(4), 183-185.
- Catty J, White S, Koletsi M, Becker T, Fioritti A, Kalkan R, Lauber C, Lissouba P, Rössler W, Tomov T, van Busschbach JT, Wiersma D, Burns T, (2012). Therapeutic relationships in vocational rehabilitation: predicting good relationships for people

with psychosis. *Psychiatry Res.* 187(1-2) 68-73.

doi:10.1016/j.psychres.2010.10.018. PMID: 21094532.

Craig, T. K., Garety, P., Power, P., Rahaman, N., Colbert, S., Fornells-Ambrojo, M., & Dunn, G. (2004). The Lambeth Early Onset (LEO) Team: randomised controlled trial of the effectiveness of specialised care for early psychosis. *Bmj*, 329(7474), 1067. doi:10.1136/bmj.38246.594873.7C

Fletcher, A. J. (2017). Applying critical realism in qualitative research: methodology meets method. *International Journal of Social Research Methodology*, 20(2), 181-194. doi:10.1080/13645579.2016.1144401

France, C. M. and Uhlin, B. D. (2006), Narrative as an outcome domain in psychosis. *Psychology and Psychotherapy: Theory, Research and Practice*, 79: 53-67. doi:10.1348/147608305X41001

Gumley, A. I., Taylor, H. E. F., Schwannauer, M., & MacBeth, A. (2014). A systematic review of attachment and psychosis: measurement, construct validity and outcomes. *Acta Psychiatrica Scandinavica*, 129(4), 257-274. doi:10.1111/acps.12172

Holma, J., & Aaltonen, J. (1997). The sense of agency and the search for a narrative in acute psychosis. *Contemporary Family Therapy*, 19(4), 463-477. doi:10.1023/A:1026174819842

Hovish, K., Weaver, T., Islam, Z., Paul, M., & Singh, S. P. (2012). Transition experiences of mental health service users, parents, and professionals in the United Kingdom: a qualitative study. *Psychiatric rehabilitation journal*, 35(3), 251. doi:10.2975/2F35.3.2012.251.257

- Jones, I. R., Ahmed, N., Catty, J., McLaren, S., Rose, D., Wykes, T., Burns, T. (2009).
Illness careers and continuity of care in mental health services: a qualitative study
of service users and carers. *Social Science & Medicine*, 69 (4): 632-639.
doi:10.1016/j.socscimed.2009.06.015"
- Kam, S. M., Singh, S. P. and Uptegrove, R. (2015), What needs to follow early
intervention? *Early Intervention in Psychiatry*, 9: 279-283. doi:10.1111/eip.12099
- Keogh, B., Callaghan, P., & Higgins, A. (2015). Managing preconceived expectations:
mental health service users experiences of going home from hospital: a grounded
theory study. *Journal of psychiatric and mental health nursing*, 22(9), 715-723.
doi:10.1111/jpm.12265
- Kirkbride, J. B., Fearon, P., Morgan, C., Dazzan, P., Morgan, K., Tarrant, J., ... & Mallett,
R. M. (2006). Heterogeneity in incidence rates of schizophrenia and other psychotic
syndromes: findings from the 3-center AeSOP study. *Archives of general
psychiatry*, 63(3), 250-258. doi:10.1001/archpsyc.63.3.250
- Kirkbride, J. B., Errazuriz, A., Croudace, T. J., Morgan, C., Jackson, D., Boydell, J., &
Jones, P. B. (2012). Incidence of schizophrenia and other psychoses in England,
1950–2009: a systematic review and meta-analyses. *PloS one*, 7(3), e31660. doi:
10.1371/journal.pone.0031660
- Lambert, M. J., & Barley, D. E. (2001). Research summary on the therapeutic relationship
and psychotherapy outcome. *Psychotherapy: Theory, research, practice,
training*, 38(4), 357. doi:10.1016/j.tree.2016.11.005
- Laugharne, R., Priebe, S., McCabe, R., Garland, N., & Clifford, D. (2012). Trust, choice
and power in mental health care: Experiences of patients with

psychosis. *International Journal of Social Psychiatry*, 58(5), 496-504.

doi:10.1177/0020764011408658

Lester, H., Khan, N., Jones, P., Marshall, M., Fowler, D., Amos, T., & Birchwood, M.

(2012). Service users' views of moving on from early intervention services for psychosis: a longitudinal qualitative study in primary care. *Br J Gen Pract*, 62(596), :183-190. doi:10.3399/bjgp12X630070

Mosselson, J. (2010). Subjectivity and reflexivity: Locating the self in research on

dislocation. *International Journal of Qualitative Studies in Education*, 23(4), 479-494. doi:10.1080/09518398.2010.492771

Pitt, L., Kilbride, M., Nothard, S., Welford, M., & Morrison, A. (2007). Researching

recovery from psychosis: A user-led project. *Psychiatric Bulletin*, 31(2), 55-60.

doi:10.1192/pb.bp.105.008532

Ross, C. K., Frommelt, G., Hazelwood, L., & Chang, R. W. (1987). The role of

expectations in patient satisfaction with medical care. *Marketing Health Services*, 7(4), 16.

Schwartz, L. A., Daniel, L. C., Brumley, L. D., Barakat, L. P., Wesley, K. M., & Tuchman,

L. K. (2014). Measures of readiness to transition to adult health care for youth with chronic physical health conditions: a systematic review and recommendations for

measurement testing and development. *Journal of pediatric psychology*, 39(6), 588-601. doi:10.1093/jpepsy/jsu028

Singh, S. P., Paul, M., Islam, Z., Weaver, T., Kramer, T., McLaren, S., ... & Harley, K.

(2010). Transition from CAMHS to adult mental health services (TRACK): a study of service organisation, policies, process and user and carer perspectives. Report for

the National Institute for Health Research Service Delivery and Organisation
Programme: London.

SITE: Mental Health service transitions for young people.

<https://www.scie.org.uk/publications/guides/guide44/planningandpracticeintransition/supporteffective.asp> Accessed 07/03/2018

The NHS Constitution for England (2015)

<https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england> Accessed 13/02/2018

Tuchman, L. K., Slap, G. B., & Britto, M. T. (2008). Transition to adult care: experiences and expectations of adolescents with a chronic illness. *Child: care, health and development*, 34(5), 557-563. doi:10.1111/j.1365-2214.2008.00844.x

Wahlbeck, K., Westman, J., Nordentoft, M., Gissler, M., & Laursen, T. M. (2011).

Outcomes of Nordic mental health systems: life expectancy of patients with mental disorders. *The British Journal of Psychiatry*, 199(6), 453-458.

Vigod, S. N., Kurdyak, P. A., Dennis, C. L., Leszcz, T., Taylor, V. H., Blumberger, D. M., & Seitz, D. P. (2013). Transitional interventions to reduce early psychiatric readmissions in adults: systematic review. *The British Journal of Psychiatry*, 202(3), 187-194.

Paper 3

Critical Reflection

Word Count (with references): 4331

1. Critical Reflection

This paper provides a critical appraisal of the work presented in the thesis. Papers 1 and 2 are both considered respectively and the implications of both are jointly considered.

Finally, personal reflections are discussed. Issues addressed in the individual papers have not been repeated but some have been elaborated on.

1.1.Rationale for Large-Scale Project

As identified in both papers, there has been a relative scarcity of research investigating the experiences of those who access Early Intervention Services (EIS) and of this limited research, There were no published syntheses of these data. Therefore, in planning the large-scale project, the researcher's aim was to synthesise the existing data relating to the experiences of those accessing EIS and gain a deeper understanding of what was valued and where potential improvements could be made.

Of these papers, only one investigated the experience of being discharged from EIS back to primary care following engagement (Lester et al., 2012). The researcher was keen to participate in a study exploring this further, extending the remit to include those also discharged to secondary care. As the researcher had previously worked in community-based services that service users were often discharged to, they had experience of some of the difficulties faced, both by service users and staff members, largely concerning the reduced level compared to that offered by EIS. Additionally, the researcher had an interest in continuity of care generally, having also worked in a medium-secure inpatient unit and observing barriers service users and staff members faced in preparing for discharge to the wider community. As such, this project provided the researcher with an opportunity to gain a deeper understanding of the barriers and facilitators of discharge from EIS from the

viewpoint of those who had experienced it and carry out a project that had potential to inform future clinical practice and service development.

2. Paper 1

2.1. Selecting the Research Question

During the initial design stage of the project, it was observed that although several papers existed exploring the experiences of service users and carers/family members accessing EIS, the data had not been collated to generate a new understanding. As such, there existed a gap in the literature. This was discussed with the wider research team and it was felt this would be an appropriate and valuable study to conduct, especially as at the time the study was being designed, the 'Implementing the Early Intervention in Psychosis Access and Waiting Time Standard' (2016) was due to be published, outlining imminent changes to EIS across the UK.

2.2. Selecting the Synthesis Approach

There are numerous potential methods of synthesising qualitative data (Ring, Ritchie, Mandava, & Jepson, 2011). The meta-synthesis approach was agreed upon by the research team as this approach, epistemologically, sits between meta-ethnography, which gathers existing, separate themes from various sources of data and interprets them into higher-order themes, and grounded theory, which is inductive and uses constant comparison to develop themes (Barnett-Page & Thomas, 2009). This therefore allowed for a critical realism approach to analysis, which, similarly, is nestled between two extremes: positivism and constructivism. Critical realism posits that it is possible to gain a knowledge of an external reality, as in positivism, yet this is mediated by one's perceptions and beliefs, as in constructivism (Fletcher, 2017). This was felt to be appropriate for analysing individuals'

experiences of accessing EIS, as it allowed for the subjective experience of individuals to form objective recommendations for future service development and commissioning.

2.3. Inclusion and Exclusion Criteria

During the initial stages of development, the inclusion of papers exploring the views of staff members was also considered. However, a brief scope and consultation with the research team led to the decision to omit these from any further searches. This decision was made for two reasons: firstly, it would be difficult to establish what constituted a ‘staff member’, that is, the term could range from a highly involved staff member, such as key worker or staff nurse, to staff members who are removed from direct service user involvement, such as commissioners or administration staff. Secondly, the experiences of staff may focus on wider systemic issues, such as economic sustainability and funding, which would arguably not contribute to an understanding of the lived experience of EIS. On a more practical level, the decision was made to exclude papers that did not separate the views of service users and carers/family members, as it was felt this would not allow for comparison and exploration of contrasting views. Studies that were not written in English were excluded, and the research team acknowledge this may be a limitation, given that EIS are implemented worldwide.

2.4. Search Process

To date, there is no gold-standard for the searching process of qualitative research (Ring et al., 2011). Therefore, it is essential that all search and retrieval processes are transparent and explicit. In accordance with this, the study followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA; Moher et al., 2009). Search terms were discussed in supervision and many initial themes such as “young person” were omitted, as it was felt these were redundant, given that at the time of the synthesis, EIS only accepted

referrals pertaining to young people (that is, under the age of 35). The inclusion of such terms as these may have subsequently generated many more superfluous results and muddied the waters during a time when the exact research question was still in formation. Similarly, terms such as “schizophrenia” and “bipolar” were included, as referral to EIS is not dependent on a specific diagnosis. This, it was decided, would reduce the likelihood of any studies being overlooked. The search terms were reviewed several times in supervision and after a selection of 18 papers were reviewed in a joint session with all members of the research team, the final 14 were settled upon after discussion and justification.

It is acknowledged that the review utilised four databases, and it could be considered a limitation that more were not accessed. However, it has been hypothesised that rather than being exhaustive, searches in meta-syntheses should aim for theoretical saturation (Campbell et al., 2011), meaning the omission of potential papers would be less likely to impact upon results. Additionally, the references of the retrieved papers were reviewed to eliminate further the likelihood of any omissions.

2.5. Quality Appraisal

The final selected papers were reviewed using the Qualitative Critical Appraisal Skills Programme (CASP). This was selected as it can be applied to studies that operate within a range of epistemological frameworks (Grounded Theory or Inductive Thematic Analysis, for instance). As the study did not exclude papers on this ground, CASP was felt to be appropriate. As the checklist does not have a formal marking system, it was modified in line with recommendations made in Duggleby (2010), allocating a score of 1-3 for each item. This was felt necessary, as it enabled the researcher to be able to easily reflect on which papers were of a better quality and therefore more applicable to the research

question. That most papers scored above 20/30 indicated that their selection and inclusion was appropriate.

During the quality appraisal process, however, the researcher reflected upon the fact that very few papers referred to the subjective reflexivity on behalf of the researchers and ethical considerations beyond seeking informed consent and ethical approval. It was reasoned that this is likely due to space constraints, in that the results sections of qualitative papers are often required to be more in-depth than quantitative papers and as such, there simply is not room to expand upon these issues. Nonetheless, it is a limitation observed of most of the papers that must be taken into account when considering the findings.

2.6. Analysis and Generation of Themes

One of the inherent difficulties with synthesising qualitative data is that it is, in essence, second-hand data, dependent upon the interpretation of the initial authors (Silverman, 2015). This was noted throughout the analysis process, yet the commonality of many themes suggested that many of the interpretations were valid and data sufficiency was met (Finlayson & Downe, 2013). The synthesising of existing data into higher-order themes was a reflective process, in that the data was continuously reviewed by the research team and returned to following any changes or developments, as is recommended practice (Walsh & Downe, 2005). The researcher acknowledged that the papers reviewed were exploring a similar area as the concurrent empirical study. This was reflected upon during supervision, should any of the data being analysed in the empirical study influence a certain viewpoint that may not have been actually reflected in the data.

3. Paper 2

3.1. Development of the Research Question and Topic Guide

The study built upon previous research by Woodward et al. (2017, in review) who investigated EIS staff attitudes regarding the barriers and facilitators of transition from EIS. It was felt that by also gaining an understanding from service users' points of view, a richer, fuller overall understanding could be gained of the discharge process, with genuine implication for future clinical practice. Likewise, it was agreed that a qualitative approach would be the most appropriate method to address this, due to the inherent potential to explore participants' experiences in-depth (Ritchie, 2013).

The topic guide therefore also built upon the one used in Woodward et al. (2017). The original topic guide was devised after consultation with service user groups and staff members and was deemed to still be largely relevant to this study, with only minor alterations needed, which were discussed in supervision. The topic guide, as is good practice, was fluid and responsive to emerging themes in interviews. Subsequently, as interviews progressed and the theme of trusting EIS staff's decisions became increasingly prominent, a question was added that directly addressed this. The researcher acknowledges that in an ideal situation, all participants would be re-interviewed once the topic guide was updated. However, due to time and practical constraints, this was not possible. It was felt, however, that the topic guide updates did not deviate too far from the original to greatly affect findings.

3.2. Recruitment and Sample

The researcher was able to draw upon existing contacts from previous employment within community-based mental health services and use convenience sampling to support recruitment. Links were established with both EIS and Community Mental Health Teams

(CMHTs) across the North-West of England, encompassing five NHS trusts, so as to broaden the chance of making contact with potential participants. The recruitment process was at times difficult, for a number of reasons. Firstly, most teams were under increasing pressure with regards to workload, so the study was understandably not a priority for staff and subsequently information was often not disseminated to other staff or service users. Secondly, although efforts were made to ensure full information of the study was passed on, this was dependent upon staff members with an already high demand placed upon them, and in a number of instances, participants who initially agreed to take part opted out once they realised they were required to be interviewed. In one instance, it was not discovered until the interview that the participant could not speak fluent English and could not therefore fully understand the questions or formulate replies. Effort was made to stress to staff the importance of all information being passed on, from both a practical and ethical point of view, yet this was not always possible. Thirdly, a number of participants did not reply to initial enquiries for unspecified reasons, which delayed the recruitment process. It may be postulated that this reflects the difficulties associated with trusting new people for many who experience psychosis (Berry & Drake, 2010) and also may reflect the chaotic nature of many individuals' socioeconomic circumstances. This last point was reflected on by many staff members, who noted that service users often moved home and frequently became hard to contact.

In line with previous research, a target of 20 participants was set at the design stage of the study (Lester et al., 2012; Woodward et al., 2017). It was decided that the inclusion criteria would require participants to be able to speak and understand fluent English, have been previously registered with an EIS and discharged within the last 12 months. This amount of time was decided upon as it was felt, in discussion, any greater length of time would possibly result in increased difficulty recalling the experience of transition. It is

acknowledged that this figure was arbitrary, and the researcher does consider that more investigation into the appropriate length of time since discharge may have been of use. As it transpired, only one of the 15 eventual participants stated difficulty in recalling. However, it was noted in a reflective journal kept concurrently, that this was felt to be largely due to difficulty talking about a problematic transition and a negative experience of EIS overall.

Although the initial target for recruitment was 20, by the 15th complete interview, it was felt that data saturation had been met, as no new themes were coded during the last three interviews. As there is no standard number for sample size in qualitative research and is rather based on data saturation (Guest, Bunce & Johnson, 2006), following consultation with the research team, recruitment ceased after the 15th full interview. The researcher accepts that it is possible continuing with recruitment may have yielded further insight, or new disconfirming data; however, due to the level of data saturation and time constraints, it is felt this decision was appropriate.

3.3. Interviewing Processes

Data was collected via interviews, which were audio-recorded. The interviews themselves highlighted to the researcher a number of important issues for consideration. Conducting interviews for qualitative research is by nature a complex process (Turner, 2010) that requires sufficient a priori planning and structure (Doody & Noonan, 2013). Although the researcher had worked in clinical environments before and had some experience of working with individuals experiencing psychosis, they had no experience of conducting research interviews. As such, preparation was achieved through listening to the interviews conducted in the Woodward et al (2107, in review) study and discussion with the wider research team. Following the first two interviews, the research team listened to the audio

recordings and offered guidance and advice on aspects of the interviews, such as asking participants to elaborate on certain issues, though in the main, no serious issues were raised.

Interviews were semi-structured, following the established topic guide and the researcher was conscious that in order to gain meaningful, rich data, they would be required to form a rapport with participants in a short amount of time (Charmaz, 2012). This was an aspect of the interviewing process the researcher was conscious of, particularly given that many individuals experiencing psychosis can find forming new relationships and building trust difficult (Berry & Drake, 2010). In most interviews, this was not problematic, and many participants were able to talk in detail about their experiences openly. There were two interviews, however, in which the researcher felt it was difficult to establish a rapport, which were noted in a reflective journal that was written concurrently with the interviews. In the entries for these two interviews, it is of note that the participants were dismissive of services and individual staff members. The researcher hypothesised that their interviews reflected a wider mistrust of health professionals in general, resulting in them being guarded or wary during interviews. These two interviews were discussed in supervision and it was reflected that during analysis, they helped form part of the theme relating to trusting the decisions of staff members based on previous experiences of services. It was not felt that these two interviews detracted from findings, but rather, helped build a more varied picture of individuals' experiences of being discharged from EIS, even if the interviews themselves were challenging.

3.4. Analysis and Theme Generation

From an epistemological viewpoint, analysis of the data again adopted a critical realist approach, using inductive thematic analysis. The researcher acknowledges that there are a multitude of different approaches that could have been taken, however this method felt most appropriate for two main reasons. Firstly, as there had been scarce research into the experience of being discharged from EIS prior to the study, there existed no theoretical framework to operate within. Thematic analysis is by nature flexible and is of benefit when working independently of any pre-existing theory, as opposed to Interpretative Phenomenological Analysis (IPA; Smith & Osbourne, 2004) or Grounded Theory (Braun & Clarke, 2006). This allows for an exploratory approach, which can provide a detailed, rich account of data, without being reductive. Secondly, by taking a critical realist, inductive approach, as with Paper 1, the researcher was able to draw on elements of both constructivism and positivism, ultimately exploring the objective reality of being discharged from EIS via the subjective experience of individual's independent accounts.

Taking this approach, the researcher developed initial themes, which were reviewed by the wider research team. Following review, several themes were merged together, or felt to not be fully reflective of the data and abandoned. The nature of the themes was debated in supervision extensively, and it was felt that although the data could have been represented in other ways, the final version reflected the data sufficiently. Expanding on this, it was suggested that the themes could have followed a similar pattern to Paper 1, in which the importance of a good relationship with a member of EIS staff mediated all other themes. Although the researcher did not disagree with this point, with the study investigating the process of being discharged, it was felt that the development of a thematic map that almost resembled a psychological formulation was more appropriate. This approach allowed for

the discharge process to be broken down into greater detail and meant that explicit recommendations could be made relating to the various aspects of discharge.

As with Paper 1, care was taken to avoid cross-contamination between the two studies. Many of the themes prominent in Paper 1 were also discussed in the interviews and therefore supervision was utilised to ensure there was a degree of separation between the two studies.

4. Implications of Papers 1 & 2

In the UK at least, Early Intervention Services are receiving increasing attention as the implications of addressing psychosis in its early stages become clearer, from both a service user perspective and a wider socio-economic viewpoint (Knapp, Andrew, McDaid et al., 2014). As such, it is likely that further research will be conducted over the coming years with regards to service provision and development, particularly in the light of the publication of the 'Implementing the Early Intervention in Psychosis Access and Waiting Time Standard' document (2016). The work presented in this thesis contributes to this field.

Both papers make clinical recommendations that have implications for both EIS and CMHTs. Both papers highlighted the importance of building and maintaining strong therapeutic bonds between service user and EIS staff members. Paper 1 elaborates on this and suggests this should also extend to service users' family members and/or carers. Such findings are in line with existing research on attachment and accessing mental health services (Berry & Drake, 2010; Bucci et al., 2014) and have direct implications for clinical practice. From a practical stance, the maintenance of a good therapeutic bond appears to play a key role in continued engagement with services. If a goal of EIS is that individuals recover from psychosis and be reintegrated into wider society ('Implementing the Early

Intervention in Psychosis Access and Waiting Time Standard', 2016), then continued engagement with services is therefore essential. Paper 2 illustrates that following EIS involvement, ensuring all handovers are gradual and managed effectively (such as disseminating relevant information and introducing service users to new staff) is vital in ensuring gains made during engagement are not lost.

Both papers make recommendations for future research. A key task for this would be increased focus on services in varying socio-economic and cultural contexts. EIS are implemented worldwide, yet the majority of research (including the work in this thesis) has been conducted in the UK and Australia and cannot therefore be classed as fully representative of the population who access services. Furthermore, if the recommendations mentioned in this thesis are implemented, future research would be required to gauge the efficacy and impact of any changes.

5. Personal Reflections

5.1. Reflexivity

As this was the researcher's first experience of designing and running a qualitative research project, the impact of their own past experiences and influences was a source of great reflection. Qualitative research is, by nature, a highly subjective process. As such, the researcher kept a reflective journal, not only to aid in analysis, but to help with supervision and self-reflection. The researcher had previously worked in a community-based mental health service, which had frequent contact with both EIS and CMHTs. This was of note, as it was possible past experiences and knowledge of staffs' viewpoints on many aspects of the discharge process may have clouded analysis of service users' accounts and led to interpretations that were not supported by the data. Discussions were held frequently in

supervision in order to minimise the risk of this happening, alongside considerations of journal entries:

[Researcher] was conscious that the participant is now under the care of [team the researcher previously worked for]... was therefore aware of issues regarding waiting times and low staff numbers within this service and how this may impact upon participant's perceived changes in care (i.e. less of it), compared with EIS... to be discussed in supervision (Reflective Journal entry regarding Participant 12).

Furthermore, the researcher was a trainee Clinical Psychologist, and as such, was concurrently learning new models of therapy across a variety of settings. This was reflected upon frequently, should it have had an impact upon the research interviews. Given the nature of the interviews and the topics discussed, there was a risk that the researcher might be pulled into a therapeutic role and feel obliged to offer support or guidance. This was avoided through supervision and monitoring of the interviews once they were completed.

5.2. Conclusions

The researcher reflected that conducting a ClinPsyD research project was a challenging, but rewarding, process. At times it was a difficult project to manage, given time constraints and competing demands, however the process of becoming immersed in the data was an experience they found both enlightening and valuable. The qualitative approach to the project fit with the researcher's interests and they feel the project examined an increasingly important issue that will hopefully be of value, both to services and to those who access them.

Interviewing individuals who had experienced psychosis and spent several years with EIS was a rewarding and humbling experience for the researcher. They were struck by the

resilience and optimism of all who took part in the study. They were also struck by the fact that when discussing what they valued most about engaging with services, most participants spoke of seemingly small factors, such as meeting for coffee in a café rather than a clinical setting. This helped the researcher bear in mind that theory without humanity matters little in mental health services.

REFERENCES

- Barnett-Page, E., & Thomas, J. (2009). Methods for the synthesis of qualitative research: a critical review. *BMC medical research methodology*, 9(1), 59.
- Berry, K., & Drake, R. (2010). Attachment theory in psychiatric rehabilitation: informing clinical practice. *Advances in psychiatric treatment*, 16(4), 308-315.
doi:10.1192/apt.bp.109.006809
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101. doi:10.1191/1478088706qp063oa
- Bucci, S., Seymour-Hyde, A., Harris, A., & Berry, K. (2014). Client and therapist attachment styles and working alliance. *Clinical psychology & psychotherapy*, 23(2), 155-165. doi:10.1002/cpp.1944
- Campbell, R., Pound, P., Morgan, M., Daker-White, G., & Britten, N. (2011). Evaluating meta-ethnography: systematic analysis and synthesis of qualitative research. *Health Technology Assessment*, 15(43), 1-49. doi: 10.3310/hta15430
- Charmaz, K. (2012). The power and potential of grounded theory. *Medical Sociology Online*, 6(3), 2-15.
- Critical Appraisal Skills Programme (2018). CASP Qualitative Checklist. [online]
Available at: <http://casp-uk.net/wp-content/uploads/2018/03/CASP-Qualitative-Checklist-Download.pdf> Accessed: 18/11/2017
- Doody, O., & Noonan, M. (2013). Preparing and conducting interviews to collect data. *Nurse Researcher*;20 (5), pp. 28-32

- Duggleby, W., Holtslander, L., Kylma, J., Duncan, V., Hammond, C., & Williams, A. (2010). Metasynthesis of the hope experience of family caregivers of persons with chronic illness. *Qualitative Health Research*, 20(2), 14-158.
DOI:10.1177/1049732309358329
- England, N. H. S. (2016). Implementing the early intervention in psychosis access and waiting time standard: Guidance. NHS England, London.
- Finlayson, K., & Downe, S. (2013). Why do women not use antenatal services in low-and middle-income countries? A meta-synthesis of qualitative studies. *PLoS Medicine*, 10(1), 1-12. doi:10.1371/journal.pmed.1001373
- Fletcher, A. J. (2017). Applying critical realism in qualitative research: methodology meets method. *International Journal of Social Research Methodology*, 20(2), 181-194.
doi:10.1080/13645579.2016.1144401
- Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field methods*, 18(1), 59-82.
doi:10.1177/1525822X05279903
- Knapp, M., Andrew, A., McDaid, D., Iemmi, V., McCrone, P., Park, A. L., & Shepherd, G. (2014). Investing in recovery: making the business case for effective interventions for people with schizophrenia and psychosis.
- Lester, H., Khan, N., Jones, P., Marshall, M., Fowler, D., Amos, T., & Birchwood, M. (2012). Service users' views of moving on from early intervention services for psychosis: A longitudinal qualitative study in primary care. *British Journal of General Practice*, 62(596), e183–e190. Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&CSC=Y&NEWS=N&PAGE=fulltext&D=emed14&AN=364361587>

- Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & Prisma Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS medicine*, 6(7). doi:10.1371/journal.pmed.1000097
- Ring, N., Ritchie, K., Mandava, L., Jepson, R. (2011). A guide to synthesising qualitative research for researchers undertaking health technology assessments and systematic reviews. Retrieved from <http://www.nhshealthquality.org/nhsqis/9937.html>
- Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (Eds.). (2013). *Qualitative research practice: A guide for social science students and researchers*. Sage.
- Silverman, D. (2015). *Interpreting qualitative data*. Sage.
- Smith, J. A., & Osborn, M. (2004). Interpretative phenomenological analysis. *Doing social psychology research*, 229-254.
- Turner III, D. W. (2010). Qualitative interview design: A practical guide for novice investigators. *The qualitative report*, 15(3), 754.
- Walsh, D., & Downe, S. (2006). Appraising the quality of qualitative research. *Midwifery*, 22, 108-119. doi: 10.1016/j.midw.2005.05.004

APPENDICES

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Appendix 1: Instructions to Authors (*Psychosis* journal)

About the Journal

Psychosis is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's [Aims & Scope](#) for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

Psychosis accepts the following types of article: Research Articles and Reviews; First Person Accounts; Brief Reports; Opinion Pieces; Letters to Editor and Book Reviews..

Preparing Your Paper

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the [Uniform Requirements for Manuscripts Submitted to Biomedical Journals](#), prepared by the International Committee of Medical Journal Editors (ICMJE).

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

Word Limits

Please include a word count for your paper.

The maximum word length for an Article in this journal is 6000 words (this limit includes tables, references and figure captions).

The maximum word length for a First Person Account is 3500 words.

The maximum word length for a Brief Report is 1500 words.

Style Guidelines

Please refer to these [quick style guidelines](#) when preparing your paper, rather than any published articles or a sample copy.

Any spelling style is acceptable so long as it is consistent within the manuscript.

Please use double quotation marks, except where “a quotation is ‘within’ a quotation”. Please note that long quotations should be indented without quotation marks.

Appendix 2: Participant Information Sheet



Participant Information Sheet

Study Title: Experiences of Leaving Early Intervention

You are being invited to take part in a research study. Before you decide whether to take part it is important you understand why the research is being done and what it will involve. Please take time to read the following information carefully. We can go over it in more detail when we meet if you like. You can also discuss it with others if you wish. Ask us if there is anything that is not clear or you would like more information about. Take time to decide whether or not you wish to take part. We hope to recruit 40 people in total, 20 service users and 20 staff.

Why is the study being done?

The study aims to look at things people found to be helpful and unhelpful when they were leaving the Early Intervention team. This study is being undertaken as student research, to fulfil the research component of a Doctorate in Clinical Psychology.

Who will be taking part?

We are hoping for up to 20 service users to take part in this study. Participants will all have experience receiving support from Early Intervention Teams, and will have left these teams in the last year. Participants will need to be aged 16-65, live in the North West of England, and be willing to be audio-recorded.

Why have I been asked to take part?

We are inviting you to take part because you have recently left an Early Intervention Team.

Do I have to take part?

It is up to you whether or not you decide to take part. If you do decide to take part you will be given a copy of this information sheet and be asked to sign a consent form. If you decide to take part you can leave the study at any time without giving a reason. If you decide to leave at any time, or not to take part, this will not affect any of the treatment you usually receive or the standard of care.

What will it involve for me?

If you agree to take part you will be asked to meet with one of the researchers. At this meeting the researcher will ask you some questions about your experience of leaving the Early Intervention team. This will last around 1 hour. At the end of this meeting you will be given £10 as a thank you for your time and to cover any costs. With your consent, this interview will be audio-recorded. The interview will take place at an NHS base (e.g. your GP surgery), or a convenient location for you.

What are the good things and bad things about taking part?

This project will help us to understand what people want when they are moving between services. It will tell us some of the helpful things services can do to support people during moves between services. It will also tell us things that services do that are not as helpful. This means that teams will be able to try and make this time as easy as possible for people in future.

We don't expect any disadvantages but it is possible that talking about your experiences may cause some distress. We will check if you have any concerns. If you wish, you will be able to talk to a clinical psychologist to discuss what to do next and what support is available. We can also speak with your clinical team if you wish.

What do I do if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to help or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 2757583 or 0161 2758093 or by email to research-governance@manchester.ac.uk.

In the unlikely event that something does go wrong and you are harmed during the research you may have grounds for a legal action for compensation against The University of Manchester and NHS but you may have to pay your legal costs.

Will my taking part be confidential?

If you agree to take part in the study, any information you give the researcher will be kept strictly confidential. We will conform to the Data Protection Act of 1998 with respect to data collection, storage and destruction. Data will be kept for 5 years. Your name will not appear on any of the forms, we will give you a study number instead. Any information you give to the researcher will not be shared with any staff without your consent. The only exception to this is if the researcher feels that either yourself or others are at risk of harm. In the case the researcher will need to break confidentiality in order to keep you and others safe. Where possible, the researcher will always try and discuss this with you before taking action.

If you agree, we will contact your GP or other appropriate professionals to let him/her know that you are taking part in the study. As you are under the care of a mental health NHS Trust, we are required to put a copy of your consent form into your usual medical notes. This copy may be reviewed by the Trust Clinical Audit Department to confirm that you have given written informed consent.

Individuals from the University of Manchester, regulatory authorities or Trust may need to look at the data collected during the study to make sure it is being carried out properly. With your permission this will include your personal data. All individuals looking at the data have a duty of confidentiality to you as a research participant

We will ask for your consent to audiotape the interview. These recordings are made to make sure that the researchers can accurately record what each person has said. This makes it easier to find common experiences between participants. These recordings will be stored anonymously and securely.

What will happen to the results of the research study?

If you take part in the study you will be informed of the results. The findings will be presented to a range of mental health professionals and service users. It is hoped that the findings will improve mental health services. We also aim to publish the results of the study in a scientific journal. Some quotes from your discussion with the researcher may appear in these results. These will all be anonymous, and no-one will know who these quotes came from.

The results will also be used by the chief investigator as part of their thesis to fulfil the requirements of a Clinical Psychology Doctorate.

Personal data will be kept for the duration of the study. Research data (i.e. interviews) will be kept for 5 years.

Who is organising and funding the research?

This study is part of a Doctorate in Clinical Psychology, undertaken at the University of Manchester. The research is organised by the University of Manchester. The research has been subject to ethical review by [REC and ref number]

Further Information

If you would like any take part or have any questions about the study, please ask the chief investigator, and student:

Matthew Loughlin
Division of Clinical Psychology
University of Manchester
Zochonis Building, 2nd Floor
Brunswick Street
Manchester
M13 9PL

Email: matthew.loughlin@postgrad.manchester.ac.uk

Appendix 3: Invitation Letter to Potential Participants



The University of Manchester

Matthew Loughlin,
Trainee Clinical Psychologist
Division of Clinical Psychology
Zochonis Building, 2nd Floor
Brunswick Street
Manchester
M13 9PL
Matthew.loughlin@postgrad.manchester.ac.uk

Dear Sir/Madam,

Re: Early Intervention Research Study Invitation

I am writing with regards to a research project, currently being undertaken by the University of Manchester as part of a Clinical Psychology Doctorate. The study aims to find out what people who have recently left Early Intervention Services found helpful and unhelpful about the discharge process.

This project will help us to understand what people want when they are moving between services. This means that teams will be able to try and make this time as easy as possible for people in future.

We are inviting you to take part because you have recently left an Early Intervention Team. It is up to you whether or not you decide to take part.

If you agree to take part you will be asked to meet with one of the researchers. At this meeting, the researcher will ask you some questions about your experience of leaving the Early Intervention team. This will last around 1 hour.

With your consent, this interview will be audio-recorded. The interview will take place at an NHS base (e.g. your GP surgery), or a convenient location for you, such as your home.

If you would like to take part or would like to find out more information, then please contact the Chief Investigator:

Matthew Loughlin
Trainee Clinical Psychologist
Division of Clinical Psychology
Zochonis Building, 2nd Floor
Brunswick Street
Manchester
M13 9PL
Email: matthew.loughlin@postgrad.manchester.ac.uk

Appendix 4: Participant Consent Form



Service User CONSENT FORM

Client Identification Number for this study:

Title of Project: Experiences of Leaving Early Intervention

Name of Researcher:

Name of Participant:

Please initial box

1. I confirm that I have read and understood the service user participant information sheet dated 04/10/16 (version 3) for the above study and have had at least 24 hours to consider it and been given the opportunity to ask questions.	
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
3. I give my consent for the interview to be audio-recorded	
4. I give my consent for my GP to be informed about my participation in the study.	
5. I give my consent for anonymised quotes to be used when publishing the results	
6. I understand that data collected during the study, may be looked at by individuals from The University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.	
7. I give my consent for my anonymised data to be used in future research	
8. I agree to take part in the study	

Points 1-3 and point 8 are required for participation in the study. All other points are optional

Name of Service user

Date

Signature

Name of Researcher

Date

Signature

Appendix 5: Topic Guide

Moderators and mediators of transition from Early Intervention in Psychosis teams - Topic Guide (service users)

Introduction

- i. Clarification of the purpose and length of the interview
We want to get your views on how it was to leave Early Intervention and move to a different service. The interview should take about an hour, and we can take a break at any time you want to.
- ii. Clarification of anonymity and confidentiality
If it's ok with you, I will audio record our conversation. It will then be transcribed, and given an anonymous number. All identifiable information will be removed. Transcriptions will be kept locked away or in password protected computer files. Quotes from the interview might be published, but they will not be identifiable. Is that ok?

1. Experiences of Early Intervention

We will seek general information about participants' time in EI services, and how they viewed this.

Can you tell me a bit about your experiences of early intervention services?

How long did you spend in the service?

What was your relationship with the staff like?

Would you say you found the service helpful?

What kind of impact did being in the service have on your life?

How did you feel about leaving EI?

Prompt – can you tell me a bit more about that?

2. General views of the transition process

We will explore participants' views of the process of leaving EI services, and their feelings about this. We will also explore the practical aspects of the move between services.

When did you find out you would be leaving EI?

Did you feel like the reasons for the change were explained to you?

Prompt – can you tell me a bit more about that?

Can you tell me a bit about that changeover period?

How much involvement did you have in the change?

How did you feel about the process of moving teams/ leaving EI?

3. Changes in care

We will explore how participants feel their experiences of care have changed as a result of the move between services.

What kinds of changes have you noticed since you left EI?

Prompt – can you tell me a bit more about that?

What things have stayed the same for you since you left EI?

Prompt – can you tell me a bit more about that?

Has the change in services has any impact on your everyday life?

4. Helpful factors

We will explore what participants found to be helpful factors in their move between services

Can you remember specific things that you found helpful in getting yourself ready to change services?

Was there anything that made the process easier for you?

What did [receiving service] do that you found helpful?

What was it about these things that made the process easier for you?

5. Unhelpful factors

We will explore what factors participants found to be unhelpful when moving between services, and what it was about these factors that caused difficulty.

Were there things about the move that you found particularly unhelpful?

What could have been better about the move/ what would have made it easier for you?

Can you remember anything that [receiving service] did that you found unhelpful?

What was it about these things that was particularly unhelpful?

Were there other things the services could have done that would have made the process easier for you?

Appendix 6: Ethical Approval Confirmation



Health Research Authority

North West - Greater Manchester Central Research Ethics
Committee

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

Dear Mr Loughlin

Study title:	Barriers and Facilitators of transition from Early Intervention in Psychosis teams: a qualitative investigation
REC reference:	14/NW/0335
Protocol number:	N/A
Amendment number:	SA1
Amendment date:	28 September 2016
IRAS project ID:	141349

The above amendment was reviewed at the meeting of the Sub-Committee held on 19 October 2016 by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The Sub-Committee noted that the Notice of Substantial Amendment Form did not give an explanation to why the Participant Information Sheets had been updated. Clarification was sought.

The Researcher informed the Committee that the Participant Information

Sheets had been updated upon request of the Sponsor, it was noted by the Sponsor that some key information had been omitted. This information had already been approved by the Committee within the study protocol. The Researcher submitted clear tracked changed documents to the Committee so it was clear what had been updated.

The Committee approved the Participant Information Sheets upon receipt of the tracked changed documents.

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Notice of Substantial Amendment (non-CTIMP)	SA1	28 September 2016
Other [REC_Form_18102016-1]		06 October 2016
Participant information sheet (PIS) [service user PIS]	3	04 October 2016
Participant information sheet (PIS) [Staff PIS]	3	04 October 2016
Research protocol or project proposal	2	28 September 2016
Summary CV for Chief Investigator (CI)		

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

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

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

14/NW/0335:	Please quote this number on all correspondence
--------------------	---

Yours sincerely



Signed on
behalf of
Dr B
Potrata

Chair

E-mail: nrescommittee.northwest-gmcentral@nhs.net

Enclosures: List of names and professions of members who took part in the review

Copy to: Reagan Blyth, Pennine Care NHS Trust

Ms Lynne MacRae, University of Manchester

North West - Greater Manchester Central Research

Ethics Committee Attendance at Sub-Committee of the

REC meeting on 19 October 2016

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Dr G Gkimpas	Clinical Fellow	Yes	
Dr B Potrata	Research Fellow	Yes	

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Jenna Woodburn	REC Assistant

Appendix 7: Transcript Excerpt Example

I: Yeah. OK, so Karen came to you with this er.. discharge plan, did you say?

P: Yeah, discharge plan

I: OK, did you have erm.. kind of, any involvement in .. in that and in the discharge? Did you have any kind of say in what was going on?

P: Erm.. no. I wouldn't say so. Er.. I'd say it was down to Dr. Warrington. He assessed whether I was well enough to be discharged and I think the maximum period in EIT is four years I think, erm.. with I think, then you just go to a Community Mental Health Team, wouldn't you?

I: mm

P: But..they just presented me with a discharge plan. Dr Warrington, on the last visit to him, went through all the notes, explaining where you've been and where you are and where you're going, because you're gonna go off.. not free, but you know what I mean? You're.. you're.. I mean Dr. Mohan, I saw him and he says "you seem really well" and you know, "see you again in five months, but I think I'll discharge you back to your GP"

I: Right OK, so did you talk about, kind of, another move already in advance..

P: Yeah, yeah, yeah, think he'll discharge me back to the GP. And I said when I was there "I feel ready to be discharged back to the GP", but it was all "oh, we'll take it a bit slow"

I: mm mm. So how did you feel, after you first met with them at Cherrywood House, how did you feel about the process of moving teams

P: Yeah, it was a good natural progression really. As I said that Dr Warrington wrote a comprehensive discharge letter erm and I was in.. because in the last visit, the last few visits to Dr Warrington, you'd be in there ten minutes, you know? It starts off, when you first go in, you might be in there an hour and then every six weeks, you might be in there ten minutes with your mental health worker first, she'll tell him what's been going on over the last six weeks, you know, coz they see you at regular intervals. But yeah, Dr Mohan.. he just said I've got to assess you to see you know, if you're ready to.. erm.. go back to your GP anyway.

I: yeah, Yeah

Appendix 8 – Quality Appraisal

Allard

Question	Score	Comments
1	2	Could be clearer?
2	3	Appropriate
3	2	Detailed process, but not as much as to why
4	3	Part of a wider study – good access to lots of p's
5	1	Little information beyond recruitment
6	1	No mention of reflexivity
7	2	Ethics approval mentioned, but no other factors
8	2	Process discussed
9	3	Discussed
10	3	Placed in context
TOTAL	22	

UK. 16 SUs (mean 22) and 16 Carers (ages n/k). Part of wider EDEN study.

Harris

Question	Score	Comments
1	3	Well defined
2	3	Justified in introduction extensively
3	3	As above
4	3	Well defined & exclusion discussed
5	2	Discussed – no mention of data saturation
6	1	Little
7	2	Approval sought and distress mentioned
8	2	Detail re: IPA, but little on bias/interpretation
9	3	Well defined and discussed
10	3	Yes
TOTAL	28	

UK EIS. Age n/k

Lavis

Question	Score	Comments
1	2	Not overtly clear
2	3	Appt
3	3	Yes
4	2	Detail, but not extensive
5	2	Saturation not discussed
6	1	Mentioned, but not expanded upon
7	1	Part of wider study, so assumed, but not mentioned
8	2	Discussed, but not in great detail
9	3	Yes
10	3	Yes
TOTAL	22	

80 carers mean age 50. UK EIS.

Lester 2012

Question	Score	Comments
1	3	Aims stated, meets criteria
2	3	Appropriate methodology
3	2	Full rationale for GT not provided
4	2	Doesn't quite meet gold standard for GT – no purposive/theoretical sampling
5	2	Lacks some info re: data collection (no discussion of saturation)
6	1	Blinding mentioned but limited reflection
7	2	Ethics sought but limited discussion in paper re: ethics
8	1	Not GT!
9	2	
10	2	Some discussion
TOTAL	20	

Stewart 2012

Question	Score	Comments
1	2	Could be clearer?
2	3	Appropriate
3	3	Yes
4	3	
5	2	Yes but not 'pure' GT method – e.g. the 2 phase sampling
6	3	Yes
7	2	To some extent
8	3	Yes
9	2	Yes
10	3	Yes
TOTAL	26	

Lester 2011

Question	Score	Comments
1	2	Outlined, but could be clearer
2	3	Yes
3	3	Justified and detailed
4	3	Detailed
5	2	Detailed but saturation not mentioned
6	2	Briefly mentioned
7	2	Ethics sought and detailed information given
8	2	Contradictory examples sought. Rigorous analysis
9	3	
10	3	
TOTAL	25	

McCann 2011a

Question	Score	Comments
1	3	Clearly defined
2	3	Yes
3	3	Well justified - detailed
4	2	Mostly
5	3	Explicit. Considered saturation
6	1	No mention
7	2	Ethical approval sought & consent. No mention of distress etc
8	2	Detail, but no mention of own role etc.
9	2	Good discussion but few explicit implications
10	3	Yes
TOTAL	24	

McCann 2011b

Question	Score	Comments
1	3	Well defined
2	3	Yes
3	3	Well justified reasons for IPA
4	1	Explained, but little detail
5	3	Very explicit – mentions interviewers' summaries
6	2	Spoke of interviewers' roles in interviews, but not analysis
7	3	Explicitly
8	3	Yes
9	3	Yes
10	3	Yes
TOTAL	27	

O'Toole 2004

Question	Score	Comments
1	2	Could be clearer
2	3	Yes
3	2	Yes, but could be clearer
4	2	Mentioned, but recruitment not covered in detail
5	2	Not in great depth
6	1	Mentioned in other paper from same larger study
7	1	Not mentioned
8	2	Could be in more detail
9	3	Detailed
10	3	Yes
TOTAL	21	

Penny

Question	Score	Comments
1	3	Very much so
2	3	Yes
3	1	Stated, but little justification
4	1	Relevant to the aims, but little info about how they were recruited
5	2	Issues re: translators detailed, but specifics omitted due to word limit
6	1	Not mentioned
7	2	Ethical approval and consent covered
8	2	Detailed, but not in great depth due to word count
9	2	Limited examples due to word count
10	3	Yes
TOTAL	22	

Sin 2012

Question	Score	Comments
1	2	Outlined, but not very clear
2	3	Yes
3	1	Barely
4	1	Barely
5	2	Elaborated on
6	1	Hardly mentioned
7	2	Mentioned, but not explicitly
8	2	As above
9	2	Yes
10	3	Yes
TOTAL	19	

Tindall

Question	Score	Comments
1	3	Yes
2	3	Yes
3	3	Explicitly
4	2	Largely, but no mention of why p's might not have
5	2	Detailed, but not overly
6	2	Explicitly, but not related to events during the study
7	1	Approval sought; no other mention
8	2	Not in great detail
9	3	Explicit and with diagram
10	3	Yes
TOTAL	24	

van Schalkwyk, 2015

Question	Score	Comments
1	2	Could be clearer
2	3	Yes
3	2	Could be more detailed
4	1	Hardly any detail
5	1	Hardly any detail
6	1	No
7	2	Ethics sought and consent discussed
8	1	Little detail
9	2	Yes
10	3	Good implications
TOTAL	18	

Jansen 2015

Question	Score	Comments
1	2	Could be clearer
2	3	Yes
3	3	Yes
4	2	Detailed, but not extensively
5	3	Very detailed
6	3	Yes
7	3	Yes
8	3	Very rigorous
9	3	Yes
10	3	Yes
TOTAL	28	