Trajectories and challenges of re-accessing services following discharge from Early Intervention in Psychosis

Claire Robinson

Candidate ID: ngw23xxu

Primary Supervisor: Dr Sophie Allan

Secondary Supervisors: Dr Sarah Reeve and Dr James Plaistow

Doctoral Programme in Clinical Psychology

University of East Anglia

Faculty of Medicine and Health Sciences

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THESIS PORTFOLIO ABSTRACT

Background: Early Intervention in Psychosis (EIP) services support individuals with psychosis for up to three years. Most patients are discharged to primary care following EIP involvement. Transitions between services are risky times for patients, leading to increased uncertainty and instability, increasing the risk of relapse. Many patients experience relapse following discharge from EIP, requiring additional support from mental health services. Care pathways and help-seeking following EIP discharge is an under-researched area. Understanding and improving care pathways can improve service provisions and patient outcomes.

Methods: A systematic review was conducted exploring care pathways following discharge from EIP services, including predictive factors and long-term outcomes. A qualitative study was conducted exploring service-user experiences of re-accessing mental health services following discharge from EIP, using semi-structured interviews and analysed using thematic analysis.

Results: 17 papers met the inclusion criteria for the systematic review. Three care pathways were identified: primary care, secondary care and tertiary care. Earlier studies reported secondary care as dominant discharge destination, whereas more recent, higher quality studies found primary care to be most common. The review reported on predictors for discharge destinations including patient characteristics and EIP treatment factors. In the empirical study, ten participants were interviewed about their experiences of re-accessing care and barriers or facilitators to help-seeking. Themes centred around significant systemic barriers including resource scarcity, rigid service processes and strict eligibility criteria; alongside interpersonal barriers related to stigma, identity, trust and safety. Facilitator themes related to ‘safer support’ and relationships.

Conclusions: The thesis portfolio identified the need for flexible, adaptable and relationally safe services for supporting access to care and engagement. Change to service design should be guided by service-users' experiences. Future research should explore family and clinician experiences of post-EIP care pathways, given they often advocate for loved ones and help navigate services.

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CHAPTER ONE

INTRODUCTION

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CHAPTER ONE

INTRODUCTION

The following introduction provides context for the thesis exploring trajectories and challenges of re-accessing services following discharge from Early Intervention in Psychosis (EIP) services.

Psychosis

Psychosis is a term used to categorise psychotic disorders such as schizophrenia, schizoaffective disorder, and delusional disorder (National Institute of Clinical Excellence, 2014). Approximately 1% of the population will experience psychosis (Sisti & Calkins, 2016). Symptoms usually develop in adolescence or early adulthood, a period of significant life changes and transitions, though this varies across individuals (NICE, 2014; Tanskanen et al., 2011). According to the continuum model, psychosis ranges from mild, subclinical experiences (common in the general population) to intense, frequent and distressing experiences (Csillag et al., 2018; Van Os et al., 2009).

Individuals with psychosis experience altered perceptions, thoughts, feelings and behaviours, including “positive” symptoms like hallucinations and delusions and “negative” symptoms like social withdrawal and emotional apathy (NICE, 2014; Richards & Gurr, 2000). Clinically significant symptoms are likely to require treatment from mental health services and are associated with increased distress and long-term functional impairment, including difficulties with memory, attention and executive functioning (Murden, 2023; Rodríguez-Blanco et al., 2017).

Psychosis is associated with high rates of comorbidities including conditions like anxiety, depression and substance use and symptoms can persist or re-emerge

throughout the lifetime (Carrà & Johnson, 2009; Wilson et al., 2020). Deficits in social integration and independent living can persist even when psychotic symptoms are well managed, such as long-term difficulties with retaining housing, employment and relationships (Chan et al., 2019).

Treatment for psychosis

EIP services have been implemented as the primary treatment for psychosis within 16 countries across the world, including England, Canada and Australia (O'Connell et al., 2022). The initiative for EIP services was supported by the critical period hypothesis proposed by Birchwood (1998) suggesting that intervention during this period could improve long-term outcomes for patients by reducing the duration of untreated psychosis (DUP) (Birchwood et al., 2013; Chan et al., 2023).

EIP services were initially introduced in Australia. The first generation of EIP was established in the 1980s, opening an inpatient unit for First episode psychosis (FEP) patients (Chan et al., 2023; Csillag et al., 2018; McGorry et al., 1996). Evaluations of this service model concluded the importance of prevention as the primary goal for psychotic disorders and the significance of delays to first treatment (Csillag et al., 2018; McGorry et al., 1996). As a result, in the 1990's a new foundation for EIP was implemented, launching the first integrated community based EIP service in Melbourne, Australia (Birchwood et al., 2014; McGorry et al., 1996). This service model focused on reducing the DUP and optimising care during the critical period (3-5 years after first episode), leading to a reduction in symptom severity, and improvements to functional outcomes and quality of life, demonstrating its effectiveness as an intervention for psychosis (Ahmed et al., 2015; McGorry et al.,

1996). This service model was later implemented internationally, including Canada, Hong Kong and the UK (Chan et al., 2023; O'Connell et al., 2022).

Since around 2001, EIP teams have been funded in England and Wales to support individuals aged 14 to 35 years who are experiencing FEP (Birchwood et al., 2014; Tanskanen et al., 2011). EIP aims to improve access to care and outcomes through early detection and treatment, reducing hospital admissions, symptom severity and relapse rates (Bergé et al., 2016; Murden, 2023; Tanskanen et al., 2011). EIP provides service-users with a holistic package of care, including pharmacological (antipsychotic medication), psychological (Cognitive Behavioural Therapy and Family Therapy) and social interventions (NICE, 2014; Puntis et al., 2018). EIP treatment should be offered to individuals with a diagnosis of FEP within the 'critical period', the first five years from onset to ensure successful recovery and remission (Birchwood et al., 1998; Catalan et al., 2021).

EIP services are also referred to as Coordinated Speciality Care (CSC), Early Psychosis Prevention and Intervention Centre (EPPIC), Early Intervention Service (EIS) or First Episode Psychosis (FEP) services.

Care pathways post-EIP

Discharge destinations are dependent on patients' stability and readiness for independent management of symptoms (Ahmed et al., 2019). According to Iris guidelines, there is an expectation that at the end of their time in EIP, patients should be stable and ready to be discharged to primary care and often limited alternatives are available due to service capacity (Ahmed et al., 2019; O'Donoghue et al., 2023; Puntis et al., 2024; Rickett et al., 2024).

Given the intensity of support offered from EIP services, individuals experience a loss of support and reduced monitoring following discharge (Woodward et al., 2019). Patients are either discharged to primary care or experience a transfer of care to an alternative service provision, such as Community Mental Health Teams (CMHTs) (Puntis et al., 2024). The receiving services note increasing pressure to accept referrals from EIP services, offering ongoing support to appropriately meet the needs of these individuals post-discharge (Baird et al., 2016; Belling et al., 2011).

In this thesis, care pathways refer to points of contact with services or sources of support following discharge including monitoring transitions between services and service involvement. Most care pathways show lengthy and complex trajectories over time due to fragmented connections between services (Kvamme et al., 2001).

Outcomes and ongoing needs

Evidence suggests the benefits gained from EIP are not always maintained following discharge (Dodgson et al., 2012). Those discharged to primary care no longer have access to specialist psychosis support, despite high relapse rates. Up to 80% of FEP patients experience relapse within the first 5 years (Alvarez-Jimenez et al., 2012; Bergé et al., 2016). Relapse remains high for individuals leaving EIP, particularly during transition periods between services, increasing vulnerability (Puntis et al., 2018). Predictors of relapse include living in deprived areas, social deprivation and lack of service access, higher rates of hospital admissions and longer DUP prior to discharge (Catalan et al., 2021; Hyatt et al., 2024; Puntis et al., 2018).

Re-accessing services and help-seeking

As most EIP patients are discharged to primary care, there is a reliance on General Practitioners (GPs) to work as gatekeepers for re-accessing further mental health support (Akbari et al., 2005). Re-accessing care refers to the process of seeking help and obtaining support during a relapse post-discharge. Access to help is shaped by stigma and help-seeking attitudes as well as systemic constraints including limited resources, missed referrals, service eligibility and waiting lists (Ahmed et al., 2019; Akbari et al., 2005; Memon et al., 2016; Murden, 2023).

Gaps in existing research

Existing research focuses on entry to EIP and outcomes during and post-EIP treatment (Lester et al., 2012; Rickett et al., 2024). Less attention has been paid to longitudinal and qualitative studies focussing on how individuals move through services post-EIP and their experience of re-accessing support during relapse. Addressing this gap is essential to improving patient outcomes; reducing relapse and readmissions; minimising inappropriate referrals and reducing the financial costs on the NHS by ensuring that individuals are supported by the most appropriate service.

Rationale and aims for thesis

EIP services have been widely implemented and are associated with improved patient outcomes, however, less is known about what happens after discharge from EIP services. Recommendations from existing literature emphasise the importance of continuity of care and relapse prevention post-EIP, although there is little clarity on the nature and experience of post-EIP care pathways. This represents a gap in research given the known relapse risk following discharge. Furthermore, there is a notable absence of service-user perspectives within the existing literature,

specifically around experiences of re-accessing care following relapse. Understanding the barriers and facilitators to accessing support is essential to ensure services are available and accessible.

Understanding post-EIP trajectories requires mapping pathways post-EIP (as demonstrated in the systematic review) and understanding lived experience of help-seeking and accessing services (as shown in the qualitative study). The systematic review aims to synthesise existing evidence on post-EIP care pathways and identify the gaps in knowledge. The empirical paper aims to explore service-users' experiences of re-accessing care to identify barriers and facilitators. Together they can offer a comprehensive understanding of trajectories and challenges post-EIP and inform discharge planning, service design and implementation.

CHAPTER TWO

SYSTEMATIC REVIEW

Care pathways following discharge from Early Intervention in Psychosis services: A systematic Review

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Care pathways following discharge from Early intervention in Psychosis services: a systematic review

Claire Robinson, Sarah Reeve, James Plaistow, Sophie M. Allan

Doctoral Programme in Clinical Psychology

University of East Anglia

ABSTRACT

Background: Early Intervention in Psychosis Services support individuals for up to 3 years following their first episode. Care trajectories following discharge are relatively understudied. Given the likelihood of relapse, understanding subsequent care pathways is important.

Aim: To synthesise evidence on care pathways following discharge from Early Intervention in Psychosis services, predictors for discharge destination and long-term outcomes.

Methods: A systematic review was conducted, and findings were analysed using narrative synthesis. The CINAHL, MEDLINE, PsycINFO and Scopus databases were searched. Included studies were published in English between 1996 to 2025, and acknowledged care pathways up to 5 years post-discharge from Early Intervention in Psychosis services.

Results: Seventeen studies met the inclusion criteria, 16 were quantitative. Mixed findings on care pathways were reported. Earlier studies reported secondary care as most common but recent, larger studies stated primary care as the dominant discharge destination. Predictive factors for discharge destination included being male, diagnoses of schizophrenia, hospital admissions, relapses, longer duration of care and substance use. Papers explored post-discharge outcomes, including relapse rates, retention in services and hospital admissions. Relapse following discharge was predicted by diagnosis, longer duration of EIP treatment, greater social deprivation, and substance use.

Conclusions: Recommendations include longer-term support from secondary care services, smoother transitions and collaboration between services and consideration

of extending Early Intervention in Psychosis services beyond 3 years. More research is warranted into service-user perspectives on post-EIP care pathways.

Key words: “Early Intervention in Psychosis”, “care pathways”, “Transition”, “continuity of care”, “discharge”, “mental health services”.

INTRODUCTION

Since 2001, Early Intervention in Psychosis (EIP) services in England and Wales have offered treatment to individuals with first episode psychosis (FEP) within the ‘critical period’, (five years from onset) to optimise successful recovery by reducing duration of untreated psychosis (DUP) and remission (Birchwood et al., 1998; Catalan et al., 2021; Puntis et al., 2024; Tanskanen et al., 2011). EIP generally covers the initial 3 years with a further 2 years support dependent on discharge destination (Birchwood et al., 1998).

EIP was expected to improved outcomes (reduced relapse, hospitalisation and better functioning) with patients less reliant on long-term services (Malla et al., 2005; McGorry et al., 1996; Randall et al., 2015). Those deemed ‘stable and well’ should be discharged to primary care (Ahmed et al., 2015; Lester et al., 2012). IRIS (Initiative to reduce the impact of schizophrenia) international guidelines provide principles of good practice for EIP services, to ensure high-quality and cost effective care for individuals experiencing FEP (Baird et al., 2012). The guidelines outline key elements of EIP service design and describe the ethos and rationale for EIP services. Within this framework, the IRIS guidelines state that a minimum of 50% of service-users should be discharged to primary care following 3 years of EIP (Ahmed et al., 2019).

Care pathways following EIP include discharge to primary, secondary or tertiary care, e.g. outreach or forensic teams (Ahmed et al., 2015; Puntis et al., 2024). Discharge destinations differ between countries and service models, with variations in the discharge criteria and planning processes (O'Donoghue et al., 2023; Rickett et al., 2024).

Given the fluctuating nature of psychosis, the period following EIP remains critical. Whether most patients are discharged to primary or secondary care, has implications for funding, workforce planning and resource allocation. Discharging all EIP patients to secondary care is not feasible (NICE, 2014; Bergé et al., 2016; O'Donoghue et al., 2023; Puntis et al., 2024; Rickett et al., 2024). Inappropriate discharges can: increase treatment wait times, causing adverse effects on patients' outcomes, increasing symptom severity and burden on services (Marshall et al., 2005; Reichert & Jacobs, 2018); have financial impact and hinder service relationships (Ahmed et al., 2015; Puntis et al., 2024). Identifying individuals at risk of relapse and ongoing need for support, reduces inappropirate referrals and improves long-term patient outcomes (Puntis et al., 2024).

The proportion of individuals discharged to lower level support versus ongoing care and the resulting longitudinal outcomes remain unclear (Chang et al., 2015; Chang et al., 2017; Dodgson et al., 2012). There is concern that the long-term benefits are not maintained following EIP despite discharge destination (Chang et al., 2016).

Discharge and care pathways following EIP is under-researched (Lester et al., 2012), unlike the extensively studied care pathways for FEP (Birchwood et al., 2013; Cabassa et al., 2018; Etheridge et al., 2004; Singh & Grange, 2006). Understanding

long-term outcomes by discharge destination informs service design. To our knowledge, no systematic review exploring care pathways following EIP has been conducted.

The systematic review aims:

Primary aim: To identify and synthesise evidence on care pathways following discharge from EIP services.

Secondary aims: To explore the factors influencing the decision making around discharge destinations and the outcomes associated with different care pathways.

METHODS

This systematic review, pre-registered on PROSPERO (CRD420250640929),summarised evidence in accordance with Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) guidelines (Page et al., 2021). Popay et al. (2006) guidelines informed this narrative synthesis.

Search Strategy

CINAHL, MEDLINE, PsycINFO and Scopus databases were searched on 22nd April 2025 for papers published between 1996 and 2025 (Appendix A). Search terms were: (“care path*” OR “Care plan” OR “Treatment path*” OR “service pathway” OR “trajector*” OR “follow-up”) AND (“discharge” OR “leav*” OR “exit” OR “transition” OR “Point* of contact” OR “discharge plan*” OR “post treatment” OR “aftercare” OR “destinations”) AND (“EIP” OR “EIS” OR “Early Intervention” OR “Early treatment” OR “Early support” OR “early detection”) AND ("Psychosis” OR “psychotic” OR "Schizophrenia" OR "Schizoaffective" OR “schizo-affective” OR "bipolar"). Duplicated studies were removed (Figure 1).

Eligibility Criteria

Inclusion criteria:

- Primary papers published in English between 1996 to 2025. EIP services were officially introduced within NHS England in 1996 (Cheng et al., 2011).
- Papers reporting on data received from individuals with a diagnosis of psychosis who had previous treatment under an EIP service and since discharged.
- Papers related to care pathways within 5 years of discharge from EIP. A five-year cut-off was applied because service models and provision have evolved considerably over the past decade, ensuring the findings better represent current practice.

Exclusion criteria:

- Non-empirical studies
- Papers reporting patient outcomes only

Study selection

Abstracts and full texts were screened by CR using Rayyan. Twenty percent of full-text articles screened for eligibility (n=16) were checked independently by a second reviewer (SA), with two discrepancies resolved by the supervisory team. Eight further full-text articles were discussed with SA. We assessed inter-rater reliability for full-text screening using Cohen's kappa. The PRISMA flow diagram (Figure 1) displays search, screening and selection findings.

Quality appraisal

Methodological quality was assessed by CR using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). The MMAT is accepted as a credible checklist for mixed methods (Pace et al., 2012). 20% (n= 4) were independently assessed by SA, with an 88.2% agreement and Cohen's kappa value of 0.692 (p = .001), indicating substantial agreement (Appendix B). Discrepancies were resolved through discussion with SA.

Data extraction and narrative synthesis

Data extracted to an Excel spreadsheet: a) study details (title, aims, authors, year of publication, study country); b) sample characteristics (sample size, gender, age, ethnicity, diagnosis); c) EIP services (description, mode of intervention, follow-up); d) outcomes (outcome measures, effect sizes, main findings, description of care pathways); e) future implications (study conclusions and recommendations).

The included studies comprised both quantitative and qualitative methodologies, although with the majority being quantitative the synthesis focused on these with qualitative studies providing context and exploratory elements. Given the methodological heterogeneity of the included studies, a narrative synthesis (Popay et al., 2006) was conducted through the development of preliminary synthesis exploring common patterns across the studies. Studies were initially organised according to the three research questions (care pathways following discharge, predictors of discharge destination and outcomes following discharge). Care pathways were grouped according to pathway type (primary, secondary, or tertiary care). Extracted findings from qualitative interview studies consisted of evidence relating to continuity of care, transition processes and post-discharge

support. Qualitative studies were used to provide additional insight into care pathways post EIP. Qualitative findings primarily contributed insight into outcomes post discharge such as engagement.

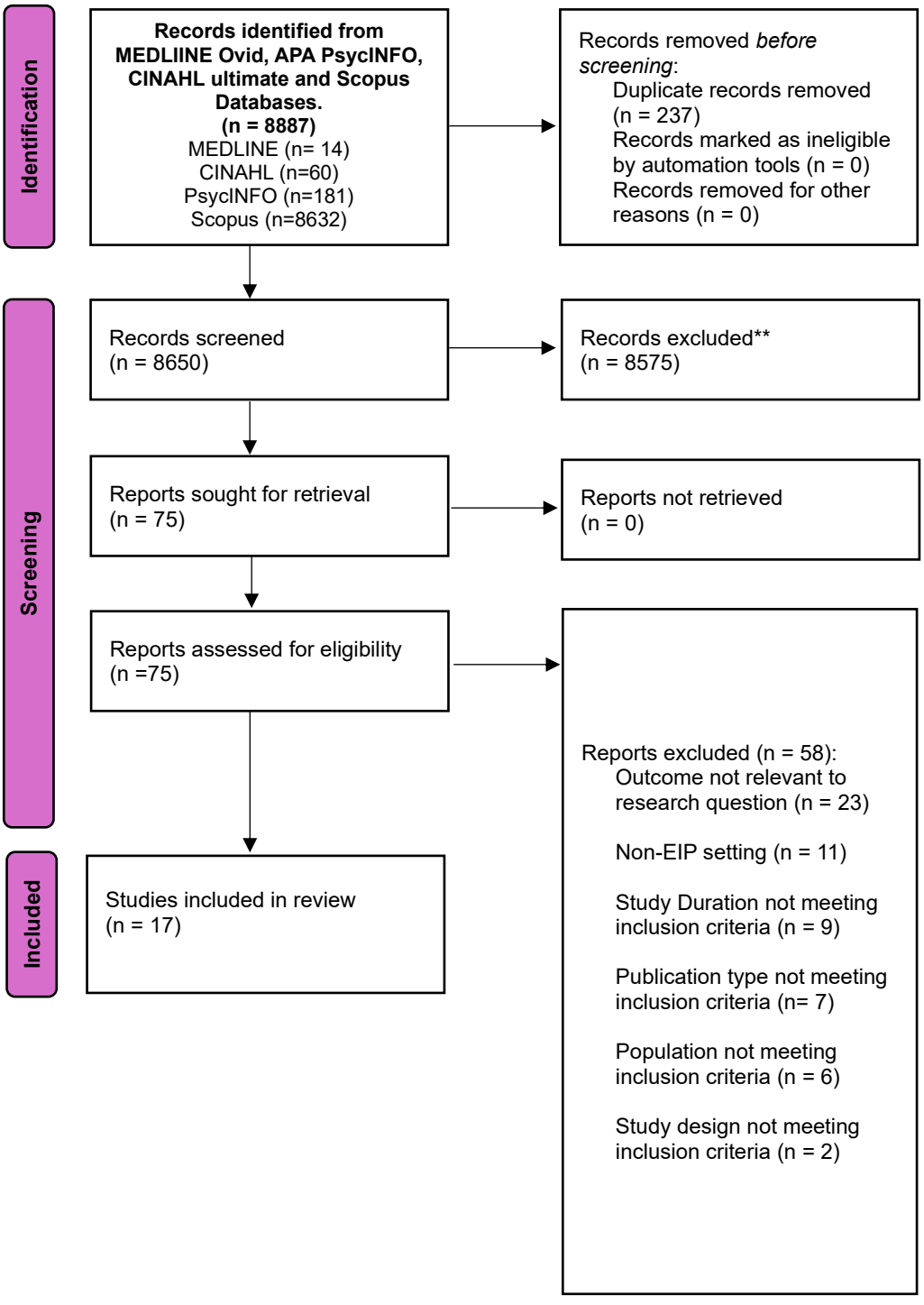
Relationships within and between studies identified similarities and contradictions. Mind maps were used to support comparison across studies and identify themes. Studies reporting similar findings were grouped together to highlight areas of agreement or disagreement.

Where conflicting findings emerged, study quality and methodological limitations were considered when interpreting findings and to assess the robustness of the synthesis. Quality was assessed using the MMAT tool and consideration of sample size, publication date and study design. Findings from studies with fewer methodological limitations held greater weight in the synthesis.

RESULTS

The database search identified 8650 studies. References were imported to endnote where duplicates where removed. The remaining papers were uploaded to Rayyan, and additional duplicates were removed manually (237 duplicates in total). Title and abstracts were screened manually against the inclusion and exclusion criteria, resulting in 75 papers remaining. 75 full texts were screened for eligibility, reasons for exclusion were recorded, leaving 17 meeting inclusion criteria (see Figure 1). A second reviewer (SA) screened 20% of the full text papers to enhance reliability and disagreements were resolved through discussion.

Figure 1
PRISMA Diagram



Study characteristics (Table 1)

Publication dates ranged from 2008 to 2024. A variety of methodologies were utilised, 16 quantitative, one qualitative.

Papers included one each from Australia, Denmark, Canada, United States; five from Hong Kong and eight from the UK. All were representative of countries with embedded EIP services within their healthcare systems (Chan et al., 2023).

Service types described the variations of EIP services, most offering a 3-year service (n=12). Average follow-up post-EIP discharge was 2.42 years (range = 3months – 5years). Sample sizes ranged from 21 (Lester et al., 2012) to 2224 (Puntis et al., 2024) (mean=443). Participants were mainly 20-25 years (range = 14-45 years) and male (50-74%). 14 papers reported ethnicity.

Table 1

Characteristics of Included Studies

Study	Study objectives	Country	Urban or Rural?	Setting	Sample size (N)	% male	Mean Age	Age range (years)	Ethnicity	Follow-up after discharge
Addington et al (2008)	To describe longer-term symptomatic and functional outcomes (1–2 years post-discharge) for individuals treated in a specialized 3-year early psychosis program.	Canada	Urban	Specialized Early Psychosis Program (EPP) 3-year service	200	67.5	23.88	Not reported	Caucasian: 76.6%	1–2 years
Ahmed et al (2015)	To examine what happens to patients after three years under an EIP service: specifically, to describe discharge destinations and status of patients 3 years after being under the EIP service. To find out how many remain under services, how many have been discharged, and where.	UK	Mixed	EIP service 3-year service	97	67.0	25.0	Not reported	Not reported	3 years

Study	Study objectives	Country	Urban or Rural?	Setting	Sample size (N)	% male	Mean Age	Age range (years)	Ethnicity	Follow-up after discharge
Ahmed et al (2019)	To determine the proportion of discharges from an EIP team to primary care vs secondary psychiatric care. To identify clinical and demographic factors influencing discharge destination. To inform future service planning and patient psychoeducation by predicting likely discharge destinations.	UK	Mixed	Psychosis Intervention and Early Recovery (PIER) service 3-year service	508	72.0	Not reported	15-42	White British: 61%, Indian: 14%, Pakistani: 2%, African: 5%, Bangladeshi: 2%, Caribbean: 2%, Mixed heritage: 5%, Other: 8%	Not reported
Bertelsen et al (2008)	To determine the long-term effects (5 years) of an intensive early-intervention program (OPUS) for first-episode psychotic patients compared with standard treatment.	Denmark	Urban	OPUS Intensive Early Intervention in Psychosis (EIP) 2-year service	547	58.0-60.0	26.6	18-45	Predominantly Danish / Northern European (exact % not heavily stratified)	3-5 years
Chan et al (2022)	To examine 10-year relapse patterns in patients with first-episode schizophrenia-spectrum disorders (FES), identify predictors of early and late relapse, and assess differential outcomes.	Hong Kong	Urban	EIP service vs. Standard Care Service (SCS)	148	50.0	21.0	15-25	Chinese	Over a 10 year period.
Chang et al (2015)	To determine whether extending a specialised early intervention (EI) service for first-episode psychosis by one year (total of 3 years) improves clinical and functional outcomes compared to	Hong Kong	Urban	Early Assessment Service for Young People with Psychosis (EASY)	160	51.0	22.9	15-25	Chinese	1 year

Study	Study objectives	Country	Urban or Rural?	Setting	Sample size (N)	% male	Mean Age	Age range (years)	Ethnicity	Follow-up after discharge
	standard 2-year EI followed by step-down care.									
Chang et al (2016)	To examine the rate and predictors of functional remission (FR) in first-episode psychosis (FEP) patients following an extended 1-year early intervention (EI) compared to step-down care after a 2-year EI service.	Hong Kong	Urban	Early Assessment Service for Young People with Psychosis (EASY)	160	51.9	22.9	15-25	Chinese	1 year
Chang et al (2017)	To investigate whether the beneficial effects of a 3-year EIP programme for first-episode psychosis (FEP) patients are sustained 3 years after completion, compared with those receiving standard care.	Hong Kong	Urban	Early Assessment Service for Young People with Psychosis (EASY) programme. 2–3year service	160	56.0	24.0	15-25	Chinese	3 years
Chang et al (2018)	To examine the rate and predictors of functional remission (FR) in first-episode psychosis (FEP), particularly investigating the roles of motivational impairment (amotivation) and diminished expression (DE) in predicting FR at 3 years post-intervention.	Hong Kong	Urban	Early Assessment Service for Young People with Psychosis (EASY) 2–3-year service	160	52.4	22.9	15-25	Chinese	3 years

Study	Study objectives	Country	Urban or Rural?	Setting	Sample size (N)	% male	Mean Age	Age range (years)	Ethnicity	Follow-up after discharge
Dodgson et al (2012)	To investigate the long-term effectiveness of an EIP service on engagement and hospital bed usage post-discharge, and to identify if there is a subgroup of patients with poor outcomes.	UK	Mixed	EIP service	75	Not reported	Not reported	14-35	Majority White British.	2 years
Gallagher et al (2022)	To evaluate whether a structured quality improvement (QI) approach could improve discharge planning ("disposition") and care continuity ("transfer") following discharge from a first-episode psychosis service (FES).	United states (US)	Urban	Specialized Treatment Early in Psychosis (STEP) 2-year service	144	68.0	Not reported	16-34	Black: 46%, interracial: 14%, Hispanic: 8%, remainder White or other.	3 months
Harrington et al (2013)	To determine medium-term outcomes of early intervention service-users after discharge. To identify characteristics measurable early in treatment that predict outcomes and could assist in discharge planning and targeted intervention	UK	Urban	EIP services 3-year service	155	70.0	21.6	Not reported	Not reported	3 years
Kam et al (2015)	To identify factors predicting post-discharge relapse and longer-term functioning in patients with first-episode psychosis (FEP) after	UK	Urban	EIP service 3-year service	163	74.0	22.4	16-35	Asian: 52%, Black: 36%, White: 12%	Median: 3.6 years

Study	Study objectives	Country	Urban or Rural?	Setting	Sample size (N)	% male	Mean Age	Age range (years)	Ethnicity	Follow-up after discharge
	completion of early intervention services.									
Lester et al (2012)	To explore service-users' perspectives of early intervention services (EIS) and primary care, in-depth and over time, focusing on the transition process from EIS to other services.	UK	Mixed	EIP services and primary care.	21	66.0	23.0	18-33	White British: 73%, Pakistani: 10%, Indian: 10%, Mixed race: 5%	6 months
O'Donoghue et al (2023)	To determine the discharge destinations from early intervention for psychosis (EIP) services. To identify baseline and intra-episode factors associated with discharge to secondary (adult) mental health care.	Australia	Urban	Early Psychosis Prevention and Intervention Centre (EPPIC) 2-year service	1101	58.8	20.0	17-22	Not reported	Over a 6 year period.
Puntis et al (2018)	To examine discharge pathways and predictors of relapse among patients treated in EIP services. To identify demographic and clinical variables associated with discharge destination and relapse after EIP treatment.	UK	Mixed	EIP services	701	65.2	22.25	14-35	White: 76.6%, Black: 4.5%, Asian: 11.4%, Mixed: 6.2%, Other: 1.2%	Median: 2.8 years

Study	Study objectives	Country	Urban or Rural?	Setting	Sample size (N)	% male	Mean Age	Age range (years)	Ethnicity	Follow-up after discharge
Puntis et al (2024)	To map care pathways after discharge from Early Intervention in Psychosis (EIP) services and identify common trajectories of care in the 12 months following EIP treatment	UK	Urban	EIP services	2,224	63.0	26.3	Not reported	White: 48.8%, Black: 17.7%, Asian: 19.3%, Mixed: 5.6%, Other: 8.6%	1 year

Quality Appraisal

Methodological quality varied (Table 2). MMAT ratings were highest for Ahmed et al. (2019), Chang et al. (2015), Kam et al. (2015), Lester et al. (2012), Puntis et al. (2018) and Puntis et al. (2024). MMAT ratings were lowest for Addington & Addington (2008), Bertelsen et al. (2008) and Chan et al. (2022).

Quantitative studies used representative samples, appropriate measurements and methodology. The stronger evidence with greater internal validity, statistical power and generalisability came from the recent and larger cohort studies (O'Donoghue et al., 2023; Puntis et al., 2024; Puntis et al., 2018). Several studies demonstrated strong measurement quality using clearly defined outcomes (Chan et al., 2022; Chang et al., 2015; Chang et al., 2016; Chang et al., 2018; Kam et al., 2015; O'Donoghue et al., 2023; Puntis et al., 2018) and validated psychometric tools (Addington & Addington, 2008; Bertelsen et al., 2008; Chan et al., 2022; Chang et al., 2016; Chang et al., 2018). Six studies (Bertelsen et al., 2008; Chan et al., 2022; Lester et al., 2012; O'Donoghue et al., 2023; Puntis et al., 2024; Puntis et al., 2018) were conducted across multiple centres and varied health care systems, increasing the generalisability and transferability across service models.

Outcomes from clinical records were relied on in 11 studies, risking incomplete and inaccurate data collection. Four studies had missing data (Ahmed et al., 2015; Ahmed et al., 2019; Harrington et al., 2013; O'Donoghue et al., 2023). Ten studies lacked consistent and clear definitions of relapse, reducing comparability and confidence in findings.

Table 2

Quality appraisal

Domain	Quality Criteria	Addington et al (2008)	Ahmed et al (2015)	Ahmed et al (2019)	Bertelsen et al (2008)	Chan et al (2022)	Chang et al (2015)	Chang et al (2016)	Chang et al (2017)	Chang et al (2018)	Dodgson et al (2012)	Gallagher et al (2022)	Harrington et al (2013)	Kam et al (2015)	Lester et al (2012)	O' Donoghue et al (2023)	Puntis et al (2018)	Puntis et al (2024)
Total Percentage (%)		71	86	100	71	71	100	86	86	86	86	86	86	100	100	86	100	100
Qualitative studies	Is the qualitative approach appropriate to answer the research question?														Y			
	Are the qualitative data collection methods adequate to address the research question?														Y			
	Are the findings adequately derived from the data?														Y			
	Is the interpretation of results sufficiently substantiated by data?														Y			
	Is there coherence between qualitative data sources, collection, analysis and interpretation?														Y			

Quantitative Descriptive studies	Is the sampling strategy relevant to address the research question?	Y	Y	Y	Y	Y							Y	Y		Y	Y	Y
	Is the sample representative of the target population?	?	?	Y	Y	?							?	Y		Y	Y	Y
	Are the measurements appropriate?	Y	Y	Y	N	Y							Y	Y		?	Y	Y
	Is the risk of nonresponse bias low?	?	Y	Y	Y	?							Y	Y		Y	Y	Y
	Is the statistical analysis appropriate to answer the research question?	Y	Y	Y	?	Y							Y	Y		Y	Y	Y
Non-randomised studies	Are the participants representative of the target population?										Y	Y						
	Are measurements appropriate regarding both the outcome and intervention (or exposure)?										Y	Y						
	Are there complete outcome data?										Y	Y						
	Are the confounders accounted for in the design and analysis?										N	N						
	During the study period, is the intervention administered (or exposure occurred) as intended?										Y	Y						
Randomised Controlled trials	Is randomization appropriately performed?						Y	Y	Y	Y								
	Are the groups comparable at baseline?						Y	Y	Y	Y								
	Are there complete outcome data?						Y	Y	Y	Y								
	Are outcome assessors blinded to the intervention provided?						Y	Y	Y	Y								
	Did the participants adhere to the assigned intervention?						Y	N	N	N								

Narrative synthesis

11 papers utilised clinical record data; two used interviews; and one high quality paper used secondary data analysis (Puntis et al., 2024; Table 3). The remaining papers did not report data collection methods.

18 psychometric outcome measures were reportedly used. Positive and Negative Syndrome Scale (PANSS) was reported in seven papers. Measures for functioning were used, including Social and Occupational Functioning Assessment Scale (SOFAS) (n=5) and the Role Functioning Scale (RFS; n=5). Depression was assessed in six papers using the Calgary Depression Scale (CDS). Seven studies did not report use of psychometric instruments (Table 3).

Care pathways (Table 3)

Discharge destinations were grouped into three categories: primary care (private psychiatrist or GP), secondary care (Community Mental Health Teams and outreach) and tertiary care (inpatient or forensic services).

Ten, reasonable quality MMAT scoring papers (Table 2) indicated secondary care as most common (41.2% to 83.5%). Five studies indicated primary care as most common (39.3% to 69.7%) (Addington & Addington, 2008; Lester et al., 2012; O'Donoghue et al., 2023; Puntis et al., 2024; Puntis et al., 2018). Chan et al. (2022) stated that approximately half were discharged to primary and half to secondary care. Dodgson et al. (2012) did not explicitly state discharge destination.

The more recent and highest quality studies with the largest sample size, found that discharge to primary care was most common (63.4% to 77.7%) (O'Donoghue et al., 2023; Puntis et al., 2024). Puntis et al. (2024) was among six studies achieving the highest ratings on the MMAT (Table 2). Of the remaining five

studies, two similarly reported primary care as the most common discharge destination (Lester et al., 2012; Puntis et al., 2018), whereas the other three studies found that discharge to secondary care was more frequent (52.55% to 69%) (Ahmed et al., 2019; Chang et al., 2015; Kam et al., 2015). O'Donoghue et al. (2023) and Puntis et al. (2024)had the greatest external validity. Although equivocal, the synthesis suggests the most common UK discharge destination is to Primary Care.

Four papers reported on discharges to tertiary services. UK studies categorised tertiary care discharge as inpatient admissions (3% to 15.5%) (Ahmed et al., 2015; Puntis et al., 2024; Puntis et al., 2018). Addington & Addington (2008) found that 29.8% were discharged to a specialist schizophrenia programme.

Predictors of Discharge Destination

Seven papers examined predictors and/or influential factors on discharge destination (Table 3). Factors associated with discharge to secondary care included: male sex (n=2), substance use (n=4), a diagnosis of schizophrenia (n=3) or personality disorder (n=2), a hospital admission at the start of EIP (n=4), relapses during EIP treatment (n=2) and a longer EIP duration (n= 3).

The largest two studies reported different predictors of discharge destinations. Both found that substance use, and previous hospital admissions predicted discharge to secondary care (O'Donoghue et al., 2023; Puntis et al., 2024). Puntis et al. (2024) reported substance misuse was more frequent in those discharged to secondary care (within 22.9%) compared to primary care (within 14.4%). Similarly, O'Donoghue et al. (2023) reported cannabis (OR=1.56) and methamphetamine (OR= 1.88) use was associated with an increased likelihood of discharge to secondary care. Those who had an admission during EIP were four times more likely

to be discharged to secondary care. Involuntary admission increased likelihood further (OR = 3.93) (O'Donoghue et al., 2023). Those discharged to secondary care had more previous days in hospital on average (Mean = 1017) compared to those in primary care (Mean = 675) (Puntis et al., 2024).

The influence of previous hospital admissions on discharge destination was reported in five papers (Ahmed et al., 2019; Harrington et al., 2013; O'Donoghue et al., 2023; Puntis et al., 2024; Puntis et al., 2018). Most of the high-quality papers (Table 2) indicated that a higher number of hospital admissions was associated with discharge to secondary care. Puntis et al. (2018) supported this, those with previous inpatient admissions during EIP were 92% more likely to be discharged to secondary care. Lower quality studies, e.g. Harrington et al. (2013), reported similar, with mean admission rates of 0.04 among those discharged to primary care compared to 0.34 among those discharged to secondary care. 62% of patients discharged to secondary care had an inpatient entry into EIP. Those entering EIP via outpatient departments were 65% less likely to later be discharged to secondary care compared to those entering via inpatient referrals (Ahmed et al., 2019).

The largest generalisable studies differed on additional predictors. O'Donoghue et al. (2023) reported that being male; not in education, employment or training (NEET); having first degree relative with psychosis and 76% increase with prior relapse, predicted discharge to secondary care. Whereas remission within 12 weeks of EIP reduced odds of discharge to secondary care by 40% and living with parents reduced the odds by 48% (O'Donoghue et al., 2023). Puntis et al. (2024) indicated that a diagnosis of schizophrenia and longer EIP duration predicted discharge to secondary care.

12.7% of patients in primary care had a diagnosis of schizophrenia compared to 39.9% to 41.7% in secondary care and 62.9% within tertiary care (Puntis et al., 2024). Ahmed et al. (2015, 2019) supported claims that diagnosis influenced discharge destination; those with chronic or enduring psychotic disorders were more likely to be discharged to secondary care (50% discharged to secondary care compared to 14% to primary care). A higher MMAT quality paper reported that all other diagnoses reduced the odds of discharge to secondary care (Ahmed et al., 2019; Table 2). Compared to schizophrenia, affective psychosis diagnosis was associated with a 76% reduction in odds of being discharged to secondary care according to a high-quality paper (Puntis et al., 2018; Table 2).

Duration in EIP was consistently reported as a predictor for discharge destination. The largest and higher quality paper with greatest external validity, found that individuals discharged to secondary care had a higher mean number of days within EIP (M= 1017) compared to primary care (M=675) (Puntis et al., 2024). The mean number of days within EIP was even higher within individuals discharged to tertiary care (M= 1052.3). Two other high-quality papers supported this. Puntis et al. (2018) found that an additional month of EIP treatment was associated with a 4% increase in likelihood of being discharged to secondary care. Ahmed et al. (2019) found that patients with an EIP duration of 3 to 4 years were six times more likely to be discharged to secondary care.

Contradictory findings from four studies reported on the influence of gender on discharge destinations (Ahmed et al., 2019; Harrington et al., 2013; O'Donoghue et al., 2023; Puntis et al., 2018). Ahmed et al. (2019) found no significant effect of gender on discharge destination. O'Donoghue et al. (2023) found that males were more frequently discharged to secondary care (64%) compared to lower intensity

services (55%), the odds ratio indicated that males had 41% higher odds of discharge to secondary care relative to females. This was supported by Harrington et al. (2013) with 71% of discharges to secondary care being male. Conversely, Puntis et al. (2018) reported females were 62% more likely to be discharged to secondary care. Both studies were deemed high quality however differences in sample characteristics may partly explain the conflicting findings. O'Donoghue et al. (2023) had a large sample; it was representative and low risk of bias. Puntis et al. (2018) was rated higher on the MMAT. Given that gender is highlighted as the predictive factor, it is likely that a larger sample size and more balanced gender split within the study would produce the most representative and trustworthy findings, suggesting that O'Donoghue et al. (2023) may present greater externally valid findings (sample size = 1101, 58.8% males) compared to Puntis et al. (2018) (sample size = 701, 65.2% males). Larger, more representative samples increase statistical power and external validity, reducing the risk of bias, therefore greater weight was given to the findings from O'Donoghue et al. (2023) (Norton & Strube, 2001).

Differences in service context (including length of EIP service, country the study took place); and premorbid diagnoses may also explain conflicting findings. O'Donoghue et al. (2023) was conducted in Australia where patients received a two-year EIP service, compared to Puntis et al. (2018), a UK three-year EIP service. Differences in discharge destination by gender may reflect differences in diagnoses within both samples, O'Donoghue et al. (2023) had a more homogeneous diagnostic profile across the sample with all participants having a diagnosis of FEP and the majority (71.1%) diagnosed with schizophrenia-spectrum disorders, compared to Puntis et al. (2018) who had a more diagnostically diverse sample, with 36.8% diagnosed with schizophrenia. Given that schizophrenia is associated with discharge

to secondary care and that males are more likely to be diagnosed with schizophrenia (Li et al., 2022), the contradicting findings may reflect differences in underlying diagnosis rather than gender alone. Consequently, the influence of gender on discharge destination remains unclear.

Outcomes post-discharge

11 papers reported on long-term outcomes post-discharge from EIP with variation in outcome types and measurements. Outcomes included relapse (n=7); retention and engagement in services (n=6); and hospital admissions (n=4).

Seven papers reported on relapse rates following discharge, overall ranging from 16% to 64% irrespective of discharge destination. Four reasonable quality studies reported the highest rates within the first few years following discharge. Most patients were discharged to primary care. Strong evidence came from Kam et al. (2015) with 41.1% of patients discharged having at least one relapse during follow-up period (46.3% first ever relapse and 51.6% treated by home treatment services). 22.8% of these relapses occurred within the first year and an overall median time for relapse post-discharge was 3.8 years. Out of those discharged to primary care, relapse ranged from 6.4% to 52% requiring referral to secondary care. Another MMAT higher quality paper found a high percentage of relapses within primary care (47.7%) (Kam et al., 2015).

Synthesis evidence was inconclusive as to higher relapse rates in primary or secondary care. The largest and most recent study with good external validity, found 6.4% discharged to primary care, relapsed and returned to secondary care within a year of discharge and 9.7% discharged to secondary care, relapsed requiring an inpatient stay (tertiary care) (Puntis et al., 2024). Ahmed et al. (2015) reported 12%

discharged to primary care, relapsed to secondary care and 7% discharged to secondary care, relapsed requiring tertiary care.

Three studies report on relapse predictors post-discharge (Chan et al., 2022; Puntis et al., 2024; Puntis et al., 2018). Two papers of the highest quality and larger cohorts found that diagnosis; duration of EIP treatment; social deprivation; and substance use predicted relapse (Puntis et al., 2024; Puntis et al., 2018). Puntis et al. (2018) reported rates were 2.96 times higher in those with personality disorder compared to non-affective diagnoses. Relapse risk rose 2% with longer EIP duration, 3% with higher deprivation and 81% with substance use. These findings suggest that predictors of relapse largely overlap with factors associated with discharge to secondary care in this population.

Four studies reported on outcomes around hospital admissions post-EIP discharge (Chang et al., 2015; Dodgson et al., 2012; Harrington et al., 2013; Puntis et al., 2024). The largest and most recent study with good generalisability found that relapsed secondary care patients spent n=5178 days in hospital, accounting for 21% of total number of hospital days one year post-discharge (Puntis et al., 2024). Harrington et al. (2013) supported these findings, with a higher mean number of hospital admissions in the first year of discharge (M=0.35) compared to those discharged to primary care without relapse (M=0.08). Similarly, the mean total number of hospital admissions per year was higher in the poor outcome group (M=0.34) compared to the good outcome group (M=0.04) (Harrington et al., 2013).

Engagement in relation to specific discharge destinations post-EIP was not well documented. Little useful evidence in this regard could be synthesised within the

review. Overall engagement ranged between 43-95.2%, the strongest evidence reported in Gallagher et al. (2022).

Six studies reported on the retention in services on follow-up. Retention in the original discharge service ranged from 48% to 92% (Ahmed et al., 2015; Ahmed et al., 2019; Harrington et al., 2013; Lester et al., 2012). Puntis et al. (2024) a higher quality paper reported 84.6% remained in primary care and 72.1% remained in secondary care for 1 year follow-up.

Several studies observed transitions between services, most commonly identifying movement from primary to secondary care on relapse (n=3), rates ranging from 5-48% and movement from secondary to tertiary care (n=2). Ahmed et al. (2015), (3-year follow-up period) found 12% of individuals discharged to primary care were re-referred to secondary care; 7% discharged to secondary care were engaged with tertiary care. Overall, 4.1% had moved to a more intensive service at follow-up. Ahmed et al. (2019), Harrington et al. (2013) and Kam et al. (2015) found that 4%, 20% and 47.7% of individuals referred to primary care moved to more intensive care. Kam et al. (2015) had the longer follow-up period and highest MMAT quality rating, demonstrating appropriate and robust analysis and low risk of non-response bias, increasing confidence in findings.

Across studies, movement from secondary care to primary care ranged from 7% to 17% with follow-up periods between one and three years. Ahmed et al. (2015) reported 8.2%; Puntis et al. (2024) 12.7%; Kam et al. (2015) 7.1% and Harrington et al. (2013) 10% moved to less intensive services during follow-up. Reported in one study only (Ahmed et al., 2015), transitions from tertiary care to secondary care were less common (3%).

Table 3

Care pathway information

Study	Outcome measures	Care pathways	Predictors of discharge destination	Outcomes following discharge	Data collection
Addington et al (2008)	PANSS, CDSS, QLS, CMRS	39.3% primary, 25.5% secondary, 29.8% tertiary.	Lower positive and negative symptoms and higher quality of life predict discharge to primary care.	Improved negative symptoms, improved quality of life, reduced depression and cannabis use.	Service databases
Ahmed et al (2015)	Not reported	37.1% primary, 41.2% secondary, 15.5% tertiary (outreach or forensic).	Patients with chronic schizophrenia-spectrum disorders were much more likely to require secondary/tertiary services.	Relapse: 4.1% moved to more intensive service. 8.2% moved to less intensive service.	Clinical records
Ahmed et al (2019)	Not reported	47.4% primary, 52.6% secondary.	Enduring psychosis diagnosis increased the likelihood of being discharged to secondary care. The longer duration in EIP increases the likelihood of discharge to secondary care. Inpatient admission at entry to EIP predicts discharge to secondary care.	Relapse: 4% moved to more intensive service.	Electronic patient records
Bertelsen et al (2008)	SCAN, SAPS, SANS, GAF	All patients after 2 years returned to secondary care services	Not reported	4% living in supported accommodation. 61% unemployed.	Interviews and clinical records.
Chan et al (2022)	CGI-SCH, PANSS, SANS, CDSS, SOFAS, RFS	Approximately half discharged to primary and secondary care.	Not reported	26.8% were relapse free over 10 years. 50% of these achieved remission at 10 years. 64% relapsed in first 3 years.	Clinical records
Chang et al (2015)	SOFAS, RFS, PANSS, CDS	All transferred to generic psychiatric services	Not reported	Extended EIP group has better global functioning and more favourable outcomes for independent living, work productivity and relationships.	Not reported

				Extended EIP group had fewer negative and depressive symptoms and fewer outpatient appointments. 16% relapsed.	
Chang et al (2016)	SOFAS, RFS, PANSS, CDS, PAS, PSST, MARS, SAS, DUP	All transferred to generic psychiatric services	Not reported	Females were more likely to achieve functional remission. Increased PSST and PANSS score, reduced odds of functional remission. Higher baseline functioning increased odds of functional remission. Those with schizophrenia diagnosis or past admissions were less likely to achieve functional remission.	Not reported
Chang et al (2017)	CDS, PANSS, SOFAS, RFS	All participants were transferred to generic psychiatric services for continuing care	Not reported	Functioning, work productivity, independent living and social network were higher in 3 year EIP group in the first year of follow-up.	Not reported
Chang et al (2018)	CB-SCID, PSST, PAS, IRAQS, MARS, SOFAS, RFS, PANSS, CDS	All transferred to generic psychiatric services (some after 2yrs, some after 3yrs)	Not reported	21.7% achieved functional remission. Higher amotivation score reduced odds of achieving functional remission. Higher functioning scores increased odds of achieving functional remission.	Not reported
Dodgson et al (2012)	Not reported	43% in contact with services 43% planned discharge 8% unplanned discharge 7% moved out of area	Not reported	43% were engaged with services at follow-up.	Database (PACE)
Gallagher et al (2022)	PANSS	69.7% referred to another provider. 11% refused further care.	Not reported	Post PDSA group were more likely to have known treatment status. 54.1% confirmed in treatment.	Clinical records

				Post PDSA group were more likely to be referred onto another provider and less likely to refuse further care.	
Harrington et al (2013)	Not reported	42% discharged to primary care. 57% discharged to secondary care.	Later age at first contact increases the likelihood of being discharged to primary care. Fewer hospital admissions in first year increased likelihood of discharge to primary care. Lower overall admissions rates increase likelihood of discharge to primary care.	Relapse: 20% of those discharged to primary care returned to secondary care services.	Review of case notes and records
Kam et al (2015)	Not reported	27% primary, 63% secondary, 7% tertiary.	Not reported	Relapse: 47.7% of those discharged to primary care were re-referred to secondary care. 41.1% had at least one relapse. 22.8% of relapses occurred in first year post-discharge. Suicide: 6% attempted suicide in follow-up period. Higher proportion of individuals were NEET at the end point of study when compared to point of discharge.	Case note review of clinical data
Lester et al (2012)	Not reported	47.6% primary, 52.4% secondary.	Not reported	71% were unemployed at follow-up. 62% were living with parents at follow-up.	Interviews
O'Donoghue et al (2023)	SAPS	46.3% primary, 36.6% secondary.	Being male, NEET, having first degree relative with psychotic disorder, cannabis or methamphetamine use, being admitted to hospital and relapse during episode of care increases odds of being discharged to secondary care. Living with parents and achieving remission within 12 weeks of first presentation reduces risk of discharge to secondary care.	Not reported	Clinical files

Puntis et al (2018)	IMD	83.5% primary, 13.5% secondary. 3% tertiary.	Those with previous inpatient admissions, longer duration of EIP, being female, diagnosis of schizophrenia increases likelihood of being discharged to secondary care.	Relapse: 31.9% of those discharged to primary care were referred back to secondary care within 2 years of discharge. Relapse rates were higher in those who had longer duration in EIP, increased social deprivation and substance use.	Clinical records
Puntis et al (2024)	Not reported	77.7% primary, 22.3% secondary, 5.5% tertiary (long-term inpatient).	Having a diagnosis of schizophrenia, previous admissions, longer EIP duration, and substance use increase likelihood of discharge to secondary care.	Relapse: 6.4% of those discharged to primary care, relapsed and returned to secondary care. 9.7% of those discharged to secondary care, relapsed requiring an inpatient stay. Predictors of relapse included a diagnosis of schizophrenia, longer duration in EIP and substance misuse.	Secondary data analysis and clinical records

Early Intervention in Psychosis (EIP); Not in Education, Employment or Training (NEET); Plan, Do, Study, Act (PDSA); Duration of Untreated Psychosis (DUP); Premorbid Schizoid-schizotypal Traits (PSST); Positive and Negative Syndrome Scale (PANSS); Calgary Depression Scale (CDS); Interview for the Retrospective Assessment of the Onset of Schizophrenia (IRAOS); Social and Occupational Functioning Assessment Scale (SOFAS); Role Functioning Scale (RFS); Medication Adherence Rating Scale (MARS); Simpson-Angus Scale (SAS); Chinese-bilingual Structured Clinical Interview for DSM-IV (CB-SCID); Scale of Assessment of Negative Symptoms (SANS); Clinical Global Impressions – Schizophrenia scale (CGI-SCH); Quality of Life Scale (QLS); Case Manager Rating Scale (CMRS); Schedule for Clinical Assessment in Neuropsychiatry (SCAN); Scale for Assessment of Psychotic Symptoms (SAPS); Global Assessment of Functioning and Symptoms (GAF); Premorbid Adjustment Scale (PAS); Index of Multiple Deprivation (IMD).

DISCUSSION

Interpretation was limited by methodology diversity. All but two studies relied on clinical record data, outcome definitions were inconsistent and use of validated measures differed. These factors limit comparability, generalisability and reduce the certainty of pooled conclusions.

Care pathway findings

Discharge destinations varied across studies, with secondary care the most common discharge destination in earlier and moderate quality studies (n=10). More recent, larger and high-quality studies, with greater external validity suggest primary care as the most frequent discharge destination (n=5). O'Donoghue et al. (2023) and Puntis et al. (2024) reporting 63.4%-77.7%. Synthesising the six studies (MMAT rated highest quality) produced mixed findings on care pathway information, reporting equivocal results for both primary (Lester et al., 2012; Puntis et al., 2024; Puntis et al., 2018) and secondary care (Ahmed et al., 2019; Chang et al., 2015; Kam et al., 2015) discharges. The expectation of discharge to primary care following EIP appears to be supported by higher quality papers but not consistently across the wider evidence base (Ahmed et al., 2019). This inconsistency indicates a need for further research.

The shift toward primary care discharge is likely shaped by changes in how mental health services are structured, funded and delivered. Over time, EIP services have evolved and expanded through prioritised funding, accepting an increasing number of patients (Kuipers et al., 2014). Across health care systems, there is an increasing pressure on secondary care services, reducing their capacity to accept referrals post-discharge from EIP (Edwards & Hensher, 1998; Thomas et al., 2021)

or a greater confidence in primary cares' management of severe and enduring mental health difficulties due to a more skilled workforce. This shift could be reflective of theNHS long-term plan (2019) introducing additional trained mental health practitioners (Bower, 2002; England & Lester, 2007), alongside the expansion of Improving Access to Psychological Therapies (IAPT) services imbedded within primary care to manage demand for mental health support (NHS England, 2019). In recent years, policies have encouraged step-down care and have shifted away from long-term management within secondary care services. These changes are underpinned by efforts to reduce the demand on secondary care by managing lower risk individuals within primary care and offer more cost-effective treatment (*The NHS Long Term Plan*, 2019). Therefore, variation between older and newer studies may be associated with the structure of health care systems at the time, not just clinical need.

Predictors of discharge destination

Predictors of discharge destination were not consistently examined. Seven high quality studies reported consistent findings, strengthening trustworthiness. Diagnosis of schizophrenia, prior hospital admissions, substance use and longer EIP duration were strong predictors for secondary care, suggesting that some individuals following EIP require ongoing high intensity care. Substance use has been associated with increased risk of relapse, increased symptom severity, poor treatment adherence and poorer outcomes which may lead to increased likelihood of discharge to secondary care (Lambert et al., 2005; Weibell et al., 2017). Additionally, substance use may act as a marker for broader socioeconomic deprivation (Belvederi Murri et al., 2025) including unstable housing, unemployment, reduced social support which are all associated with poorer outcomes (Baumann et al.,

2007). Together these factors may explain why substance use predicted discharge to secondary care.

Inconsistent findings, in the two studies reporting on gender as a predictor of discharge destination may be a result of internal validity and generalisability issues e.g. setting, sample size, gender split and sampling bias. O'Donoghue et al. (2023) recruited from a youth-specific EIP service based in Australia compared to Puntis et al. (2018) a UK NHS service model (adolescents to adults). Males are likely to have an earlier onset than females, O'Donoghue et al. (2023) is likely to capture the peak onset for males, leading to a higher proportion of unwell young males (Ochoa et al., 2012).

Overall, those that display greater complexity, need and past relapses or instability are discharged to more intensive services for ongoing support.

Outcomes post-discharge

Post-discharge outcomes were heterogeneous. Across the 11 papers, there was inconsistency in outcome measurement and definition across primary, secondary and tertiary care, questioning comparability. Primary care may be underrepresented, as outcome measures may be used less frequently (Ashworth et al., 2005; Mead & Bower, 2002).

Relapse terms were defined differently in each paper, some categorising relapse as an admission to hospital (Chan et al., 2022; Chang et al., 2015); any referral to more intensive care (Ahmed et al., 2015; Harrington et al., 2013; Kam et al., 2015; Lester et al., 2012; Puntis et al., 2024; Puntis et al., 2018) or an increase in symptom severity (O'Donoghue et al., 2023). This may be reflective of the discharge

destination and stepped care approach. Predictors for relapse, mirror the predictors for discharge to secondary care as previously stated.

Despite good engagement with services post-discharge across all discharge destinations (43-95.2%) relapse rates remain 16-64% overall. Findings were mixed on whether relapse rates were higher in those discharged to primary compared to secondary care. Retention rates suggest patients are largely being discharged to relevant discharge destinations where they are being appropriately supported without the need for movement to more intensive support (Harrington et al., 2013). As most patients are discharged to primary or secondary care, interpretation focussed on movement between these services.

At follow-up, many remained in the same service (48-92%). Movement from primary to secondary care ranged from 5-48% compared to 7-17% being stepped down from secondary care to primary care. This suggests that although secondary care is holding patients well, preventing worsening of mental health, once in secondary care fewer patients are improving enough to no longer rely on mental health services.

The higher proportion of patients moving from primary to secondary care questions the effectiveness of primary care in managing relapse and whether further guidance and training is required to upskill primary care settings (Forbes & King, 2015; Macdonald et al., 2018; O'Callaghan et al., 2010).

Strengths and Limitations

This review extends prior research by examining discharge destinations and their predictors, rather than focusing solely on post-discharge outcomes (Lally et al., 2017; Santesteban-Echarri et al., 2017).

Strengths include the review being pre-registered, and use of a comprehensive and systematic search strategy, alongside the use of a recognised framework for narrative synthesis (Popay et al., 2006). A mix of evidence was included, enhancing depth, validity and usefulness of the findings. Given the heterogenous evidence, the use of the MMAT strengthened the confidence in the findings, increased methodological coherence and supports credibility.

The diversity of studies in relation to study design, outcome measures and follow-up periods limited findings. Given the inclusion of international papers within the review, the variation in care pathway data could be linked to service design, differences between health care systems (funding and legislation) and service provisions (eligibility criteria and thresholds for services); variation in the prioritises and international guidelines. For example, in the UK EIP is shaped by national standards such as the National Clinical Audit of Psychosis (NCAP) standards and decisions regarding transitions upon EIP discharge are influenced by local commissioning, eligibility thresholds and legislation such as the Mental Health Act 1983 (NHS England, 2023). International variation in legislation and commissioning may contribute to differences in post EIP pathways (Knapp et al., 2006). In Australia, mental health care is delivered and funded through both federal Australian government and state governments (Rosenberg & Harvey, 2021) whereas in USA access to mental health services is determined by insurance coverage (Hoffman & Paradise, 2008). This concept is complicated by how different countries may represent recovery or stability.

Limitations in the follow-up period post-EIP reduced longitudinal findings. Inclusion of a 10-year follow-up period may have provided more rich and detailed data on the long-term care pathways and outcomes following discharge. A five-year

cut-off was decided to ensure greater generalisability to present day service designs following increased changes over the last 10 years.

Many studies included in the review highlighted where people went after EIP however they did not measure how well people were at discharge, without measures of symptom severity it is difficult to know the degree of deterioration upon relapse or whether in fact their needs simply changed over time, therefore it is difficult to judge whether the discharge destination was appropriate. It may be that discharge to primary care was appropriate but then their symptoms worsened requiring subsequent referrals to secondary care which may contradict previous literature that may define this discharge destination as inappropriate. Without symptom severity data, the appropriateness of discharge destinations is difficult to assess.

Clinical and research implications

Primary care discharge is increasingly common. Qualitative evidence suggests that GPs may lack the appropriate knowledge and training for supporting individuals with psychosis (Lester et al., 2012). Given the growing proportion of service users being discharged to primary care, there may be value in upskilling the primary care workforce to increase confidence in their management of severe and enduring conditions and improve service capacity to manage demand.

The review supports evidence that transitions are high risk periods for relapse (ranging 16-64%), suggesting that EIP discharge needs to be well planned to promote stability, recovery and prevent decline (Puntis et al., 2018). Easy access to care upon relapse is essential to ensure patients access support in a timely manner and experience smooth transitions between services.

Identifying individuals of higher risk of relapse prior to discharge can support identification of appropriate discharge destination and reduce patients returning to secondary services. The synthesis identifies predictors for relapse at the point of discharge, providing a basis for identifying those at high risk of relapse or deterioration, this allows services to identify those individuals who are most likely to require ongoing secondary care and tailor discharge planning and follow ups accordingly. Predictors for discharge destination were not well documented despite extensive literature on predictors for long-term outcomes in FEP (Penttilä et al., 2014; Peralta et al., 2022; White et al., 2009). Further research into predictors for discharge destination is required. Where studies did report predictors of discharge destination, a relatively consistent pattern found that diagnosis, prior hospital admissions, substance use and longer EIP duration was associated with discharge to secondary care, indicating that clinical severity and instability are predictors for ongoing support.

Literature on predictive factors can help create discharge and transfer criteria. The findings from this review could be operationalised in practice through a preliminary framework or development of a clinical tool for decision making regarding discharge planning and destinations, which incorporates clinical (diagnosis, previous relapses and clinical stability), social (deprivation and availability of informal support) and service factors (service capacity and feasibility for ongoing care). Integrating these factors into discharge planning in a more structured way can support with appropriate discharges and reduce subsequent referrals to secondary care. Those individuals with higher clinical need and complexity are prioritised for transfer to secondary care services upon discharge from EIP. Increasing capacity and resource within secondary care services to accommodate transitions from EIP could help to

prevent unnecessary transfers of care and reduce subsequent readmissions. Suggestions to extending EIP for high-risk individuals as a potential way of reducing relapse and improving long-term outcomes, needs further research (Puntis et al., 2020).

The role of ethnicity on post-EIP care pathways and decision making was overlooked, despite 14 papers reporting demographic data on ethnicity. This is noticeable given that ethnicity is a well-researched area within the FEP literature (Anderson et al., 2014).

Two studies have explored service-user perspectives of post-EIP care, primarily focussed on decision making and onward discharge planning (Lester et al., 2012; Rickett et al., 2025). The findings suggest a need for more qualitative research into post-EIP care pathways, and the importance of understanding barriers and facilitators to re-accessing care during relapse.

Conclusion

Discharge pathways following EIP are variable. Evidence suggests a shift towards primary care discharge, whereby patients are supported by GP and reliant on family support (Macdonald et al., 2018; Puntis et al., 2024). For individuals displaying complexity and risk, discharge to secondary care is deemed more appropriate. Discharge planning should incorporate predictors for discharge destinations to ensure appropriate and robust discharge plans. Further research should be undertaken into developing the literature on predictors for discharge destinations post-EIP.

Despite many patients being discharged to primary care, relapse remains a substantial concern post-discharge, resulting in referrals to more intensive care. The

review highlighted concerns about primary care's ability to effectively manage psychosis long-term and identified relapse as a predictable outcome for many individuals, yet there is limited evidence on what happens following relapse. While the review demonstrated that re-referrals to secondary care occur upon relapse, service-users' experiences' of re-accessing care and the potential barriers they encounter remain unclear. Given the existing literature stating that poorly managed transitions of care can lead to worsening symptoms, delayed help-seeking and the consequential costs on services, understanding service-users' experiences of re-accessing care is crucially required (Puntis et al., 2018).

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CHAPTER THREE

BRIDGING CHAPTER

Word Count: 501

CHAPTER 3: BRIDGING CHAPTER

This chapter aims to summarise the findings of the systematic review and provide context for the rationale to the empirical paper.

Summary of systematic review

From the 17 papers included in the review, the findings emphasised variation in care pathways following discharge from EIP services. Three main pathways were identified: primary care, secondary care and tertiary care. Contrary to previous literature into discharge destinations and IRIS guidance, earlier papers found that most patients were discharged to secondary care, whereas more recent studies suggested a shift towards primary care discharge following EIP involvement (O'Donoghue et al., 2023; Puntis et al., 2018; Rickett et al., 2024).

Considerations of complexity and risk contributed to decisions around discharge destination, those deemed more complex or risky were discharged to secondary care. Complexity and risk were determined by diagnosis, substance use, hospital admissions, relapses and duration of EIP involvement (Ahmed et al., 2019; Catalan et al., 2021; O'Donoghue et al., 2023).

The review findings were broadly consistent with existing evidence suggesting that transitions between services increase the risk of relapse, increasing the need for continued care beyond EIP or future service involvement (Macdonald et al., 2018; Puntis et al., 2018; Rickett et al., 2024). For those discharged to primary care, relapse required service-users to re-access and engage with secondary care services.

The findings identified a lack of consistent reporting on outcomes across studies.

The variation in care pathways raises the question of how discharge decisions are experienced by service-users. Two out of the 17 papers used interviews, the rest were reliant on quantitative data from clinical records, therefore little depth was reported around patient's experience of discharge and re-accessing care during relapse.

Rationale for the Empirical paper

As established in the systematic review, a high percentage of service-users will require additional support upon relapse following discharge from EIP, despite the discharge destination. Poorly managed transitions between services has a detrimental effect on patients, including an increase in symptom severity and functional decline, resulting in increased burden and costs on patients and services (Puntis et al., 2018).

While the systematic review provides the structure of care pathways post-EIP and identifies the discharge destinations, adding to existing research, it remains unclear how these pathways are experienced by service-users. Without understanding lived experience of post-EIP care, any changes made will not be patient informed. The review lacks insight into the emotional, relational and systemic experiences of re-accessing care, alongside a lack of understanding around the barriers and facilitators to re-accessing help during relapse.

The empirical paper aims to fill this gap in research, exploring service-users' experiences of re-accessing care following discharge from EIP. The empirical paper will build on the findings from the review and provide in-depth analysis and knowledge into the impact on patients themselves using qualitative interviews. This has the potential to identify barriers to accessing care and inform service designs and provisions such as changes to eligibility criteria, methods for accessing

appointments, enhancing cooperation between primary and secondary care and informing staff training.

CHAPTER FOUR

EMPIRICAL PAPER

Service-users' experiences of re-accessing mental health services following discharge from Early Intervention in Psychosis services

Prepared for submission to Psychosis

Word Count: 6000

Service-users' experiences of re-accessing mental health services following discharge from Early Intervention in Psychosis services

Claire Robinson, Sarah Reeve, James Plaistow, Sophie M. Allan

ABSTRACT

First episode psychosis patients receive treatment in Early Intervention in Psychosis services for up to three years and if stable are discharged to primary care. A proportion will relapse, requiring re-access to secondary care. Despite substantial research on first episode psychosis care pathways, studies have not explored service-user experiences of re-accessing care; barriers and facilitators of help-seeking. This study explores these following discharge to primary care. Participants were recruited via Community Mental Health Teams and social media. Ten participants completed qualitative semi-structured interviews, analysed using thematic analysis. Participants had complex care pathways following discharge, often involving multiple transitions between services. They experienced barriers to re-accessing care, resulting in delays and disengagement and had repeated negative experiences, moving from “containment to a cliff edge” and having to “negotiate power and control in the fight for care”. Perceived barriers to access included stigma, rigid systems, resource scarcity and reduced trust in services. Fewer facilitators were identified. Participants valued safe, consistent and respectful care. Changes to service design should prioritise flexibility, reasonable adjustments, responsivity and trust. Future research should consider family and clinician’s perspectives of post Early Intervention in Psychosis care.

Keywords: “Care pathways”, “Discharge”, “Early Intervention”, “Help-seeking”, “Psychosis”, “Thematic analysis”

INTRODUCTION

Early Intervention in Psychosis (EIP) services have improved short-term outcomes, although long-term gains following discharge are in question (Adamson et al., 2018). The containing and intensive EIP model is not sustained post-discharge, meaning transitions can create instability (Addington & Addington, 2008; Ahmed et al., 2015; Ahmed et al., 2019; Woodward et al., 2019). Many patients experience persistent symptoms, functional impairment and relapse risk beyond 3 years (Adamson et al., 2018). 41% discharged to primary care relapse within the first year (Kam et al., 2015), approximately 31.9% requiring subsequent secondary care referrals (Puntis et al., 2018) but the barriers and facilitators of re-accessing care remain understudied.

Access to care for first episode psychosis (FEP) indicates that help-seeking is shaped by systemic barriers (e.g. inflexible appointments, rigid eligibility criteria and service scarcity) (Martin et al., 2018; Swigart et al., 2025); interpersonal barriers (e.g. perceived power imbalances and negative past experiences) (Anderson et al., 2013; Causier et al., 2024; Tiller et al., 2023); individual factors (e.g. cultural and ethnic barriers, reduced insight) (Anderson et al., 2014; Islam et al., 2015; Jones et al., 2021) and societal barriers (e.g. stigma) (Gronholm et al., 2017; Skrobinska et al., 2024). To overcome access barriers, many rely on informal support (e.g. family and friends) to initiate help-seeking (Macdonald et al., 2018; O'Callaghan et al., 2010). Timely access to support is crucial for psychosis, as delays cause significant deterioration (Marshall et al., 2005; Reichert & Jacobs, 2018). Evidence suggests that access barriers persist post-EIP (Loughlin et al., 2019; Rickett et al., 2025; Woodward et al., 2019).

Little is known about access barriers on re-accessing care which may be different and relevant at relapse. The extent these barriers persist, how access differs post-EIP; and patients lived experiences is under-researched.

Considering relapse prevalence and support needs post-EIP (Bergé et al., 2016) alongside NHS drives for ease of access and timely treatment (Lord & French, 2025), understanding re-accessing care experiences post-EIP warrants attention.

Research Questions

- **Main research question:** What are service-users' experiences of re-accessing secondary mental health services following discharge to primary care from EIP services?
- **Secondary research question:** What are the barriers and facilitators to help-seeking following relapse after discharge from EIP?

METHODS

A qualitative design, using reflexive thematic analysis (Braun & Clarke, 2006, 2021) explored themes within participants experiences of re-accessing services following discharge from EIP, using one-to-one interviews. A qualitative methodology aimed to access meanings and lived experiences to understand how individuals experience barriers and facilitators to help seeking in order to inform the development of services and care pathways post EIP. A qualitative approach enabled exploration of how experiences are understood and shaped by broader factors such as social and systemic influences. Reflexive thematic analysis was chosen to allow for the exploration of experiences in a deeper way, considering both individual experiences and the wider social and service contexts whilst recognising the active role of the researcher in the interpretative process. Alternative approaches such as

interpretative phenomenological analysis (IPA) were considered less appropriate as it typically focuses on detailed exploration of lived experience within a smaller sample. Given the limited research on re-accessing care following discharge from EIP, this study aimed to identify broader themes and patterns across a more diverse sample to provide an overview of experiences.

Patient and Public Involvement (PPI)

During the planning stages, meetings were held with local NHS clinical teams, primarily EIP, adult CMHT and Youth services, to explore areas of clinical importance, focus on how transitions following EIP are currently managed, identify barriers experienced during and after discharge and information on the challenges in re-accessing care.

Two PPI members with lived experience from the Clinical Psychology Doctorate service-user and carer involvement group supported with study development, co-writing the interview topic guide and advising on participant documentation (including patient information sheet, consent form and demographic form) to ensure suitability and representation. Feedback informed revisions to study materials.

Participants

To include individuals who had (un)successfully re-accessed services, participants (n=10) were recruited from social media and secondary care teams across Norfolk and Suffolk NHS Foundation Trust (NSFT) and Cambridge and Peterborough NHS Foundation Trust (CPFT) (Appendix D). Inclusion criteria were: 1) UK based 2) aged 18-65; 3) has a psychotic disorder e.g. psychosis, schizoaffective disorder, schizophrenia, delusional disorder, Bipolar disorder type 1 (either current or historical); 4) minimum 2 years EIP involvement (to ensure adequate relapse

prevention work was undertaken); 5) since been discharged to primary care within previous 10 years and attempted to re-access help; 6) fluency in English.

51 participants consented. 41 were ineligible and excluded (n=24 no psychosis diagnosis; n=12 non-attendance at interview). Four participants did not schedule an interview, and one withdrew.

Ethics

NHS Research Ethics Committee and Health Research Authority approval was granted pre-commencement (reference 25/NW/0042; Appendix C). Appendices D to H show study documentation; participant information sheet, consent-to-contact and demographics form.

Participants' anonymity and confidentiality was maintained and protected. A participant ID was assigned. Minimal identifiable data was collected and identifiable information removed.

Data was uploaded to a secure password protected UEA OneDrive to prevent from being stolen or compromised.

To minimise harm, the distress protocol, risk assessments and management plans were followed (Appendix L). The interview schedule was given in advance to minimise power imbalances, distress, and promote safety and engagement.

A debrief form outlining support was provided post-interview (Appendix K), no distress was reported.

Procedure (Appendix M)

Participants were recruited through advertisement materials distributed by NHS teams and social media (Appendix D), directing them to study documentation (Appendix E to H).

After consenting and confirming eligibility, an online interview was arranged. Consent forms were provided at least 24 hours before interview, including an option to receive study findings (Appendix G). Participants were thanked by a £10 shopping voucher.

Interviews

Interviews occurred between May and December 2025 lasting up to 90 minutes. Interviews were recorded and conducted by CR, a doctoral-level researcher with training and experience of working with psychosis. The interview schedule (Appendix I and J) was co-written by CR, PPI members, and the supervisory team (SA and SR) to ensure relevance, clarity and appropriateness of the questions, although it was not formally piloted. Topics included EIP discharge, service contact and perceived barriers and facilitators to help-seeking. Interviews began with an introduction to the study aims and rationale, an informal assessment of participants wellbeing and suitability to take part, eligibility and identity check, confirming consent to take part and for the interview to be recorded. Questions were designed to explore participants background experiences within EIP, including the duration of EIP treatment and discharge experience. Participants were then asked about their experiences following discharge from EIP including confidence in managing relapses, help seeking behaviours, sources of support, ease of accessing help, any delays to treatment and their overall satisfaction related to attempts to access help (including barriers and facilitators to re-accessing care).

Thematic saturation was achieved and assessed through the data coding process, with no new themes emerging and further data unlikely to add meaning.

Analysis

CR transcribed and analysed the interviews. Inductive reflexive thematic analysis (Braun & Clarke, 2006) was chosen to fit the critical realist epistemological position of the researcher. Codes and themes were constructed through sense-making of participants narratives and the researcher's knowledge. Analysis used NVIVO and paper following Braun and Clarke's (2006) six stages (Appendix N).

Reflexivity

A critical realist epistemological stance was adopted. Psychosis was considered a real and measurable phenomenon. Societal, systemic and contextual factors shape service-user experiences and interactions with services. This perspective supported the use of qualitative interviews to explore service users experiences alongside consideration of how wider contextual factors, such as healthcare systems, social factors and service designs may contribute to barriers and facilitators to accessing care.

A reflective diary considered the influence of CR's professional experience of working as a therapist in services (Appendix P).

Credibility and Rigour

The Consolidated Criteria for Reporting Qualitative Research guidelines were used to maintain credibility and rigour (Tong et al., 2007; Appendix O). This was chosen as it is an established and widely used reporting framework which enhances

transparency and reporting quality. It focuses on the research team, reflexivity, study design and analysis and is largely appropriate for interview-based qualitative studies. However other tools such as the reflexive thematic analysis reporting guidelines (RTARG) may be a closer fit with reflexive thematic analysis (Braun & Clarke, 2024). Future studies may benefit from using this framework.

An audit trail documented the analytic decisions and theme development (Rodgers & Cowles, 1993; Appendix T). Coding and interpretation were checked through research team discussions, challenging interpretations, identifying blind spots and strengthening credibility.

Triangulation was supported through national and local recruitment, inclusive of participants from different services and contexts. This facilitated comparison of experiences across different settings and increased the breadth of perspectives represented within the data. **RESULTS**

Demographics

Participant demographics are shown in Appendix Q. A total of 10 participants were recruited, most were female (70%, n=7) and identified as white (60%, n = 6). Participants were aged between 25 and 60 years, with the majority between 25-40 years (80%, n = 8). Diagnoses included FEP (40%, n = 4), bipolar disorder type 1 (30%, n = 3), schizophrenia (20%, n = 2) and other psychotic disorders (10%, n = 1). Time since discharge ranged from less than 3 years to 10 years, 40% (n = 4) were discharged within the last 3 years.

Care pathways

Appendix S shows an amalgamation of participants' discharge trajectories and service contacts following EIP. Care pathways occurred exclusively in the UK. 60% of participants had a minimum of five service contacts following discharge before

accessing appropriate support (Mean =4.5) (Appendix R). 50% had family or friends' involvement in help-seeking. The first contact following relapse was GP (n=4) or emergency support (crisis teams or emergency helplines/services) (n=4). All participants accessed GP support at some time post-discharge.

Experiences of re-accessing mental health services following discharge

Ten participants (identified by ID number) were interviewed; analysis identified six overarching themes. Diagrams of themes for research questions are given in Appendix U, V and W. Quotations are in italics and verbatim.

Theme 1: From "containment" to a cliff edge

This theme reflects the contrast between the protective, consistent and containing experience of EIP and the abrupt, destabilising experience of discharge. Leaving EIP came suddenly for many participants with poor communication and limited preparation, increasing feelings of uncertainty, anxiety and loss. Transitions between services were experienced as fragmented and disjointed.

Subtheme 1.1 EIP as a protector

Most participants reported positive experiences of EIP services, and relationships with staff, describing EIP as containing, consistent and the "*complete package" (Participant 9)*. They valued the intensive support, continuity of staff, relational safety and one comprehensive service without the need for navigating fragmented systems.

"self-contained like there wasn't this whole annoying referrals between different services…seeing the same people consistently" (Participant 3)

Participants referred to difficulty in replicating this level of support post-EIP. Participants expressed retrospective feelings of gratitude, suggesting that such satisfaction was not the norm following EIP.

“early intervention service is quite bespoke” (Participant 5)

Subtheme 1.2: “Abrupt endings and uncertainty”

Discharge was experienced as sudden, poorly communicated and destabilising. Participants were uncertain about EIP duration, experiencing unexpected endings and lack of decision-making involvement. There was ambiguity around what to expect post-discharge and uncertainty around the support they would receive, leaving them preparing for the unknown, exacerbating anxiety and loss of control.

“it was very abrupt. I was told, kind of like the 11th hour…it was a real shock to me” (Participant 9)

“discharge actually came as a surprise from EIP… I just didn't feel like they…included me in the decision about discharge…it just happened” (Participant 10)

Subtheme 1.3: Emotional ambivalence at discharge

Participants experienced conflicting emotions at discharge, from feeling relief, optimism and empowerment (e.g. *“I was so excited, ready to explore the world again” - Participant 4),* to fear, dependency, and anxiety.

“I just remember feeling…anxious and… feeling daunted…where do I go from here?” (Participant 9)

Feelings of anxiety were driven by changes in the intensity of support provided and related to how individuals viewed discharge, representing recovery and independence (e.g. “*my own responsibility for things” - Participant 1),* versus loss, abandonment and vulnerability (e.g. *“felt like I've just been thrown on the scrap heap” - Participant 9).*

These feelings arose from experiences of *“broader…vaguer, and…less personalised care” (Participant 10).* Some participants reported reduced access to help following discharge from EIP.

“*I knew that I would be moving down to a lower level of care” (Participant 3)*

Subtheme 1.4: Disjointed pathways and broken continuity

Participants experienced post-EIP pathways as disjointed with poor communication, inadequate handovers, and lack of joint-up working between services. Participants had to repeat stories, starting fresh, leading to increased feelings of frustration, exhaustion and concerns about the continuity of care.

“The biggest problem I experienced was having to now start…fresh” (Participant 4)

Due to poor collaboration between services, information was not effectively passed on, requiring chasing referrals or actions when things were missed.

“the systems clearly aren't all connected…People don't have access to all the information… I've had to…chase it” (Participant 3)

Transition periods resulted in long waits or delays to accessing care. Participants described feelings of uncertainty around transfers of care and ongoing support.

“I didn't know what was happening… where I was going, to who, when” (Participant 6)

Theme 2: Negotiating power and control in the “fight for care”

This theme represents the burden placed on individuals to navigate a disempowering system of imbalance and control. Participants experience being unable to self-advocate, fighting for care and access that depends on compliance not need. Those that are most unwell may be less able to do what is needed to access help. This theme reflects the need for patients to self-advocate or have someone to do this for them and adoption of strategies to feel heard and seen.

Subtheme 2.1: Loss of autonomy

Participants describe decisions being made for them during and following relapses, needing professionals’ permission and confused responsibility of care, often being told what to do without negotiation or collaboration.

“That was a decision that was basically made for me. I didn't agree to it or anything. It was a decision that was made unilaterally” (Participant 9)

Participants experienced pressure to accept what was offered with a lack of choice or alternatively disengaging. Experiences highlighted power imbalances between patient and professional, unable to have a voice or speak up to authority.

“I don't have a voice in what is happening around me” (Participant 4)

Subtheme 2.2: Having to fight to be seen as legitimate – “not being believed or taken seriously”

Power imbalances amplified feelings of invalidation and dismissal. Powerlessness was associated with the label of being “unwell”.

“But you would say that because you don't know how unwell you are” (Participant 1)

Participants feeling unheard and treated like tick box exercises, reinforced powerlessness. Participants described concerns of being ignored; only treated based on professional’s assumptions and diagnosis.

“they said because I was so psychotic, my events are not matching their events and there's nothing they really can do” (Participant 7)

Subtheme 2.3: The power or burden of articulation in “working the system”

Access depends on an individuals’ ability to articulate their needs. Due to not being believed or taken seriously, participants resort to ‘working the system’ by saying the right things or strategically presenting themselves (e.g. “saying the right things” - participant 17 or emphasising symptoms in order to get help) to access support and regain power or choice. Resulting feelings of guilt and reduced honestly presented within the patient-professional relationship.

“how best to get what you need…involve[s]…having to be strategic…selective in what you do or don't say… that makes you feel dishonest even though you know you're just trying to survive” (Participant 8)

Subtheme 2.4: Family/ friends as gatekeepers and advocates

Perceived powerlessness in accessing care, led participants to rely on family to advocate and negotiate with services.

“if it wasn't for the support of family members, there's definitely no way I would have got the support that I needed” (Participant 9)

The need for family advocacy empathises that access is dependent on someone having the ability to intervene and navigate the system.

The barriers and facilitators to help-seeking following relapse after discharge from EIP

Theme 3: Symptoms, identity and the weight of stigma

This theme represents the relationship between stigma and attitudes towards self, shaping help-seeking behaviours and incorporating internal and external barriers.

Subtheme 3.1: Stigma and internalised shame

Experiences reflect the ongoing external stigma and internalised negative beliefs specific to psychosis. Participants described exposure to negative experiences because of their diagnosis, being treated as a ‘case rather than a person’. Participants reported being labelled as “difficult” or “complicated” patients, contributing to increased feelings of shame or undeserving of help. These experiences shaped identity and discouraged disclosure or help-seeking. Participants anticipated judgemental and rejection, limiting connection or trust towards services. Lack of connection extended to feeling separated from other service-users, feeling ‘different’, isolated or alone within the healthcare system.

“there being…a distance between a doctor and…patient…[treated] more like a case to be examined than a person…I know I'm complicated…I'm difficult in some ways…I'm not just a basic patient” (Participant 3)

Participants described professionals feeling ‘frightened’ to offer care to “complicated” patients.

“We medicalise and are too scared of psychosis” (Participant 10)

Subtheme 3.2: Identity erosion

Participants described a fractured sense of self, reduced confidence and increased self-blame, exacerbating feelings of failure and being a burden.

“One of the things about being psychotic is it…massively knocks your confidence in yourself because it completely scrambles your sense of self” (Participant 10)

Identity was shaped through repeated experiences of judgement, rejection and stigma. Shifts in identity developed as a response to long-term engagement with services, being a ‘service-user’ or being ‘unwell’.

Feelings of shame and failure link to individuals’ perceptions of life beyond EIP and the meaning of discharge (Theme 1). Those who associated discharge with recovery and independence were more likely to feel increased shame and failure upon relapse and reliance on help.

“Have a relapse and be unwell and fail” (Participant 1)

These beliefs impact on participants desire for seeking help from services (e.g. *“I don't deserve to be helped - Participant 14” or “if I kept it to myself, then at least it was just me dealing with the stress - Participant 2”).*

Subtheme 3.3: “Fear of relapses and consequences”

Participants described avoiding or delaying help-seeking due to fear of hospitalisation or others judgement and panic. For most, the fear of such consequences arose from initial pathways into care and traumatic past experiences of becoming unwell. Past experiences amplified fear, making help-seeking feel unsafe and scary. This relates to the experiences of feeling powerless and a lack of control over decision making and help-seeking (Theme 2).

“I'm not the most help-seeking person ever 'cause, I've still got a lot of trauma from being sectioned, so I do tend to try and avoid help-seeking” (Participant 1)

Subtheme 3.4: Personal Growth, insight and acceptance

Insight and acceptance developed over time through recovery, self-development, normalisation, and belonging. Increased understanding and trust in oneself contributed to greater resilience, reduced fear, and honest communication with others.

“I'm almost not as scared of myself as I was” (Participant 6)

Acceptance reduced internalised stigma, participants no longer defined themselves by their diagnosis or felt shame in needing support. Being in a “different place” psychologically allowed individuals to become more open to help, prioritise their mental health, and feel more deserving of care.

“I'm also in a different place myself to accept stuff” (Participant 1)

Theme 4: “Falling through the gaps”: A system not built for psychosis

This theme reflects how systemic and procedural barriers alongside resource limitations create difficulties in accessing care. Participants describe re-accessing care as navigating a system that is overstretched, disjointed and poorly designed for severe mental illness.

Subtheme 4.1: Rigid systems and procedural harm

Rigid procedures such as punishing responses to missed appointments (e.g. "*discharging me, which is further delaying my ability to access care" - Participant 3)*, technological barriers including use of online booking systems, and rule-bounded care increased distress, disengagement and mistrust.

"If you don't have a smartphone, then you'd have difficulty…If you're mentally not in a good place… that would be a barrier to you actually accessing the service" (Participant 5)

Participants perceived access to be shaped by policies and unadaptable processes that may not adequately account for severe mental illness. Participants described that harm accumulated across repeated encounters rather than isolated incidents.

"you have to ring up at 8:00 AM and if you're not sleeping…holding on the phone lines can be really stressful" (Participant 6)

Subtheme 4.2: "Not fitting the mould"

Participants described multiple referrals and experiences of being rejected from support due to rigid eligibility criteria. Participants were unable to access care due to being "*not severe enough or I'm too severe" (Participant 2)*, not fitting the mould.

Participants described rules restricting access to more than one service at a time.

"you're open to their services, so you can't be open to our services" (Participant 9)

Systemic inflexibility contributed to feelings of frustration, falling through the cracks and feeling shoehorned into a box.

“you don't fit into this or that box” (Participant 8)

Subtheme 4.3: Resource scarcity and delays

Long waiting times, delayed responses, missed care and limited availability reflected service capacity issues to meet increasing demands and contributed to worsening distress and reduced confidence in services.

“I end up falling through the cracks more than not…the NHS is cracking…everyone's stretched” (Participant 3)

Participants acknowledged NHS resource and funding struggles, leading to expectations of waiting lists and delays whilst highlighting the emotional burden and impact on engagement.

“There are long waiting times, delayed responsivity. So, it can seem a cold and lonely process” (Participant 8)

Post-EIP support relied on primary care and less experienced staff, with limited specialist psychosis training and access to other services. The perceived lack of expertise outside of specialist care, impacted on participants trust and engagement with services.

“they haven't got the funding to know more or train more” (Participant 7)

Participants voiced concerns about primary cares’ competence of managing severe mental illness. The role of perceived skill, training and confidence in professionals’ ability to adequately assess, treat and manage relapses was essential for fostering a trusting relationship.

“you feel like, you know, far more than they do” (Participant 8)

Participants described the pressure of accepting any care offered (e.g. *“this is the only help I'm going to have” - Participant 3)* or seeking private support due to resource limitations within the NHS.

“I decided I can't wait…That's how I ended up seeking private help” (Participant 4)

Subtheme 4.4: Symptoms as a barrier

Symptoms of psychosis obstructed engagement and access to care. Memory problems, paranoia, anxiety, lack of motivation and fluctuating mood made it harder to attend appointments, retain information, and navigate services.

Participants described a lack of adjustments, e.g. written information to support memory, alternative communication methods and accounting for psychotic symptoms and behaviours. The inflexibility leading to disengagement.

“there's an assumption that somebody would be behaving in the way you'd expect any other person to be acting” (Participant 3)

“Not very good with the adjustments” (Participant 6)

Theme 5: Navigating relapse alone – “left to fend for myself”

This theme represents the impact of systemic barriers and repeated rejections of help resulting in patients relying on their own resources. Participants’ accounts suggested poor guidance and realistic information about post-discharge care pathways creating confusion and anxiety about where to seek help and what support is available. Repeated disappointments led to reduced trust and hope in services, resulting in disengagement and reliance on self-help to avoid further disappointment and rejection.

Subtheme 5.1: Living without a map

Participants described lacking clear information and knowledge about what services can and cannot offer, and uncertainty and confusion about how to navigate the system to get help during a relapse. Participants valued open and honest communication about realistic expectations following discharge.

“who should I seek support [from]? How should I handle it[?]…I had no such knowledge with me” (Participant 4)

Participants reported being expected to seek alternative support themselves with little guidance.

“people are…left on their own devices after they've been discharged…[I] had to find out about this service on my own” (Participant 9)

Subtheme 5.2: Erosion of trust and hope in the tiring process of help-seeking

Accounts indicated that repeated systemic barriers, disappointment, rejection and abandonment, led participants to become wary of services and engagement with professionals, approaching care cautiously and defensively. Participants described exhaustion from help-seeking (e.g. “*I just don't have the energy to go through that process again” – Participant 9)*.

Participants expressed a loss of trust and hope in accessing help, giving up, leading to forced self-reliance.

“the safest way for me to protect myself is to rely and build on my own resources and have confidence in myself” (Participant 8)

“I've kind of given up and I've lost trust” (Participant 2)

Theme 6: Safer spaces

Relational safety and trust were described as important for fostering meaningful engagement and positive help-seeking. When formal care feels unsafe, participants may turn to informal support.

“I almost trust that more than services…because…people…know you in different capacity” (Participant 6)

Access appeared to be enabled through relationships that reduce fear. Participants valued environments where they felt heard, seen and respected.

Subtheme 6.1: Peer and family support as refuge

Participants reported shared experiences, sense of community, normalisation and mutual understanding, feeling more understood, less judged and less exposed to power imbalances when seeking help from informal support. Peer support supported openness, safety, connection and belonging.

“I just found it a safe space…you're not going to be judged or…ostracised” (Participant 9)

Subtheme 6.2: Humanistic and respectful care

Respect appeared to support engagement and the development of positive relationships with professionals. Participants described experiences of being treated as a human rather than diagnosis, with kindness, and genuine care.

“differentiate between…experiences of illness and them as individuals…that gave me the human validation to recognise, I wasn't just an ill entity, I was a human with an illness” (Participant 8)

Subtheme 6.3: Relational safety through consistency and trust

Participants described the importance of consistency of staff and familiarity as important facilitators for help-seeking and trust. Participants described consistency as enabling disclosure and contributing to increased confidence and feeling safe.

“If I know the professional…I’ll probably open up to them but if hadn't met them before, I probably wouldn't” (Participant 7)

DISCUSSION

Discharge from EIP is a difficult and vulnerable period, marked by loss and uncertainty. Patients discharged to primary care, feel abandoned, with increased responsibility, amplifying fear and anxiety (Addington & Addington, 2008; Ahmed et al., 2015; Ahmed et al., 2019). Vulnerability and poor preparation are exacerbated by poor collaboration, handovers of care and planned discharges (Loughlin et al., 2019; Nordgaard et al., 2021; Rickett et al., 2025; Woodward et al., 2019). Patients lack confidence and knowledge about available support post-EIP, with relapse plans that are vague and limited. These findings are consistent with broader literature identifying transitions between healthcare services as periods of heightened vulnerability. Similar findings have been reported across transitions from child to adult mental health services, where service users described a lack of resources and knowledge, poor continuity, isolation and restrictive eligibility leading to difficult and complicated transitions (Broad et al., 2017; Paul et al., 2015). These findings suggest that difficulties experienced following discharge from EIP may reflect wider systemic challenges associated with transitions across the healthcare system rather than specific issues related to psychosis services.

Post-EIP services may not always meet the needs of individuals with psychosis. Strict eligibility criteria, inflexible processes, limited resource availability and a lack of reasonable adjustments led to repeated referrals between services,

rejections and delayed access to care, mirroring studies by Causier et al. (2024) and Tiller et al. (2023). Patients are expected to adapt to the inflexible processes to access care, a long-standing barrier for this population across multiple access points (Causier et al., 2024; Memon et al., 2016; Swigart et al., 2025). Professionals operate in a resource-limited system, with scarce service provision for psychosis following EIP. Access becomes risk or threshold focussed. Across the healthcare system, resource is limited resulting in access to care being determined by risk management rather than clinical need (Causier et al., 2024). Resource is stretched across increasing demand, contributing to higher caseloads, lower intensity and less frequent care (NHS England, 2019). Patients accept inadequate care or strategically present to access support. Similar patterns have been reported across secondary mental health services, where individuals learn to navigate systems that rely on satisfying eligibility criteria or meeting service thresholds (Causier et al., 2024; Liberati et al., 2022).

Access to care is not solely about symptom severity but about patients' ability to navigate the system; being articulate or having someone to advocate; most requiring family support to access help. Those unwell have difficulty meeting these requirements, resulting in rejection from help at the point of greatest need. These findings suggest that healthcare systems may assume that service users have the capacity and resources to access care however it is possible that the system may be too difficult for service-users to navigate alone. The importance of informal support in help-seeking has been widely reported on (Macdonald et al., 2018; Martin et al., 2018; O'Callaghan et al., 2010). Informal support continues to be required for successful access (Oduola et al., 2021; Rickett et al., 2025; Salaheddin & Mason, 2016). Similar concerns have been identified in other patient groups including

learning disabilities and older adults, where successful access to care depends on support from family (Rajanala et al., 2020; Redley et al., 2012). Not all individuals have supportive others to advocate, leaving them vulnerable and less able to access care.

Patients feel defined by their diagnosis, treated as “difficult” or “complicated” by services. Repeated experiences of judgement and rejections accompanied by power imbalances and loss of control restrict patients’ ability to make decisions about their care, leaving them unheard and powerless. These findings were supported by previous research highlighting the impact of judgement, dismissal, stigma and reduced agency on help-seeking(Anderson et al., 2013; Causier et al., 2024; Tiller et al., 2023). Help-seeking is experienced as unsafe and scary, and repeated unsuccessful attempts reduce hope and trust in services. Self-reliance becomes a protective barrier against further disappointment and rejection. Help-seeking attitudes develop from repeated not isolated incidents, indicating the need for system change to promote trust and engagement. Patients highlighted the importance of safe, respectful and consistent care. This is supported by evidence on stigma and help-seeking (Gronholm et al., 2017; Murden, 2023; Skrobinska et al., 2024).

Strengths and Limitations

To the authors knowledge this is the first study exploring re-accessing care post-EIP, ensuring patients long-term needs and relapse are not overlooked.

PPI ensured research was relevant, reflected real-world priorities and patient-focused; increasing ecological validity (Biggane et al., 2019).

Response bias may have influenced findings, participants largely experienced difficulties in accessing care or negative experiences. Those with smooth and

supportive re-entry into care may be less motivated to participate, contributing to fewer identified facilitators.

The demographics of the sample may have influenced the findings and their transferability. The sample was predominantly female (70%) despite psychosis being more common in males (Jongsma et al., 2019). However, we know from literature that women are more likely to engage in both help-seeking and research (Galea & Tracy, 2007; Mackenzie et al., 2006), therefore the barriers faced by males may be underrepresented. Although the sample included participants from diverse ethnic backgrounds, many identified as white (60%). Existing literature reported that individuals from minoritised ethnic groups experience poorer access to care, more coercive pathways to care (Bhui et al., 2003; Halvorsrud et al., 2018), greater mistrust of services (Wood et al., 2025) and poorer outcomes. Also, individuals from minoritised groups are less likely to take part in research (Brown et al., 2014; George et al., 2014). Overall, the barriers identified in the findings may not truly reflect the experiences of those from ethnic minority populations.

The transcripts were not returned to participants to verify meaning and credibility due to time constraints, increasing researcher bias.

Clinical and Research Implications

Discharge from EIP should be framed as a process not an ending. Many leave EIP with extreme anxiety and hypervigilance or unrealistic relapse expectations. Early discussions should inform patients about EIP duration, expectations and post-EIP pathways. Collaborative discharge planning and handover meetings build preparation, relational continuity and realistic expectations of post-EIP care (Rickett et al., 2025).

Services need flexible re-entry pathways for individuals experiencing psychosis, that allow timely re-access with minimal gatekeeping. Delayed access to intervention post-EIP leads to symptoms worsening and emergency intervention (Marshall et al., 2005). Reasonable adjustments to service designs are required, including flexible appointment systems, tolerance of non-attendance and proactive follow-up procedures. Eligibility criteria should be reviewed, identifying gaps in service provision and reducing referrals between services.

Lack of insight has been identified as a major barrier to help-seeking, resulting in others initiating help-seeking (Nordgaard et al., 2021). Our findings found delayed help-seeking was not due to lack of insight but a protective response. Individuals recognised relapse, articulated difficulties but delayed access resulted from systemic and interpersonal barriers. Services should explore identity beyond diagnosis, promoting safe and non-judgemental relationships, prioritise consistency and minimise power imbalances. Greater integration of peer support may reduce stigma and foster engagement.

Exploring clinician or family perspectives may identify shared systemic barriers on post-EIP care.

Conclusions

Individuals experiencing psychosis face significant barriers to accessing care in a timely manner. Barriers to care were categorised by systemic barriers including inflexible processes, strict eligibility criteria and a reliance on individuals knowing how to navigate the system alongside interpersonal barriers such as repeated experiences of rejection, dismissal and poor communication resulting in reduced trust in services. Services should prioritise reducing gatekeeping, reasonable

adjustments to facilitate engagement and systemic changes to promote flexible, responsive and tailored services.

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CHAPTER FIVE

DISCUSSION AND CRITICAL EVALUATION

Word Count: 2105

CHAPTER 5: DISCUSSION AND CRITICAL EVALUATION

Overview of findings

The systematic review on care pathways following discharge from EIP services, found 17 papers meeting the inclusion criteria. Across the papers, the majority (n=11) used clinical records to identify care pathways post-EIP. The more recent (published in 2023 and 2024) and higher quality papers (assessed using the MMAT tool) indicated primary care as the predominant discharge destination. The review reported on predictors for discharge destination, although these were not consistently examined. Patient characteristics including having a diagnosis of schizophrenia and substance use were identified as predictors for discharge to secondary care. Treatment factors such as the number of hospital admissions, relapses during EIP treatment and a longer duration within EIP services were also predictors of discharge to secondary care. Reports on outcome data post-EIP was variable. 16 papers reported on long-term outcomes post-EIP. There were significant differences in the way outcomes were measured and defined. The most common post-EIP outcomes analysed included relapse rates, engagement and retention in services. The review highlighted the importance of smooth transitions and collaboration between services and discharge planning, to minimise inappropriate referrals, reduce the risk of relapse and promote engagement with services; as well as greater attention paid to primary care workforce and service designs.

The empirical paper explored service-user experiences of re-accessing care following discharge from EIP, as well as identifying barriers and facilitators to help-seeking. The findings suggested a need for reducing the points of contact with services during relapse, ensuring that individuals access the appropriate care in a timely manner, given the impact of delayed care on symptom severity and recovery.

The paper identified increased levels of uncertainty following discharge from EIP, including a lack of guidance on where and how to access help during relapse. Patients reported difficulty navigating systems to access initial appointments for help due to inflexible processes. Access to care depended on service capacity and availability, patients experienced delays to care, waiting lists or being turned away due to rigid eligibility criteria. Patients reported difficulties in articulating their needs to professionals in order to access the appropriate support, often leading to rejection from help, dismissal or invalidation. Experiences of feeling unheard or not believed impacted on patients' willingness to seek help and trust in services. This was significantly related to experiences of judgement and stigmatisation from others. Successful help-seeking was shaped by safe and trusting relationships, reduced stigma, normalisation and acceptance.

Taken together, the findings of the papers identified variations in post-EIP pathways among patients, with the majority being discharged to primary care. Patients accessed a variety of different services but themes around how they navigated the NHS and the associated feelings were similar. Most patients experienced multiple points of contact with services and gatekeeping before reaching the appropriate help, placing an additional burden on service-users to navigate the system. The findings emphasised inconsistencies in care pathways and the impact this has on service-users themselves, resulting in an effortful help-seeking process. Both papers suggested a need for preparing service-users to better navigate these care pathways post-EIP and promoting realistic expectations about life beyond EIP.

Relapse was a prominent factor presenting in both papers. The systematic review identified relapse as a predictor of discharge to secondary care. Both papers

emphasised the high risk of relapse among many psychosis patients leaving EIP, whilst recognising the lack of service capacity and availability within secondary care to accommodate all discharged service-users. Many of those discharged to primary care, experienced systemic barriers impacting on re-access to care including eligibility thresholds, power imbalances, resource limitations and inflexible service procedures. Service designs contribute to delayed help-seeking. Overall, these findings suggest that timely access to support post-EIP may not always be achieved within NHS services.

Clinical implications

Discharge is a process, not an ending

Discharge should be a gradual, relapse-informed process, to prepare individual for life beyond EIP regardless of the planned discharge destination or expectations for recovery. Services should work with patients to reframe the expectations that relapse is a failure and instead work towards normalising relapse (Gumley, 2007). The process of re-accessing care should be explicitly and clearly understood by patients upon discharge so they are equipped with appropriate guidance on where and how to seek support during a relapse. Re-accessing care can be either validating or alienating. Therefore, services need to understand that gatekeeping shapes future help-seeking behaviours. Negative experiences of accessing care increase avoidance or delayed help-seeking which become costly to both the individual and services. Relapse is not simply down to individual pathology but is instead associated with a patients sense of vulnerability, service acceptability and the relational interactions.

Changes to service design

Traditional service models assume linear trajectories of care such that patients experience the onset of psychosis, they are treated within EIP, stabilise and then are discharged from the service to be independent. There is an assumption that once treated in EIP, many patients will no longer rely on services. Discharge to primary care remains the standard practice following treatment. However, services are not always designed for the reality that recovery is not linear. Given the fluctuating nature of psychosis and the continued high relapse rates (approximately 41%; with reported rates ranging from 16 to 64%), following discharge from EIP, many patients will require ongoing care (Kam et al., 2015). However, there is a lack of appropriate resource and help for patients post-EIP, paired with strict processes that limit access. This inevitably leads to multiple points of contact before appropriate help is obtained. As a result, patients develop unhelpful help-seeking cycles whereby when their mental health deteriorates, they are faced with rejections of help, leading to disengagement or delayed help-seeking. Consequently, emergency services become the default re-entry method.

Both papers highlight the need for flexible and adaptable services, that offer reasonable adjustments for psychosis such as flexible methods for accessing appointments, reduced reliance on articulation, proactive follow-up and care coordination approaches. Peer support should be more widely incorporated into services to offer an increased sense of belonging and advocacy. Services could adopt EIP informed models to improve access and engagement.

Research implications

The findings challenge insight-based models of help-seeking, introducing an alternative explanation for delayed help-seeking in psychosis patients. The assumption that help-seeking is delayed due to lack of insight was not supported by this study. Delayed help-seeking could be a protective response to stigma, fear and previous negative experiences with services, framing this in a different light to existing literature that states delayed help-seeking is a result of lack of insight or awareness of early warning signs (Nordgaard et al., 2021).

Future research should focus on extending the breadth of experiences such as accessing patients who have disengaged entirely or alternatively those who have successfully accessed care with few barriers. Further research needs to be more inclusive and diverse, recruiting wider ethnic variation and the involvement of clinicians or family perspectives.

In order to improve discharges and transitions between services, we need more evidence on how decisions about discharges from EIP are made, exploring clinician's perspectives and the consistency of discharge decisions across EIP teams. It would be helpful to analyse the number of appropriate versus inappropriate referrals post-EIP to establish how well current discharge processes are working. To inform and improve discharge planning and handovers of care to either primary or secondary services, further research must focus on predictors for discharge destinations given that this is not well documented to date.

Given that most patients are discharged to primary care, further research could explore the confidence of the primary care workforce in managing the psychosis populations post-EIP treatment. Research exploring staff perspectives of the barriers to accessing support for psychosis within both primary and secondary care can

contribute to evidence on services' ability and capacity to support psychosis patients post-EIP, alongside informing service re-design and funding.

Continued research into long-term outcomes for patients post-EIP could focus on comparing the impact of care pathways and discharge destinations on patients' outcomes.

Critical appraisal – Strengths and limitations

The thesis portfolio provides breadth through the systematic mapping of care pathways and additional depth through qualitative exploration of lived experiences. The empirical paper responds directly to the gaps identified in the systematic review. The methodologies of both papers complement each other, capturing both organisational structures of care pathways post-EIP and the experiences of patients.

Both papers contribute to an under researched area. Most existing literature focuses on pathways into care or the effectiveness of EIP services, but there remain few studies capturing care pathways after EIP. Understanding pathways of care post-EIP and more importantly how pathways are experienced by service-users themselves is essential to informing service development or change. Given the high relapse rates reported it is extremely clinically relevant and has a direct impact on patients.

The thesis portfolio should be interpreted with some limitations in mind. The systematic review lacks qualitative data and in-depth investigation into post-EIP care pathways given its reliance on mostly clinical record data. The findings presented in the empirical paper may be skewed towards individuals who struggled to access care. The findings underrepresent a wider ethnic population and rural contexts. From

both the systematic review and empirical paper, most participants were from white backgrounds.

Given the limitations around recruitment of participants, findings may not be representative of the voices of those who were fully unsuccessful in accessing care. The use of social media placed restrictions on some individuals taking part such as those who do not have access to technology. This is a crucial factor to consider given that technology was identified as a barrier to accessing help from services, which could extend to a barrier to accessing research.

Dissemination

A summary of results has been sent by email to participants who opted in to receive a copy of the findings (as indicated on the consent form).

Both papers will be submitted for publication and submitted for presentation at the UEA ClinPsyD research conference.

Reflective Account on the research process

I adopted a critical realist perspective, allowing me to acknowledge the existence of phenomena such as ‘relapse’ and ‘care pathways’. I understood care pathways as organisational structures that are shaped by formal processes. I recognise psychosis as a real and measurable phenomenon in terms of its symptoms and relapses. But individuals experience of psychosis and interactions with services are shaped by societal contexts, beliefs and relationships. The findings of the thesis were co-constructed based on patients’ experiences and the researchers’ interpretations. I understood and narrated on patients’ experiences through the lens of my own knowledge and professional understanding.

Within interviews, I adopted a therapeutic style, offering validation to promote engagement and psychological safety. I was aware of the role of a researcher in solely gathering information. However, on reflection I feel this helped me enable richer discussions and increase participants' confidence in disclosing more sensitive information.

My professional background shaped how I interpreted participants' meanings. The analysis process required careful attention to my own preconceptions, prior reading and familiarity of the existing literature. I entered the analysis process with awareness of common barriers to accessing care. To mitigate the risk of generating themes based on what I expected, I ensured that themes captured the shared meaning across multiple participants and regularly revisited codes and themes, removing any codes that were too general or not representative. Themes were repeatedly reflected upon with the research team.

My own experience of being a 'service-user', including difficulties accessing care and experiences of dismissal, drew me to focus on identifying areas of improvement, risking under-representation of positive experiences. To address this, I systematically checked themes against the data and included themes of personal growth, relational safety and experiences of successful help-seeking.

Overall, the experience of analysis was both exciting and overwhelming. Anxieties arose around 'doing it right' and following the process of thematic analysis such as organising large numbers of codes and ensuring the themes were not too broad. Also, the pressure to capture patients full experience, increased anxiety about discarding codes or subthemes, due to fear of repeating experiences of dismissal

and exclusion. I addressed this by taking regular breaks and revisiting the data with fresh eyes. **Conclusions**

In conclusion, the thesis provides important insight into the barriers and facilitators for accessing care following discharge from EIP services. Relapse exposes significant systemic barriers in NHS systems leading to post-EIP pathways that are fragmented and lengthy. Services should aim to be flexible and responsive, and re-design of services should be guided by service-user experiences. This may reduce treatment delays, promote help-seeking and engagement. Further research is required to add breadth to understanding care pathways post-EIP, an under researched area.

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APPENDICES

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APPENDIX A: Search strategy

Care pathways related terms: (“care path*” OR “Care plan” OR “Treatment path*” OR “service pathway” OR “trajector*” OR “follow-up”)

AND

Service discharge related terms: (“discharge” OR “leav*” OR “exit” OR “transition” OR “Point* of contact” OR “discharge plan*” OR “post treatment” OR “aftercare” OR “destinations”)

AND

Service use related terms: (“EIP” OR “EIS” OR “Early Intervention” OR “Early treatment” OR “Early support” OR “early detection”)

AND

Psychosis related terms: ("Psychosis” OR “psychotic” OR "Schizophrenia" OR "Schizoaffective" OR “schizo-affective” OR "bipolar")

APPENDIX B: Cohens Kappa

Symmetric Measures

		Value	Asymptotic Standard Error[a]	Approximate T[b]	Approximate Significance
Measure of Agreement	Kappa	.692	.196	3.254	.001
N of Valid Cases		20			

a. Not assuming the null hypothesis.

b. Using the asymptotic standard error assuming the null hypothesis.

APPENDIX C: NHS research ethic committee approval

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

MISS CLAIRE ROBINSON
Norwich Medical School
University of East Anglia
NORWICH
NR4 7TJ

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

06 March 2025

Dear MISS ROBINSON

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Experiences of re-accessing secondary mental health services following discharge from Early Intervention in Psychosis (EIP)**
IRAS project ID:	**347363**
Protocol number:	**N/A**
REC reference:	**25/NW/0042**
Sponsor	**University of East Anglia (UEA)**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **347363**. Please quote this on all correspondence.

Yours sincerely,

Mathew Barnes
Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *MS TRACY MOULTON*

APPENDIX D: Advertisement materials (Poster, advertisement cards and social media post)



University of East Anglia



LOOKING FOR PARTICIPANTS FOR AN ONLINE STUDY!

AIM TO IMPROVE PATIENT EXPERIENCES OF ACCESSING CARE

WE WANT TO HEAR FROM YOU!

Are you aged 18-65, have a diagnosis of psychosis and have been previously supported by Early Intervention in Psychosis (EIP) team?

FIND OUT MORE HERE

Key Information

- An interview lasting up to 90 minutes online
- Information will be kept confidential and anomalous
- You will be gifted a £10 voucher to say thank you!

Questions about the study?
Claire Robinson (Research Lead, Trainee Clinical Psychologist) Claire.robinson@uea.ac.uk
Sophie Allan (Clinical Psychologist) s.allan@uea.ac.uk

University of East Anglia

SIGN UP NOW

Please sign the consent to contact form by visiting: https://tinyurl.com/3wxmmpzp
Or by scanning the QR code

APPENDIX E: Participant information sheet (Full Version)



Experiences of re-accessing secondary mental health services following discharge from Early Intervention in psychosis (EIP)

Patient information sheet

I would like to invite you to take part in a research study. The study is taking place as part of the researchers Doctorate in Clinical Psychology (ClinPsyD) at University of East Anglia (UEA). UEA are the sponsor organisation for this project.

It is your choice as to whether you decide to take part. Before you decide please read the information below to make sure you understand what the research is about, why the research is being conducted and what taking part will involve. If you wish I can go through the following information with you to assist in your decision making and answer any questions you might have. Please let me know if there is anything that is not clear or that you would like more information about. Take your time to decide whether or not to take part. You are welcome to discuss this study with family or friends if you wish.

About the research

This research is looking at understanding people's experiences of discharge from Early Intervention in psychosis (EIP) services and the barriers or facilitators (i.e. what made it easier or difficult) to accessing care following discharge. We know it is important that changes between services are as smooth and effective as possible to support recovery outcomes and ensure that individuals can access the support they need at the time they need it. We want to understand what contributes to effective changes between services and what might get in the way or make these difficult.

In this research study we will ask for information from you. We will only use information that we need for the research study. Only the research team (4 people) will know your name or contact details and only if they really need it for this study. Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules. At the end of the study, we will save some of the data in case we need to check it and for future research but not your name or anything that identifies you. We will make sure no one can work out who you are from the reports we write.

This research study is not a route to accessing care or services. It is not therapy. The research team will not be able to support with gaining access to specific support or services as part of this study.

A group of people who have experienced psychosis have been involved in designing this study, supporting to write this information sheet, decide on questions that should be asked during the interview and will help with data analysis.

Who can take part?

You can take part in the study if you agree with the following statements:

- I am aged between 18-65
- Currently living in the UK
- I have a diagnosis of a psychotic disorder (such as Psychosis, schizoaffective disorder, schizophrenia, delusional disorder, Bipolar disorder type 1).
- I have previously been supported under an EIP service for a minimum of 2 years.
  EIP is a service where people receive specialist psychosis support in the community for up to 3 years. This may be referred to as EIP or Cameo.
- I have been discharged from EIP services in the last 10 years and have since tried (successfully or unsuccessfully) to access mental health support for psychosis.
- I have either responded to an advertisement card, poster or social media post or are currently being supported under Cambridge and Peterborough NHS Foundation Trust (CPFT) or Norfolk and Suffolk NHS Foundation Trust (NSFT) mental health service.

Do I have to take part?

It is your choice on whether you accept this invitation. We aim to provide you with all the relevant information through this information sheet and will answer any questions you might be left with. If you agree to take part, we will ask you to sign a consent form to show you have agreed to take part in the study. You are free to withdraw at any time before the interview, without giving a reason. Taking part in the study will not affect any care you are currently receiving.

What will happen to me if I take part?

If you decide to take part, you will complete an online interview with the researcher via Microsoft teams. The interview will last up to 90 minutes (including a break if required). The researcher will need you to turn your camera on initially. You will need to provide an email address for us to contact you with details and instructions for accessing the interview. The interview will be recorded in order for the researcher to transcribe into text, but any identifiable information will be removed, keeping the data anonymous and confidential. The recording of the interview will be deleted following the transcription process. Participants should expect to spend a maximum of 2 hours in total when taking part in the study.

Will I be paid?

As a thank you for taking part, you will be offered a £10 shopping voucher at the end of the interview.

What will I have to do?

If you take part, you will be interviewed by the researcher who will ask you some questions about your experience of discharge from EIP and what support you

pursued following discharge. There are not any right or wrong answers to the questions, we are simply interested in your experience and opinions in order to improve things for the future. You do not have to answer any questions that you do not feel comfortable with.

What are the possible disadvantages and risks of taking part?

Some people may find that talking about their experiences can be distressing. In the event of this happening, you can stop the interview at any time. We will provide you with relevant information on how to seek support following the interview.

What are the possible benefits of taking part?

Your experience and opinions will be heard and listened to. We value what you have to say and feel this is beneficial to understanding and contributing towards improving discharge and transitions between services in the future.

What if there is a problem?

If you have any concerns about any aspect of this study, you can speak to the researcher, Claire Robinson by email Claire.robinson@uea.ac.uk. Or alternatively, you can contact her supervisor, Sophie Allan on s.allan@uea.ac.uk. If you remain unhappy and wish to complain formally you can do this through Patient Advice and Liaison service (PALS) using the following link: https://www.nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service/

Or if you would like to contact a member of course staff independent to the study: **Professor Sian Coker (Programme Director for UEA Clinical Psychology Doctorate programme)** Doctoral Programme in Clinical Psychology, Department of Clinical Psychology, Norwich Medical School, University of East Anglia, Norwich, NR4 7TJ. Email: S.Coker@uea.ac.uk‘

How will we use information about you?

We will need to use information from you for this research project. All information which is collected about you during the course of the research study will be kept strictly confidential. The study is due to run till September 2026.

This information will include your name and contact details (email address), which will be used to contact you to arrange the interview and to send you your participation voucher. People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

UEA is the sponsor of this research and are responsible for looking after your information. We will keep all information about you safe and secure by keeping any identifiable information confidential.

Your personal details will be stored separately from your anonymised study data (clinical information or interview transcript) in a password protected file. They will not be able to be linked by anyone outside of the research team. Your personal details will be deleted once they are no longer required.

The researcher will record the interviews. As soon as the interview has been terminated the researcher will upload the file onto a secure OneDrive. There is no possibility your data will be compromised.

The interviews will be transcribed to written text with anything that might identify you (e.g. reference to where you live, your name) will be removed. You will be allocated a participant ID number. Transcripts of the interviews will be accessed by members of the research team. If you wish, this will include members of the public and patient involvement (PPI) group.

Short examples (quotations) of what you have said in the interviews will be used as examples in the final report, journal articles or at conference presentations. These will not contain identifiable information. However, you may be able to identify yourself in the written report based on your interview answers.

Any data collected will be handled in accordance with the General Data Protection Regulations (GDPR).

What are your choices about how your information is used?

You can withdraw from the study at any time prior to the interview. However, once the interview has been completed you will be given one week to withdraw should you wish to.

You have the right to ask us to remove, change or delete data we hold about you for the purposes of the study. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this

Where can you find out more about how your information is used?

You can find out more about how we use your information,

- by asking one of the research team or
- by sending an email to dataprotection@uea.ac.uk

What will happen to the results of the research study?

The results of the study will be submitted to the UEA and published in an academic journal. The results aim to improve local and national services. The researcher may present results to clinical teams or at conferences to help improve services for the better. You are welcome to have a copy of the results if you wish. You will not be identified in any report or publication. The research report is due to be available by September 2026.

Further information and contact details

If you would like further information about the research or have any questions, you can contact the researcher, Claire Robinson on Claire.robinson@uea.ac.uk.

If you would like advice about whether or not to participate in this study, you can contact health professionals involved in your care or talk to family or friends.

APPENDIX F: Participant information sheet (Easy read)



Service-users' experiences of re-accessing mental health services following discharge from Early Intervention in psychosis services

Patient information sheet

I would like to invite you to take part in a research study. It is your choice as to whether you decide to take part. Before you decide please read the information below to make sure you understand what the research is about, why the research is being conducted and what taking part will involve.

About the research
This research is looking at understanding individuals' experiences of discharge from Early Intervention in psychosis (EIP) services and the barriers or facilitators to accessing care following discharge. We know it is important that transitions between services are as smooth and effective as possible to support recovery outcomes and ensure that individuals can access the support they need in a timely manner. We want to understand what contributes to effective transitions and what might get in the way or make these difficult.

This research study is not a route to accessing care or services.

The study is taking place as part of the researchers Doctorate in Clinical Psychology at the University of East Anglia (UEA), who are the sponsor organisation for this project.

Do I have to take part?
It is your choice on whether you accept this invitation. We aim to provide you with all the relevant information through this information sheet and will answer any questions you might be left with. If you agree to take part, we will ask you to sign a consent form to show you have agreed to take part in the study. You are free to withdraw at any time, without giving a reason. Taking part in the study will not affect the care you are currently receiving.

What will happen to me if I take part?
If you decide to take part, you will complete an online interview with the researcher. The interview will last up to 90 minutes. You will need to provide an email address for us to contact you with details and instructions for accessing the interview. The interview will be recorded in order for the researcher to transcribe into text, but any identifiable information will be removed, keeping the data anomalous and confidential.

You can find out more about how we use your information by contacting dataprotection@uea.ac.uk

If you take part you will be interviewed by the researcher who will ask you some questions about your experience of discharge from EIP and what support you pursued following discharge. There are not any right or wrong answers to the questions, we are simply interested in your experience and opinions in order to improve things for the future. You do not have to answer any questions that you do not feel comfortable with.

Will I be paid?
As a thank you for taking part, you will be offered a £10 shopping voucher at the end of the interview.

What are the possible disadvantages and risks of taking part?
Some people may find that talking about their experiences can be distressing. In the event of this happening, you can stop the interview at any time. We will provide you with relevant information on how to seek support following the interview.

What are the possible benefits of taking part?
Your experience and opinions will be heard and listened to. We value what you have to say and feel this is beneficial to understanding and contributing towards improving discharge.

If you have any questions or would like further information, please contact Claire Robinson on claire.robinson@uea.ac.uk

APPENDIX G: Consent to contact form



CONSENT FORM

Experiences of re-accessing secondary mental health services following discharge from Early Intervention in psychosis (EIP)

Name of researcher: Claire Robinson

- I understand that the researcher will contact me via email to arrange the interview at a mutually convenient time.
- I am aged 18-65 years and currently living in the UK.
- I have experienced psychosis and have a diagnosis of e.g. First episode psychosis (FEP), schizoaffective disorder, schizophrenia, delusional disorder, bipolar disorder type 1 etc.
- I have previously been supported under an Early Intervention in psychosis (EIP *) team in the UK (NHS) for a minimum of 2 years.
  **EIP is a service where people receive specialist psychosis support in the community for up to 3 years. This may be referred to as EIP or Cameo.*
- I have been discharged from an Early Intervention in psychosis (EIP) team within the last 10 years.
- Since leaving EIP, I have attempted (successfully or unsuccessfully) to access mental health support for psychosis e.g. through GP, 111, Crisis teams, community mental health teams, wellbeing service etc.
- I am fluent in English speaking to a good conversational level.

1. I can confirm that I meet all of the above criteria for this study **(Required). If you do not meet the above criteria, please do not take part in this study.**

   ◯ Yes I meet the above criteria

   ◯ No I do not meet the above criteria

- I confirm that I have read the patient information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactory.
- I understand that my participation is voluntary and that I am free to withdraw at any time prior to the interview without giving a reason, without my medical or legal rights being affected.
- I understand how my data will be used in this study. I understand that any personal data will be held confidentially by the research team and deleted at the end of the study. I understand that my anonymised interview transcript will be available to members of the research team and available for use by future researchers.
- I agree to the interview being recorded.
- I understand that should I disclose any information that raises significant concerns about my safety or the safety of others, the researcher will take this seriously and provide information on where to access support. However, the researcher is not responsible for my clinical care and therefore it is my responsibility to seek this support independently from the research study.

2. I confirm that I consent to all of the above statements and therefore I agree to take part in the above study **(Required).**

   ◯ Yes, I consent

   ◯ No, I do not wish to take part

3. Please provide your email address here in order to take part **(Required):**

4. I would you like to receive a copy of the results of the study? **(Optional)**

   ◯ Yes

   ◯ No

5. Please sign your full name below to confirm you are happy with the completion of this form **(Required):**

If you would like a copy of the completed consent form, please download a copy online. A copy of the completed consent form will be retained by both researcher and participant.

APPENDIX H: Demographics form



DEMOGRAPHICS FORM

Experiences of re-accessing secondary mental health services following discharge from Early Intervention in psychosis (EIP)

Name of researcher: Claire Robinson

If you require any support with answering any of the following questions or have any concerns or queries, you can contact the researcher, Claire Robinson on Claire.robinson@uea.ac.uk or alternatively discuss this at the beginning of the research interview.

Gender:

- ☐ Female
- ☐ Male
- ☐ Other

Age: _____

First language: _____

Ethnicity:

a. WHITE

- ☐ English/ Welsh / Scottish / Northern Irish / British
- ☐ Irish

Other white background (please state)

b. MIXED / MULTIPLE ETHNIC GROUPS

☐ White and Black Caribbean

☐ White and Black African

☐ White and Asian

Any other mixed / multiple ethnic background (please state)

c. ASIAN / ASIAN BRITISH

☐ Indian

☐ Pakistani

☐ Bangladeshi

☐ Chinese

Any other Asian background (please state)

d. BLACK / AFRICIAN / CARIBBEAN / BLACK BRITISH

☐ African

☐ Caribbean

Any other black / African / Caribbean background (please state)

e. OTHER ETHNIC GROUP

☐ Arab

Any other ethnic group (please state)

☐

Are you currently under a specialist mental health team Yes/No

If yes, please choose the most suitable option below

☐ Cambridgeshire and Peterborough

☐ Norfolk and Suffolk

☐ Elsewhere in UK

Other (please state) _____

Diagnosis _____

Number of years under an Early Intervention in psychosis (EIP) team: **(multiple choice question) (optional):**

1year / 2 years / 3 years

Number of psychotic episodes **(optional):**

Appendix I: Interview schedule (version sent to participants)



Service-users' experiences of re-accessing mental health services following discharge from Early Intervention in psychosis services

Interview schedule

1. Thinking back to the day of discharge from EIP, can you remember that? How did you feel? What was the first thing that went through your mind?

2. Can you tell me a bit about how you felt following discharge from EIP?
   - How confident did you feel in managing relapse following discharge from EIP?

3. Can you tell me about your experience since discharge from EIP?
   - When did you realise that you required further mental health support following discharge from EIP?

4. What happened next?

5. Since discharge from EIP have there been places you have gone to seek support? (e.g. formal or informal places of support). Some people find it helpful to draw it out on a map, can we do this together?

6. Can you tell us about your experience of accessing support following discharge from EIP?
   - How easy did you find it to access support from services?
   - How long following discharge from EIP did you go without support from services? If so, did you experience any changes in your mental health during this time?
   - How confident did you feel about your ability to access further support following discharge from EIP?

7. Looking back over this time following discharge from EIP, how do you feel about the help you received?
   - How satisfied were you with the process of gaining further support from services following discharge from EIP?

8. Thinking about your experience of discharge from EIP, overall what do you feel went well?

9. Is there anything specific that could have been improved on/ done differently?

10. When you first realised that things were becoming difficult, did you feel able to talk to anyone about this?
    - If yes, where did you go to get help? What was that like? What was good about the help you received? What got in the way? Did it make things better or worse?
    - If no, what stopped you from talking about it or seeking help?

11. Is there anything that might have supported you to get help post-discharge?

12. Is there anything else you'd like to mention that we haven't talked about already?

Appendix J: Interview schedule (Full version)

Service-users' experiences of re-accessing mental health services following discharge from Early Intervention in psychosis services

Interview schedule

Before audio recording starts:

Thank you for meeting with me. The purpose of this interview is to find out a bit more about your experience of discharge from Early Intervention in psychosis (EIP) services and hear about the barriers or facilitators to accessing care following discharge.

Can you please confirm that you still consent to taking part in the study and consent to this interview being recorded? [Check verbal consent for taking part in the study and recording]

How are you feeling today? [check that it is appropriate to go ahead with the interview. Give option to reschedule interview at this point].

Are you happy for us to continue with the interview and start to work together to understand your experience? [If yes, start recording. If no, ask the participant if they would like to withdraw from the study or reschedule the interview].

Start recording

1. Thinking back to the day of discharge from EIP, can you remember that? (If cannot recall, go to question 2) how did you feel? What was the first thing that went through your mind?

2. Can you tell me a bit about how you felt following discharge from EIP?
   - How confident did you feel in managing relapse following discharge from EIP?

3. Can you tell me about your experience since discharge from EIP?
   - When did you realise that you required further mental health support following discharge from EIP?

4. What happened next?

5. Since discharge from EIP have there been places you have gone to seek support? (e.g. formal or informal places of support). Some people find it helpful to draw it out on a map, can we do this together?

6. Can you tell us about your experience of accessing support following discharge from EIP?
   - How easy did you find it to access support from services?
   - How long following discharge from EIP did you go without support from services? If so, did you experience any changes in your mental health during this time?
   - How confident did you feel about your ability to access further support following discharge from EIP?
   - Were there any barriers to accessing support post-discharge?

7. Looking back over this time following discharge from EIP, how do you feel about the help you received?
   - How satisfied were you with the process of gaining further support from services following discharge from EIP?

8. Thinking about your experience of discharge from EIP, overall what do you feel went well?

9. Is there anything specific that could have been improved on/ done differently?

10. When you first realised that things were becoming difficult, did you feel able to talk to anyone about this?
    - If yes, where did you go to get help? What was that like? What was good about the help you received? What got in the way? Did it make things better or worse?
    - If no, what stopped you from talking about it or seeking help?

11. Is there anything that might have supported you to get help post-discharge?

12. Is there anything else you'd like to mention that we haven't talked about already?

Stop recording

Before we finish, I wondered if you have any questions for me?

How are you feeling after talking about all this with me today? [If participant states they are feeling or appears to be distressed, talk through what might have upset them. Conduct a risk assessment if necessary. For all participants, discuss and provide them with the debriefing sheet].

Thank you again for taking the time to talk to me.

Appendix K: Debrief sheet

University of East Anglia

DEBRIEFING SHEET

Title of project: Experiences of re-accessing secondary mental health services following discharge from Early Intervention in psychosis (EIP)

Name of researcher: Claire Robinson

Thank you for taking part in the above study.

Some people find that talking about their experiences can be difficult or distressing. If this has been your experience following taking part in the above study, you can contact the following for support:

If you are currently receiving support under a community mental health team:

1. Contact the person you usually seek support from within the community mental health team (CMHT) directly.
2. Contact the duty worker within the community mental health team (CMHT) by calling during the office hours of Monday to Friday, 9am to 5pm.

If you are not currently receiving support under a community mental health team, you can seek support from the following services:

- Call your GP for an appointment.
- The Samaritans telephone helpline on 116 123 (open 24 hours a day).
- Contact Shout by texting “SHOUT” to 85258.

If you are worried that you may need more urgent or emergency support or you feel that you are in mental health crisis, you can contact the following:

1. Call 111, option 2 (24-hour helpline for crisis or emergencies)
2. Call 999
3. Or take yourself to A&E department.

Kind regards



Claire Robinson

Trainee Clinical Psychologist, University of East Anglia

Appendix L: Distress protocol



Protocol for responding to Participant Distress or Reports of Concern

Qualitative Study: Experiences of re-accessing secondary mental health services following discharge from Early Intervention in psychosis (EIP)

Name of researcher: Claire Robinson

Supervisors: Sophie Allan, Sarah Reeve and James Plaistow

The nature of this research may result in participants re-visiting distressing experiences, causing participants to think about issues that could lead to some distress.

Where possible, distress to participants should be avoided and interviewers should be prepared to prevent and minimise distress. Distress could result from causes unconnected with the research.

This document provides guidance to interviewers which should be applied in such circumstances throughout the research process.

1. Before the interview

Participants are being invited to take part voluntarily in the research. It is vital that potential participants have full information about the nature of the research and the potential distress it might cause in order to make an informed decision about their participation. Information provided to potential participants will make the nature of the research clear.

The participant information sheet will be sent out to all interviewees before the interview and the researcher will be responsible for making sure the participant understands the information before they consent to taking part. The information sheet and consent process will give participants further chance to decide on whether or not to take part in the research. They are informed they can stop or withdraw at any time.

Capacity to consent will be assessed by the referring clinician within the community mental health service prior to the interview taking place.

The researcher will confirm with the interviewee that they are happy to proceed with the interview prior to the interview beginning and assess the appropriateness of the

interview going ahead. The interviewer will be prepared to stop the interview in the event of any signs of distress.

2. **The interview process**

At the start of the interview process

It is important to highlight the following points prior to the start of the interview:

1. Remind the participant that the aim of the research is to hear about their personal experiences.
2. Interviewers will reassure participants that they may stop the interview at any point should they wish to.
3. Interviewer will tell participants that they do not have to share any information that they do not feel comfortable sharing.

During the interview

1. Throughout the interview, the interviewer should be aware of any indications of distress. If present, they should pause and check that the participant is ok.
2. The interviewer will remind the participant that they can take a break or choose to stop the interview if they need to.
3. The interviewer will prioritise responding to distress above completing the interview and discuss help-seeking resources if appropriate.
4. If the interviewer senses that a participant is uncomfortable answering a particular question, they can offer to move to the next question and offer reassurance that they are free to refuse to answer any question or stop the interview if they wish to. However, the interviewer should check if there is anything that might support them to answer the questions and remind the participant that answers will remain anonymous, and their views will be respected.
5. If the participant discloses information regarding serious incidents not previously reported to anyone, the interviewer should take this seriously and encourage the participant to disclose this to someone they trust and feel comfortable to do so. The interviewer will provide supportive resources and advice about where to go to report such incidents. They should remind participants that they can report suspected crime to the police. The interviewer may need to remind participants that they are not responsible for providing support themselves. If the interviewer has any concerns about the safety of the participants or others, they should respond to these concerns by providing the relevant support contact details and encouraging participants to seek support via their GP or Mental health community team.

After the interview

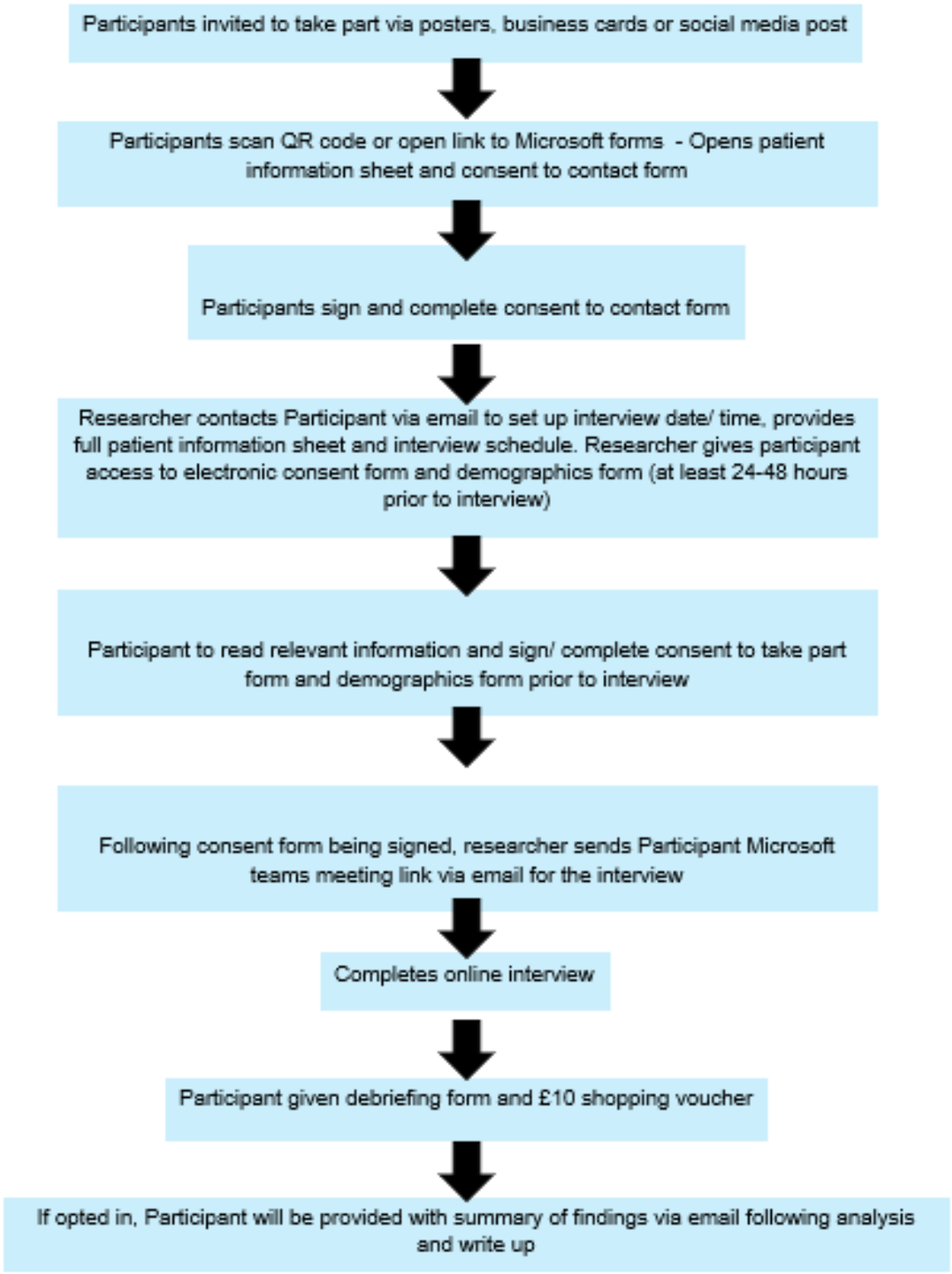
A debriefing form will be provided to participants including information on how to seek further support following the interview.

3. Interviewer Safety and support

The researcher is trained to identify and assess risk or safeguarding concerns. The interviewer can access support from the research team. The researcher will use supervision with the research team if concerns about participants are raised. The research team is made up of Clinical Psychologists who have clinical and research experience of working with this client group (psychosis) and have links with local NHS clinical teams within East Anglia.

Interviews will take place online to support interviewer safety. The interviewer will follow lone working policies.

Appendix M: Procedure flow chart



Appendix N: Thematic Analysis Process

Analysis stage	Procedure
1. Data familiarisation	Familiarisation happened through the researcher conducting the interviews and transcription process. Transcripts were further read twice and annotated with initial ideas and reflective notes. Examples of annotations and initial ideas are provided in Appendix T.
2. Coding	Transcripts were uploaded to NVIVO to support the coding process. Transcripts were annotated with initial codes. Coding was conducted by one researcher (CR). 259 codes were developed. Initial codes are provided in Appendix T.
3. Searching for themes	Codes were grouped together to start to identify initial themes, depending on shared meanings. Themes were data driven. Examples of how codes were grouped into subthemes are presented in Appendix T.
4. Reviewing themes	Thematic maps were drawn (Appendix U,V,W). Themes created were compared with initial codes. Some themes were discarded “Left without a safety net” or “perceived improvements”. Some themes were merged such as “Living without a map in the search for safety was merged with “Erosion of trust and hope”. Examples of theme refinement are provided in Appendix T.
5. Defining and naming themes	Researcher created narrative around data within each theme and used participant wording to name the themes.
6. Producing the report	Findings written up for publication in journal.

APPENDIX O: Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Table 1 Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description
Domain 1: Research team and reflexivity		
Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*
3.	Occupation	What was their occupation at the time of the study?
4.	Gender	Was the researcher male or female?
5.	Experience and training	What experience or training did the researcher have?
Relationship with participants		
6.	Relationship established	Was a relationship established prior to study commencement?
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. *personal goals, reasons for doing the research*
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*
Domain 2: study design		
Theoretical framework		
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*
Participant selection		
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*
11.	Method of approach	How were participants approached? e.g. *face-to-face, telephone, mail, email*
12.	Sample size	How many participants were in the study?
13.	Non-participation	How many people refused to participate or dropped out? Reasons?
Setting		
14.	Setting of data collection	Where was the data collected? e.g. *home, clinic, workplace*
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*
Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?
20.	Field notes	Were field notes made during and/or after the interview or focus group?
21.	Duration	What was the duration of the interviews or focus group?
22.	Data saturation	Was data saturation discussed?
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?
Domain 3: analysis and findingsz		
Data analysis		
24.	Number of data coders	How many data coders coded the data?
25.	Description of the coding tree	Did authors provide a description of the coding tree?
26.	Derivation of themes	Were themes identified in advance or derived from the data?
27.	Software	What software, if applicable, was used to manage the data?
28.	Participant checking	Did participants provide feedback on the findings?
Reporting		
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. *participant number*
30.	Data and findings consistent	Was there consistency between the data presented and the findings?
31.	Clarity of major themes	Were major themes clearly presented in the findings?
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?

Appendix P: Reflexivity

Considerations were given to the differences in the researcher and participants meaning of using services, continuation of care was viewed as ‘good practice’ by the researcher whereas for many participants independence away from services was an indicator of success. This symbolised the difference in views of re-accessing care and help-seeking. The awareness of this difference allowed for more comprehensive and refined interpretation.

During the interviews, the researcher noticed a pull towards adopting a therapeutic stance through offering validation. However, this conflicted with the role of a researcher in collecting data. After consideration, it was concluded that this style of interviewing was a positive, supporting engagement and psychological safety.

The researcher began with pre-existing assumptions about services, in regard to limited resources and systemic barriers to accessing care which were shaped by CR’s professional experience working within mental health settings as well as personal experience of accessing care as a service-user via primary care settings. Due to this, during the analysis the researcher became aware of the tendency to represent accounts of negative experiences within the themes, overlooking positive experiences unless these were related to personal growth within the individual themselves rather than service successes. This was understood in relation to the researcher’s desire to facilitate service improvements. The emotional tone and language used by participants further contributed to this analytic pull. To address this, the researcher revisited transcripts with a focus on searching for positive experiences.

Throughout the analysis process, the researcher noted fears of missing important data or failing to fully represent participants’ experiences. This manifested

in difficulty discarding subthemes. Theme development was supported by reflective discussions with supervisors and maintaining focus on the research questions and aims.

APPENDIX Q: Participant Demographics

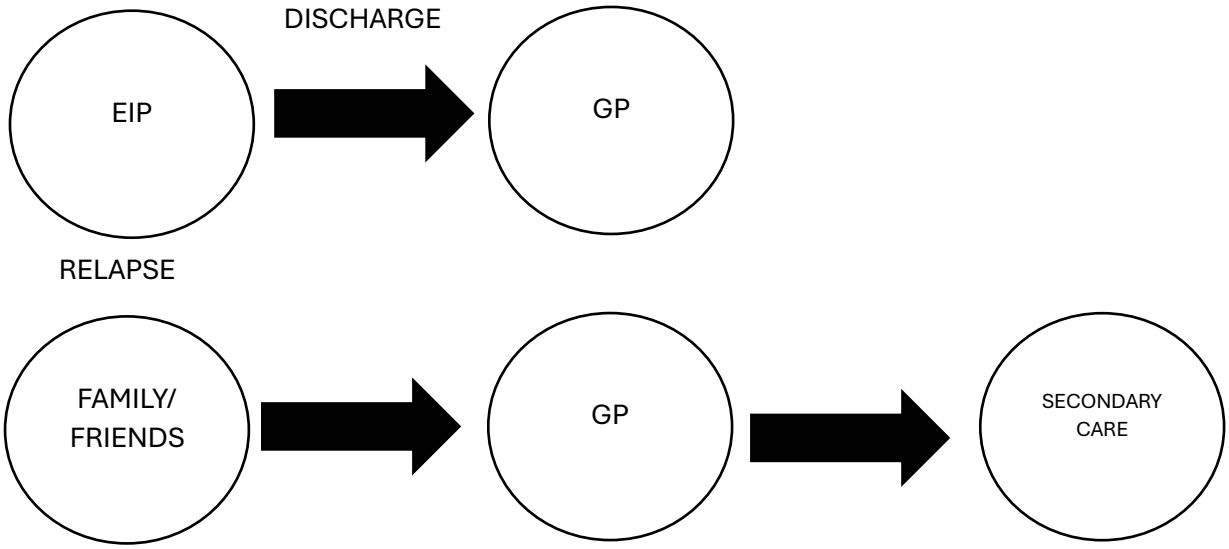
Characteristics	N (%)
Gender	
Male	3 (30%)
Female	7 (70%)
Age (years)	
25-30	4 (40%)
35-40	4 (40%)
40-50	1 (10%)
50-60	1 (10%)
Ethnicity	
White (any background)	6 (60%)
Black (any background)	1 (10%)
Asian	1 (10%)
Mixed	2 (20%)
Diagnosis	
Schizophrenia	2 (20%)
Bipolar type 1	3 (30%)
FEP	4 (40%)
Other	1 (10%)
Time since discharge (years)	
0-3	4 (40%)
4-6	3 (30%)
7-10	3 (30%)
Number of relapses	
1-3	7 (70%)
4-6	3 (30%)

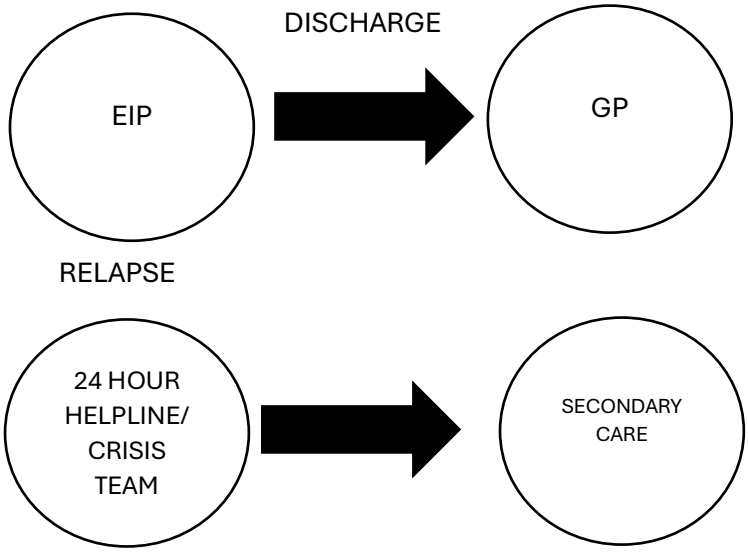
Service use	
Currently in services	6 (60%)
Not in contact with services	4 (40%)

Appendix R: Points of contact with services on re-accessing care

Characteristics	N (%)
Points of contact	
1-2	1 (10%)
3-4	3 (30%)
5 or more	6 (60%)

Appendix S: Care Pathway diagrams





APPENDIX T: Audit trail and theme development

Stage 1:
Data Familiarisation (annotations of initial ideas and notes of individual transcripts)

Example 1:

Initial ideas/ reflections:

- Lack of trust in professionals and services
- Inappropriate referrals
- Support not accommodating for those who are employed
- Support aimed at mild/moderate
- Focussed on the diagnosis not the person/ quality of life – ignoring the whole picture
- Promises made but not kept
- Harder to seek support from informal sources (different type of rship with professionals, more boundaries and more able to be open and honest – less of a emotional burden). Problem shared is a problem doubled. Not dealing with others emotions.
- Little oversight = need for low level consistent support
- Optimism/ expectation vs reality
- Medication focussed post discharge
- If coping don't need more support – leads to private support
- Need to advocate for self and be proactive
- Basic needs not followed up
- Isolation
- Not taken seriously – imbalance of power
- Let down by services – "give up"
- Bounced around services

Example 2:

Initial ideas:

- Delays in care
- Having to advocate for self – chase services – tiring and frustrating – not able to do when unwell (low energy and motivation)
- Not with correct services – lack of knowledge about what should be getting
- Poor communication between services e.g. no handover, lack of letters/ notes
- Having to repeat story multiple times
- Difficulties with relationships with professionals – feeling judged, feeling criticised, lack of understanding, difficult power dynamics/ authority
- Not able to access relapse plan – self destructive
- "difficult" patient or "complex" – services not set up for it – need for care coordination – outreach support
- Difficulties with discharge processes due to non engagement

Example 3:

Initial ideas:

- Poor responsiveness from services
- Long wait times
- Difficulty to get access to GP
- Lack of understanding of psychosis in GP
- Importance of shared experiences/ peer support
- Stereotyping
- Assumptions that if articulate = well
- Declined from support because don't fit a box
- Unable to rely on services
- Need for a safety net but it is not there

Stage 2:
Coding (Table of examples of initial codes)
Here are some examples of the initial codes created and the associated quotes. This is not an exclusive list.

Code	Description	Number of participants	Example quote
Power imbalance	Terrified of being placed in hospital. Lack of control. Not knowing your rights as a patient. Getting told what to do. Treated like a case rather than a person. Authority. Self doubt and believing those in authority. Feeling unable to make a complaint. Unable to speak up. Decisions made for you. Having to play by the rules. If you do not comply, labelled “non compliant”.	6	“you just get told what to do” “It's an uncomfortable position to be in and I kind of kind of picture the sort of power dynamic there around, you know” “he's in a position of authority, where does that place you? “
Lack of knowledge	Not understanding how services work or where to go to get help. Lack of understanding about professionals roles and what they do. Feeling that staff do not have enough knowledge about psychosis to help. Not enough training for staff. Only providing patients with generic knowledge about support and places to seek help.	6	“I didn't understand how the services worked, but I mean to a certain extent, can you expect somebody to do that, like I didn't know really what I should have been getting and like.” “having a good situational awareness of service provision and issues, you know having that information does mitigate against uncertainties”
Judgement	Not wanting to help me due to diagnosis. Only helping because of the policy. If medical professionals cant be understanding than who can? Professionals being critical. Fear of others reactions. Shy away from sharing. People don’t want to employ you. Assumed that they are attention seeking or putting it on.	8	“sometimes you sort of will throw out a probe in terms of to figure out how somebody is going to react and if they react negatively to that”

			“And if a medical professional can't be understanding about that, then who can be?”
Difficult procedures	Discharged for missing appointments which further delays care. Have to sign agreements about attendance with no choice. If missed appointments get put back to the end of the waiting list. Passwords and encrypted emails which are hard to use. Need for technology knowledge or devices to access questionnaires. Lot of information to take on and remember. Placed in hospitals outside of area/ away from home and family. Time limits for filling out online forms. Having to make multiple requests for different conditions or problems. Having to call up for appointments at 8am when you are struggling with sleep then often placed in a queue or on hold which is stressful.	5	“there might be an agreement that you turn up or whatever. And well, you don't have any, any option but to sign it.” “it's problematic sometimes, particularly when you are struggling and you have to ring up at 8:00 AM and if you're not sleeping, you don't want to then have to set an alarm to wake up.”
Shared experience	Shared experience allows the sharing of coping strategies, use them as a support or resource, relate to each other, feel more connected and a community, lack of judgement. Boosts own self confidence and belief in ability to cope. Not alone. They understand. Can be open and honest. Safe space.	**6**	“There's kind of something about needing someone who can relate to kind of how you're feeling and the things that you're going through that makes it more helpful and maybe more kind of desirable to reach out to them for support.” “it was invaluable, really. The fact that you could discuss your psychotic episodes without worrying them because they had been there”

Mixed feelings on discharge	Apprehensive. Feeling lucky to have had the service. Nervous. Optimistic. Alone. Isolated. Mixed of emotions. Sad. Not confident. Unknown. Uncertainty. Shocked. Overwhelmed. No one wants you. In limbo.	7	“And I suppose I was kind of, you know, like, nervous, apprehensive. But I was kind of quite optimistic.” “it just felt like a mixture of emotions and it was quite sad to see the person leave.”
Wait times	Rapid recall list which means little wait. Expectation of long waits. Often having to chase things up. If miss appointments you go to the end of the waiting list. Things get worse while you are waiting for help. Cant afford to wait. Lack of communication while waiting. Waiting longer for face to face appointments. Accepting other help due to a shorter wait.	9	“you expect there to be a month long wait often and then if it's many months then it's like well, is it actually just normal or is this? And then eventually you do chase it up.” “It can seem hard. There are long waiting times, delayed responsivity. So it can seem a cold and lonely process.”
Turning to informal support	Reaching out to friends or family over services or professionals. They cant section you. They know your broader story and context of your life. They can reach out for support for you. They are an ally. They help articulate what you want and need. Feels easier as you can trust them. More autonomy and control over how much and what I share.	8	“I do sort of kind of reach to my social network first, I suppose. Before I would go professional.” “the reliance on supportive people such as friends to talk to, so I have a very strong supportive network”
Poor communication between services	Services aren’t connected. Professionals not reading notes. Lack of joint up working. Letters not being passed on. Having to repeat story and information to multiple professionals. Electronic systems are not	5	“regional services aren't very well connected.”

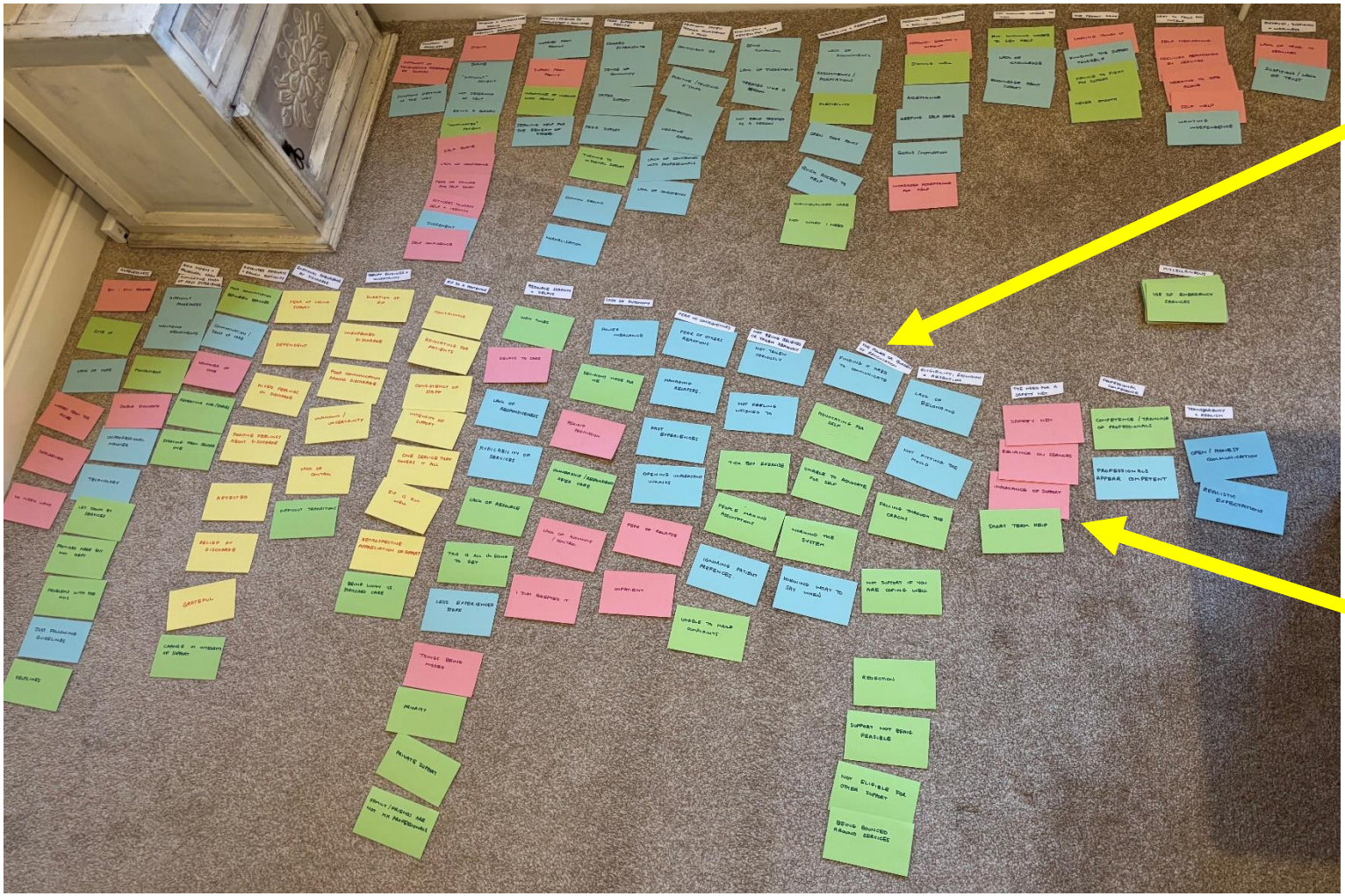
	linked up. Lack of access to notes. Starting from square one each time. Promises being made but not kept. People not passing on information properly. Lack of responsivity from services. Disjointed. Lack of communication between professionals within teams. Lack of joint up care between primary care and secondary or between mental health services and physical health services.		“Systems aren't linked up. People don't have access to all the information.”
Not eligible for other support	Not eligible for other support. Time since last service means not eligible for more support. Not the correct service. Cant say certain things otherwise you wont be eligible. Asked for help and not got any because coping well. Either too severe or not severe enough. Cant help certain diagnosis. Not enough specialist support. Services not available or not accessible to access. Help being declined. Don’t fit in that box. Cant use two services at the same time. Rigid rules.	6	“they said that my conditions were too severe for them to be able to manage.” “But because of their rigid rules, it was like, well, you're open to their services, so you can't be open to our services. You can't do two things at the same time.”
“complicated” patient	Too complex. Complicated. Not just a basic patient. Variable. More complex needs. No clear answer or solution. Severe and enduring mental health. Couldn’t help. Too severe. Not enough specialist support. Too frightened of diagnosis. Seen as attention seeking. They don’t understand the diagnosis.	6	“I maybe have more needs than some other people and it's a bit more complicated” “Oh, you're too complex or whatever.”
Stigma	Assume its down to your mental health. Too complex. Seen as a label. Too unwell. Too complicated. Negative reactions from others and judgement. Lack of understanding. Damaging diagnosis. Labelled for life. Push people away. Frightens others. Don’t want to employ you. Negative attitudes. Attention seeking. Seen as a group of symptoms not treated as a person. Stereotyped. First impressions. Scared.	8	“Probably just seen label and assumed.” “No, because you have a label.”

Stage 3:
Theme development (codes – subthemes):
Here are some examples of how the codes were grouped into subthemes. This is not an exclusive list.

Subthemes	codes	Description of subtheme
Abrupt endings and uncertainty	• *Duration of EIP (8)* • *Unexpected discharge (2)* • *Poor communication around discharge (2)* • *Unknown / uncertainty (3)* • *Lack of control (5)* • *Difficult transitions (4)*	*This subtheme reflects how discharge from EIP was often experienced as sudden, poorly communicated, and disempowering. Participants described uncertainty about timelines, unexpected endings, lack of involvement in decision-making, and limited clarity about what support would follow. Discharge was frequently characterised by loss of control and anxiety, with transitions feeling unclear and unsupported rather than planned or collaborative.*
Disjointed pathways and broken continuity	• *Poor communication between services (5)* • *Communication / joined-up care (4)* • *Handover of care (6)* • *Repeating information (2)* • *Starting from square one (3)* • *Experiences of secondary care (4)*	*This subtheme describes fragmented care pathways marked by poor communication, inadequate handovers, and lack of joined-up working across services. Participants often had to repeat their stories, re-establish relationships, and "start from square one," leading to frustration, emotional exhaustion, and a sense that continuity of care was fragile or absent.*
Eligibility, exclusion, and rejection (Not fitting the mould)	• *Lack of belonging (4)* • *Not fitting the mould (2)* • *No support if you are coping well (4)* • *Rejection (3)*	*This subtheme captures experiences of being excluded from support due to rigid eligibility criteria. Participants described being rejected for being "too well" or "too unwell," not fitting service criteria, or being bounced between services. These exclusions contributed to feelings of falling through the cracks and reinforced perceptions of systemic inflexibility.*

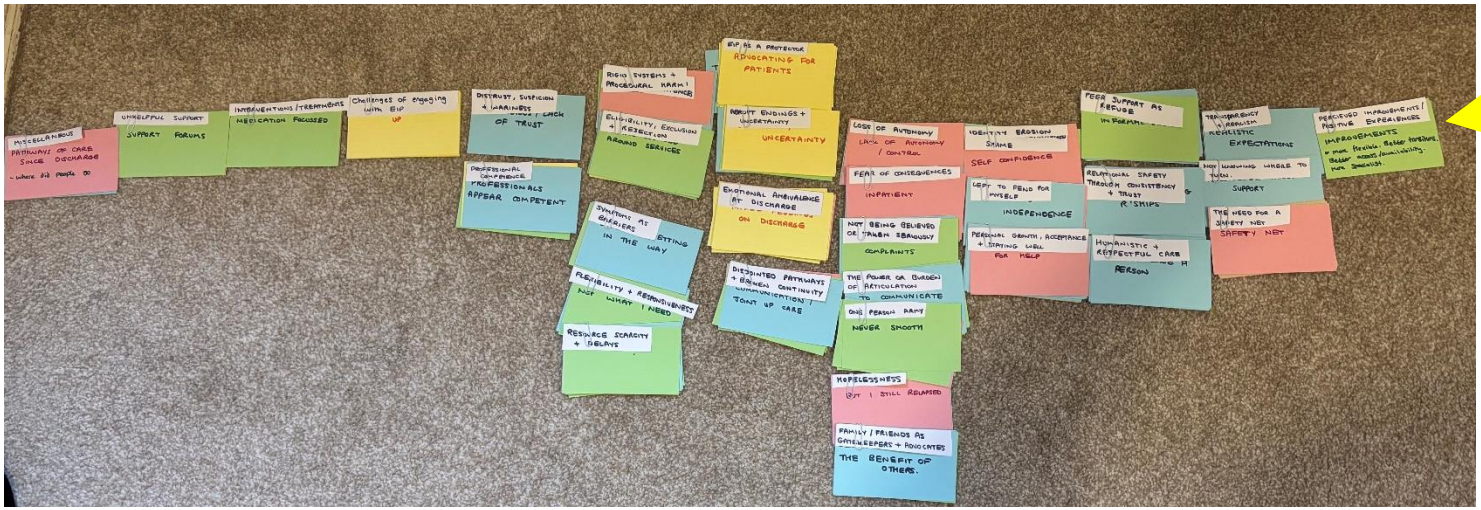
	• *Support not being feasible (2)* • *Not eligible for other support (6)* • *Being bounced around services (7)* • *Falling through the cracks (5)* *Different stages of recovery (2)*	
Flexibility and responsiveness	• *Lack of adjustments (2)* • *Adjustments and adaptations (4)* • *Ignoring patient preferences (3)* • *Flexibility (3)* • *Individualised care (4)* • *Not what I need (4)* *Travel (1)*	*This subtheme reflects the value of adaptable, responsive care. Adjustments to appointments, open-door policies, rapid access, and individualised approaches reduced barriers and made support more accessible. Inflexibility, by contrast, often led to disengagement.*
Articulation in working the system	• *Knowing what to say when (2)* • *Working the system (2)* • *Unable to advocate for self (3)* • *Advocating for self (4)* *Finding it hard to communicate (1)*	*This subtheme reflects how access to care depended heavily on the ability to articulate needs effectively. Participants described needing to "say the right things," work the system, or strategically present distress to receive help. Those unable to advocate for themselves or communicate clearly were particularly disadvantaged, highlighting articulation as both a resource and a burden.*

Hopelessness (give up on services)	• *But I still relapsed (2)* • *Lack of hope (6)* • *Give up (4)* • *Hopelessness (6)* • *Lack of confidence (6)*	*This subtheme reflects emotional exhaustion and loss of hope following repeated relapses, failed interventions, and unmet needs. Participants described giving up on services, worrying about the future, and feeling that there was "no magic wand." Hopelessness emerged as both an emotional state and a consequence of repeated systemic failures.*
Not knowing where to turn	• *not knowing where to get help (2)* • *lack of knowledge (6)* • *knowledge about support (3)*	*This subtheme reflects uncertainty and confusion about navigating the system. Participants lacked clear knowledge about where to seek help, what services offered, and how to access support, particularly during crisis or relapse.*
The need for a safety net	• *Safety net (6)* • *Importance of support (7)* • *Reliance on services (4)* • *Short term help (2)*	*This subtheme reflects the importance of knowing support is available when needed. Participants valued safety nets such as rapid recall, ongoing support, and continuity, particularly given the limitations of short-term interventions and fear of relapse.*



White labels represent initial groupings for initial subthemes.

Post it notes represent individual codes



Subthemes groups based on shared meanings and patterns to create possible main themes.

Theme development (subthemes – main themes):

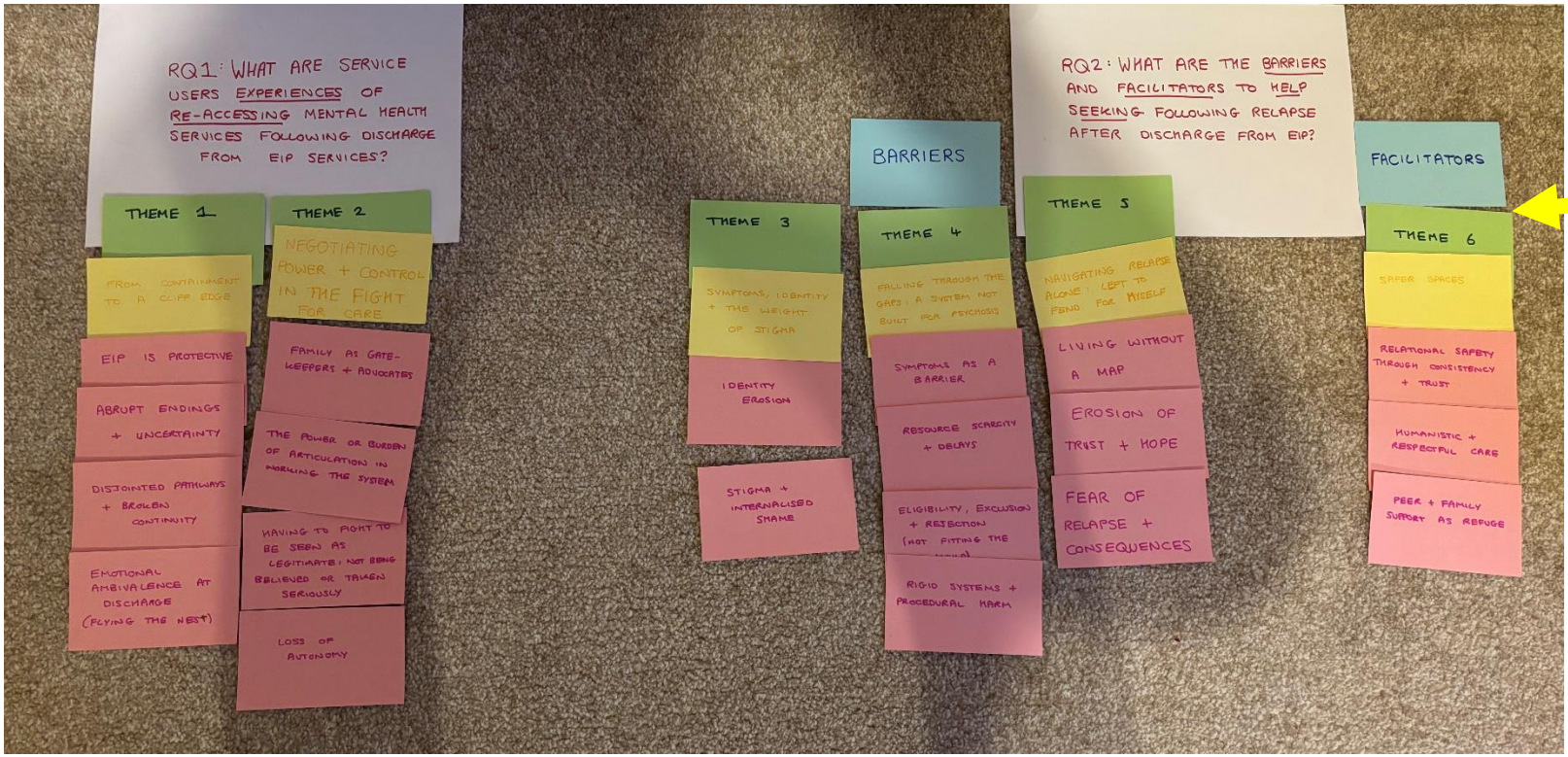
Here are some examples of how the subthemes were grouped into main themes. This is not an exclusive list.

Theme	***Possible Title***	***Subthemes included***	***Description of overarching theme***
Theme 1	*From containment to a cliff edge* *OR* *Containment to uncertainty* *OR* From containment to fragmentation: the shock of discharge/ leaving EIP OR The cliff Edge of Discharge	• *EIP as a protector* • *Abrupt endings and uncertainty* • *Emotional ambivalence at discharge* • *Disjointed pathways and broken continuity*	*This theme reflects the stark contrast between the protective, consistent, and relational care experienced within EIP and the abrupt, disorienting experience of discharge. Participants described EIP as a safe, intensive, and holistic service that offered continuity, advocacy, and emotional support. Leaving this environment often came suddenly, with poor communication and limited preparation, generating uncertainty, anxiety, and a sense of loss. Transitions into other services were frequently fragmented, requiring participants to repeat their stories and navigate disjointed pathways, amplifying emotional ambivalence and the feeling of being unprepared for life beyond EIP.*
Theme 2	*Rigid systems and procedural harm* *OR* Falling through the gaps: A system not built for psychosis OR Fitting through narrow spaces OR	• *Rigid systems and procedural harm / Cumulative harm of past experiences by services* • *Eligibility, exclusion and rejection* • *Resource scarcity and delays* • *Symptoms as barriers* • *Flexibility and responsiveness*	*This theme highlights how systemic inflexibility, procedural barriers, and resource limitations create obstacles to accessing effective care. Participants describe re-accessing care as navigating a system that is overstretched, disjointed, and poorly designed for severe mental illness. Participants described cumulative harm from rigid procedures, punitive responses, broken promises, and inconsistent support. Eligibility criteria often excluded those in need, while long wait times, scarce resources, and delays further restricted access. Symptoms of psychosis compounded these barriers, making engagement more challenging. Conversely,*

	Blocked pathways *and conditioned care* *OR* *Access issues* OR *A system that overpromises and underdelivers*		*services that offered flexibility, individualised adjustments, and rapid responses were valued, underscoring the critical role of adaptability in mitigating systemic shortcomings.*
Theme 3	*Fragmented re-entry through disempowerment and invalidation* *OR* *Burden of self-navigation* *OR* *Power and control* *OR* *Fighting for care in a scarce system*	• *Loss of autonomy* • Having to fight to be seen as legitimate: *Not being believed or taken seriously* • *The power or burden of articulation in working the system* • *One person army* • *Fear of consequences* • *Family / friends as gatekeepers and advocates*	*This theme captures the burden placed on individuals to navigate an unsupportive and often disempowering system. Participants reported experiencing a loss of control over decisions about their care, needing to constantly advocate for themselves, and being challenged to prove the legitimacy of their needs. The idea that access depends on obedience not need.* *The "one person army" of self-navigation, fear of relapse or negative consequences, and repeated invalidation contributed to exhaustion, hopelessness, and a sense of isolation. Those that are most unwell are least able to do what is needed to access help. Family and friends frequently assumed advocacy roles, highlighting gaps in formal support and reliance on informal networks to access care.*
Theme 4	*Left without a net* *OR*	• *Transparency and realism* • *Not knowing where to turn* • *The need for a safety net*	*This theme reflects the anxiety, confusion, and vulnerability that arise when participants lack clear guidance or reliable support. Participants often did not know where to access help, what services could offer, or what to expect from care pathways. Transparency, open*

	Clarity, navigation and the need for a reliable safety net *OR* *Knowing what to expect and where to turn* *OR* *Living without a map in the search for safety* *OR* *Containment to uncertainty*		*communication, and realistic information were highly valued in mitigating uncertainty. The presence of a "safety net", short-term support, rapid access, or ongoing reassurance, provided critical reassurance and a buffer against potential crises, emphasizing the importance of predictable and accessible support systems.*
Theme 8	Challenges of engaging with EIP	• *Rocky start with services* • *Not feeling heard* • *Rejecting help* • *Trust building* • *Lack of acceptance of diagnosis* *Hard to speak up*	*This theme captures the challenges participants faced when engaging with EIP services. Early experiences were sometimes marked by rocky starts and difficulties establishing trusting relationships. Participants often struggled to feel heard, speak up about their needs, or accept the clinical framing of their experiences, which at times led to rejecting help. These experiences highlight the relational and communicative barriers that can impact engagement even within a supportive service.*
Theme 9	Perceived improvements and positive experiences	• *Improvements* *What was good*	*This theme captures participants' recognition of positive aspects of mental health services. Improvements included more flexible services, better coordination, support during transitions, 24-hour psychiatric access, and specialist support. Participants also valued being understood, receiving timely help, support for family, and professionals who could spend time with them. Overall,*

these experiences highlight facilitators of engagement, recovery, and satisfaction within the system.



Initial names given to main themes.

Main themes grouped according to research question.

Stage 4:
Reviewing themes (discarding and merging themes):
Here are some examples of how the themes were reviewed and refined. Some themes were merged together, some themes were discarded and some were reviewed/ refined.

Theme	***Possible Title***	***Subthemes included***	***REFINED/ REVIEWED, MERGED OR DISCARDED***
Theme 1	*From containment to a cliff edge*	• *EIP as a protector* • *Abrupt endings and uncertainty* • *Emotional ambivalence at discharge* • *Disjointed pathways and broken continuity*	*Refined and reviewed.*
Theme 2	Falling through the gaps: A system not built for psychosis	• *Rigid systems and procedural harm / Cumulative harm of past experiences by services* • *Eligibility, exclusion and rejection* • *Resource scarcity and delays* • *Symptoms as barriers* • *Flexibility and responsiveness*	*Refined and Reviewed.*
Theme 3	*Power and control: Fighting for care in a scarce system*	• *Loss of autonomy* • Having to fight to be seen as legitimate: *Not being believed or taken seriously* • *The power or burden of articulation in working the system* • *One person army* • *Fear of consequences* • *Family / friends as gatekeepers and advocates*	*Merged.*
Theme 4	*Living without a map in the search for safety*	• *Transparency and realism* • *Not knowing where to turn*	*Merged.*

	Combined with… Erosion of trust and hope	• *The need for a safety net* ***Combined with*** • *Professional competence* • *Distrust, suspicion and wariness* • *Hopelessness*	
Theme 5	Symptoms, identity and the weight of stigma	• *Identity erosion* • *Stigma and internalised shame* • *Left to fend for myself* • *Personal growth, acceptance and staying well*	*Refined and Reviewed.*
Theme 6	Safer spaces outside the system	• *Peer support as refuge* • *Humanistic and respectful care* • *Relational safety through consistency and trust*	*Refined and Reviewed.*
Theme 8	Challenges of engaging with EIP	• *Rocky start with services* • *Not feeling heard* • *Rejecting help* • *Trust building* • *Lack of acceptance of diagnosis* • *Hard to speak up*	*Discarded. This theme did not feel relevant to the research question as the aims were focussed on Post-EIP care.*
Theme 9	Perceived improvements and positive experiences	• *Improvements* • *What was good*	*Discarded. This theme was discarded as this was not representative of the whole sample and many of the positive experiences were represented in other themes.*

Stage 5:
Defining and naming themes (Final theme explanations):

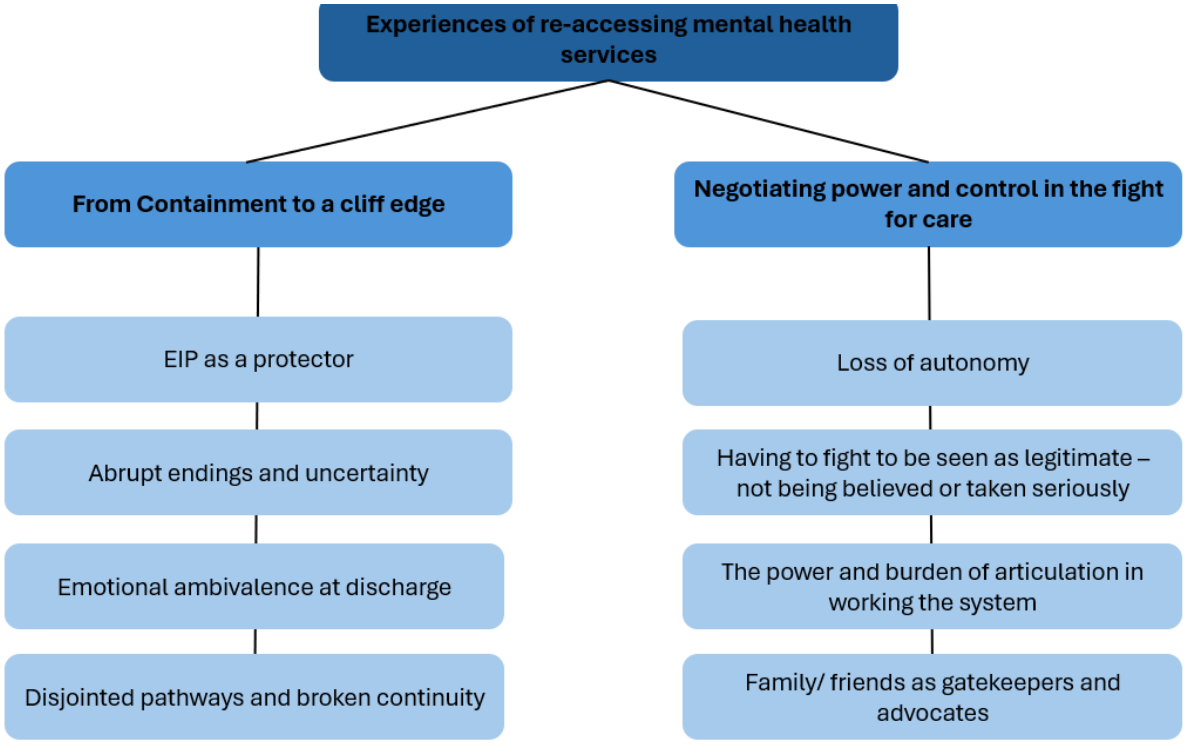
Theme	*Possible Title*	*Subthemes included*	*Description of overarching theme*
Theme 1	*From containment to a cliff edge*	• *EIP as a protector* • *Abrupt endings and uncertainty* • *Emotional ambivalence at discharge* • *Disjointed pathways and broken continuity*	*This theme reflects the stark contrast between the protective, consistent, and relational care experienced within EIP and the abrupt, disorienting experience of discharge. Participants described EIP as a safe, intensive, and holistic service that offered continuity, advocacy, and emotional support. Leaving this environment often came suddenly, with poor communication and limited preparation, generating uncertainty, anxiety, and a sense of loss. Transitions into other services were frequently fragmented, requiring participants to repeat their stories and navigate disjointed pathways, amplifying emotional ambivalence and the feeling of being unprepared for life beyond EIP.*
Theme 2	*Negotiating power and control in the fight for care*	• *Loss of autonomy* • Having to fight to be seen as legitimate: *Not being believed or taken seriously* • *The power or burden of articulation in working the system* • *Family / friends as gatekeepers and advocates*	*This theme captures the burden placed on individuals to navigate an unsupportive and often disempowering system. Participants reported experiencing a loss of control over decisions about their care, needing to constantly advocate for themselves, and being challenged to prove the legitimacy of their needs. The idea that access depends on obedience not need.* *The "one person army" of self-navigation, fear of relapse or negative consequences, and repeated invalidation contributed to exhaustion, hopelessness, and a sense of isolation. Those that are most unwell are least able to do what is needed to access help. Family and friends*

			frequently assumed advocacy roles, highlighting gaps in formal support and reliance on informal networks to access care.
Theme 3	Symptoms, identity and the weight of stigma	• *Identity erosion* • *Stigma and internalised shame*	*This theme reflects the interplay between mental health symptoms, identity challenges, and societal stigma. Participants described diminished self-confidence, self-blame, and fear of being a burden, compounded by experiences of external judgement and internalised shame.*
Theme 4	Falling through the gaps: A system not built for psychosis	• *Rigid systems and procedural harm* • Not fitting the mould *(Eligibility, exclusion and rejection)* • *Resource scarcity and delays* • *Symptoms as a barrier*	*This theme highlights how systemic inflexibility, procedural barriers, and resource limitations create obstacles to accessing effective care. Participants describe re-accessing care as navigating a system that is overstretched, disjointed, and poorly designed for severe mental illness. Participants described cumulative harm from rigid procedures, punitive responses, broken promises, and inconsistent support. Eligibility criteria often excluded those in need, while long wait times, scarce resources, and delays further restricted access. Symptoms of psychosis compounded these barriers, making engagement more challenging. Conversely, services that offered flexibility, individualised adjustments, and rapid responses were valued, underscoring the critical role of adaptability in mitigating systemic shortcomings.*
Theme 5	*Navigating relapse alone: Left to fend for myself*	• *Living without a map (transparency and realism/ not knowing where to turn)* • *Erosion of trust and hope (professional competence/ distrust,*	*Following discharge from Early Intervention in Psychosis services, participants described experiencing relapse in the absence of clear guidance on how or where to seek help. A lack of transparent communication and realistic information about post-discharge care pathways generated*

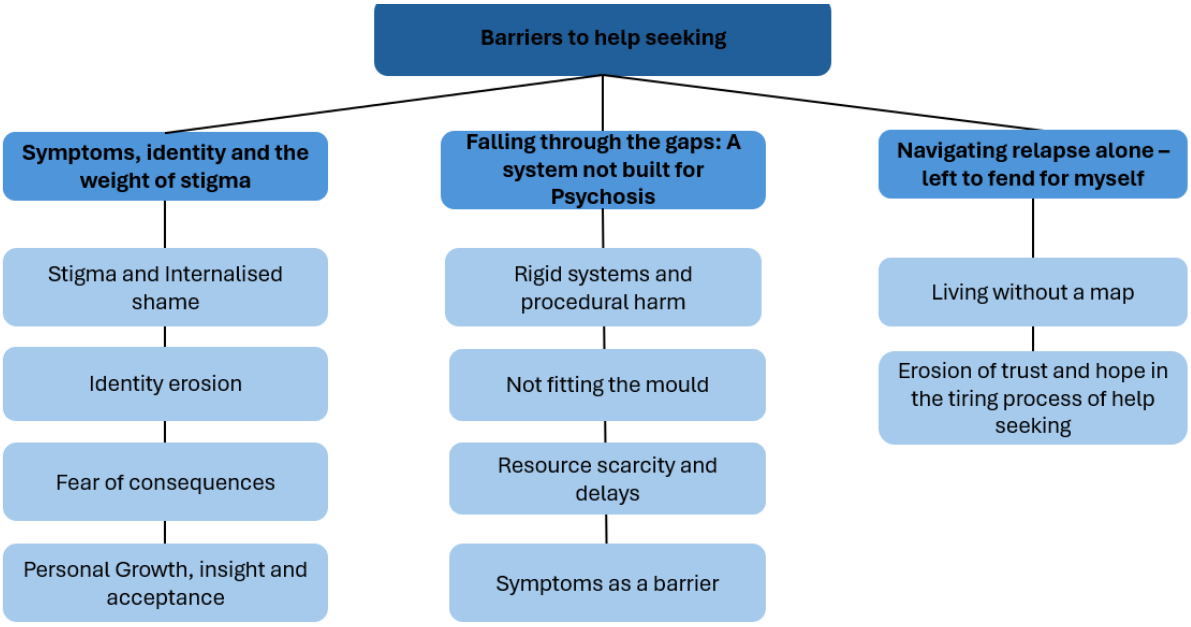
		suspicion and wariness/ hopelessness and giving up on services/ left to fend for myself) • Fear of relapses and consequences	*confusion, anxiety, and vulnerability, leaving individuals uncertain about what support was available or appropriate. Initial difficulties in navigating services were often compounded by encounters perceived as inconsistent, neglectful, or incompetent, which progressively eroded trust in professionals and confidence in services. Over time, repeated disappointments diminished hope that services could offer meaningful help, leading some participants to disengage, give up on seeking support, or rely on self-management as a protective response to anticipated harm. Together, uncertainty, diminished trust, and emotional exhaustion acted as significant barriers to help-seeking following relapse.* *Fear shaped help-seeking behaviour. Participants described avoiding or delaying support due to fear of hospitalisation, relapse consequences, judgement, re-traumatisation, or reopening painful experiences. Past negative encounters amplified this fear, making help-seeking feel risky rather than supportive.*
Theme 6	Safer spaces	• *Peer and family support as refuge* • *Humanistic and respectful care* • *Relational safety through consistency and trust*	*This theme highlights the importance of relational safety, respect, and trust in fostering meaningful engagement. Participants valued environments where they felt heard, known, and treated as human beings rather than diagnoses. When formal care feels unsafe, participants turn to informal support. Peer support offered a non-judgemental, validating space with shared experiences and community, creating a refuge from the power imbalances and inconsistencies of formal services.* *Access is enabled through relationships that reduce fear. Consistent, trusting relationships with professionals further*

reinforced feelings of safety and connection, demonstrating the foundational role of humanistic care in supporting wellbeing.

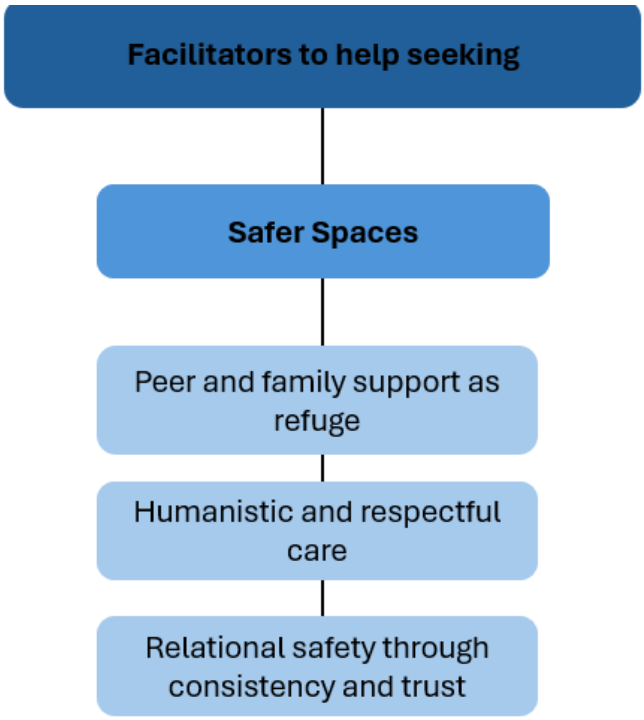
Appendix U: A diagram of themes for Research Question 1



Appendix V: A diagram of themes for Research Question 2 – Barriers to help seeking



Appendix W: A diagram of themes for Research Question 2 – Facilitators to help seeking



Appendix X: Further supporting quotes

Theme 1: From containment to a cliff edge	
1.1 EIP as a protector	*'self-contained like there wasn't this whole annoying referrals between different services…that ends up being such a pain…which made it really easy…seeing the same people consistently for a long time, which is good. (Participant 14)'* *'the early intervention service is quite bespoke…[you have] 1 to 1 with a care coordinator who has a relatively small amount of patients compared to other services…I felt that I was lucky to be accepted. (Participant 17)'* *'it was the complete package, it was the complete service (Participant 45)'*
1.2 Abrupt endings and uncertainty	*'it was very abrupt. I was told, kind of like the 11th hour…it was a real shock to me (Participant 45)'* *'discharge actually came as a surprise from EIP… I just didn't feel like they…included me in the decision about discharge…it just happened (Participant 47)'* 'it was going into the unknown a bit, so there's always that uncertainty. (Participant 43)
1.3 Emotional ambivalence at discharge	*'I think at that stage I just wanted…my own responsibility for things. (Participant 1)'*

	'I'm now going to be independent, I don't need people to surround me with support…I was so excited, ready to explore the world again (Participant 15)' *'I was…nervous, apprehensive. But I was…optimistic. (Participant 2)'* *'I just remember feeling…anxious and…this overwhelming feeling of feeling daunted…where do I go from here? (Participant 45)'* *'felt like I've just been thrown on the scrap heap now (Participant 45)'* *'I was scared, leaving my care Co...and…that close relationship. The idea of losing her was hard initially. (Participant 6)'* *I wasn't prepared to start the whole journey again with somebody else. (Participant 42)'* *'I knew that I would be moving down to a lower level of care…I knew that the early intervention service was…really intensive. (Participant 14)'* *'I had this great service and then that service was downgraded (Participant 45)'* *'It does feel like I get less (Participant 47)'*
1.4 Disjointed pathways and broken continuity	*'There's a, there's a lot of repeating the same information to lots of different people…I don't know how many times since…I've had to tell a story…just takes a long time… and, that's wearing. (Participant 14)'*

	'the biggest problem I experienced was having to now start a fresh (Participant 15)' *'it's just really bad just how all of these professionals just don't work together…it's just not joined up…There was no joined up way of working…Very disjointed. (Participant 45)'* *'And the systems clearly aren't all connected…People don't have access to all the information…that should have been caught on a form as soon as I was referred to the GP…and it just wasn't. I've had to…chase it (Participant 14)'* *'the information is sometimes formally passed on, but to what extent people actually process it and use it in a useful way to support people can be variable. (Participant 43)'* *'I didn't hear anything for a long time, so I didn't know what was happening…nothing was happening…just make you feel like no one wants you…it did…cause more distress by the end because…I just didn't know where I was going, to who, when (Participant 6)'*
Theme 2: Negotiating power and control in the fight for care	
2.1 Loss of autonomy	*'I don't have a voice in what is happening around me (Participant 15)'* *'It's an uncomfortable position to be in…the sort of power dynamic there…because he's in a position of authority,*

	where does that place you? And that's an unhelpful dynamic…it doesn't leave you feeling good (Participant 14)' *'I have to like play by the rules (Participant 2)'* *'That was a decision that was basically made for me. I didn't agree to it or anything. It was a decision that was made unilaterally (Participant 45)'* *'people don't want to give me the option to decide what's best for me or like help me make decisions. It's just like, ok, this is what we advise, do that and then if it's not, then you're called non-compliant. (Participant 2)'* *'I'm not delighted with the outcome, but I'm prepared to accept it. (Participant 47)'*
2.2 Having to fight to be seen as legitimate - Not being believed or taken seriously	*'But you would say that because you don't know how unwell you are. (Participant 1)'* *'I did raise a complaint…they said because I was so psychotic, my events are not matching their events and there's nothing they really can do. Basically, like I've made it all up (Participant 42)'*
2.3 The power or burden of articulation in working the system	*'know the pitfalls as well, but I was confident in knowing that I could get help if I wanted to by saying the right things and pushing. (Participant 17)'* *'Understanding what it is, how best to get what you need. Sadly, that does sometimes involve…having to be strategic, to put it euphemistically, and selective in what*

	you do or don't say to get your need, which is not helpful, that makes you feel dishonest even though you know you're just trying to survive. (Participant 43)'
2.4 Family/ friends as gatekeepers and advocates	*'if it wasn't for the support of family members, there's definitely no way I would have got the support that I needed because I wouldn't have gone to these places for one reason or another. (Participant 45)'* *'there were a few occasions where I did go into the emergency services myself, but there were other times where family members got in touch with the home treatment team. (Participant 45)'* *'my sister, my mum, my best friend, the neighbour, all trying to phone an ambulance, trying and get me sectioned because I was so unwell (Participant 42)'*
Theme 3: Symptoms, identity and the weight of stigma	
3.1 Stigma and internalised shame	*'there being a barrier…a sort of a distance between a doctor and his patient…more like a case to be examined than a person (Participant 14)'* *'they often struggle to see you as human. (Participant 47)'* *'I'm not asking them to care. I'm just asking them to be professional, but for them they just see people like service users as nothing. (Participant 45)'*

	'I know I'm complicated…I'm difficult in some ways…I'm not just a basic patient…if you consider all patients that a GP sees, I'm probably one of the more complicated ones (Participant 14)' *'Because you're judged very much on superficial presentation (Participant 43)'* *'Because the bipolar diagnosis, people always seem to…push you away…too frightened to open up someone with bipolar (Participant 42)'* *'We medicalise and are too scared of psychosis. If we can learn to accept psychosis as a like a normal thing, even that happens to some people and work out ways to like help people live it rather than always need to treat it out of them, that would help. (Participant 47)'*
3.2 Identity erosion	*'I was not scared because I felt confident with the services that I received and I was already empowered with all the processes that we had gone through…I believed in myself to that extent. Not knowing what would happen next, unfortunately I was not that strong. (Participant 15)'* *'I didn't want to kind of fall into that pattern of being a service user in that kind of setup again. (Participant 6)'* *'One of the things about being psychotic is it, like, massively knocks your confidence in yourself because it completely scrambles your sense of self in like a super*

	chaotic way. And then you spend a long time just like rebuilding who you are. So, like you can't advocate for yourself if you don't know who you are anymore. (Participant 47)' *'I don't deserve to be helped. (Participant 14)'* *'Have a relapse and be unwell and fail. (Participant 1)'* *'I feel that a problem shared is a problem doubled and it's just like then everyone else is getting stressed out by your mental state…if I kept it to myself, then at least it was just me dealing with the stress. (Participant 2)'*
3.3 Fear of relapses and consequences	*'feeling like absolutely terrified, like worried about people jumping the gun or assuming I needed to go in the hospital. (Participant 1)'* *I'm not the most help seeking person ever 'cause, I've still got a lot of trauma from being sectioned, so I do tend to try and avoid help seeking where at all possible. (Participant 1)'* *'I was quite scared of the like consequences of seeking help because I really didn't want to go back to hospital. (Participant 47)'* *'I get worried that I could end up back in hospital depending on like what people do…you just don't know…I guess I just don't trust that…you've got no control at all. (Participant 6)'*

3.4 Personal growth, insight and acceptance	*'I think I'm also in a different place myself to accept stuff. (Participant 1)'* *'I've generated a much better understanding, and I'm almost not as scared of myself as I was (Participant 6)'*
Theme 4: Falling through the gaps: A system not built for psychosis	
4.1 Rigid systems and procedural harm	*'Not turning up to appointments and then you end up getting discharged and it's like, well, I'm not turning up because I'm not feeling very well. And then you're discharging me, which is further delaying my ability to access care. (Participant 14)'* *'I've missed one appointment and then and then I'm back to the back of a six month queue (Participant 14)'* *'it's just so hard to access GP for anything. You know there is supposed to be an electronic booking system for appointments, but it's never available. If you ring first thing in the morning for an appointment, you can't get through or you get the message they're not answering appointments. it's nigh impossible to get a response (Participant 43)'* *'If you don't have a smartphone, then you'd have difficulty. I guess if you're not tech friendly then that will be quite irritating. If you're mentally not in a good place and you're having all these barriers, then that would be a barrier to you actually accessing the service. (Participant 17)'*

	'It's all done online. Online forms that only give you 5 minutes to fill out before it crashes or has to be resubmitted. And you have to do it between half eight and eight o clock in the morning, otherwise you don't get anywhere with it. But you can only do one request at a time, so if it's depression or anxiety or bipolar, you have to do three different requests. It's just not simple and not easy at all. (Participant 42)' *'It's, it's problematic sometimes, particularly when you are struggling and you have to ring up at 8:00 AM and if you're not sleeping, you don't want to then have to set an alarm to wake up…holding on the phone lines can be really stressful…to try and explain your problem in a few words is quite tricky. And you don't necessarily want to talk about it over phone when you're in a queue of like 30 people. (Participant 6)'*
4.2 Not fitting the mould	*'They said they couldn't help with the bipolar. They said that my conditions were too severe for them to be able to manage. (Participant 42)'* *'I can't access any of that, because it's all during working hours…Like, everything is for the assumption that you're unemployed (Participant 2)'* *'being told either I'm not severe enough or I'm too severe. (Participant 2)'*

	'if you don't fit into this or that box, they don't want anything to do with you. It's quite concerning. (Participant 43)' *'being in a rock and a hard place…because of their rigid rules…you're open to their services, so you can't be open to our services. You can't do two things at the same time. (Participant 45)'*
4.3 Resource scarcity and delays	'I end up falling through the cracks more than not often with these services…the NHS is cracking…everyone's stretched (Participant 14)' 'I have experienced…delays to care because somebody hasn't done something or…because they left…it can lead to delays of months…you expect there to be a month long wait often and then if it's many months then it's like well, is it actually just normal…eventually you do chase it up… the reality of using the NHS nowadays, but it doesn't mean it doesn't suck (Participant 14)' 'in that period of time where you've kind of waited, things can get a lot worse (Participant 14)' 'There are long waiting times, delayed responsivity. So, it can seem a cold and lonely process. (Participant 43)' 'it's NHS…the waiting lists are huge, they can only see you for a short period of time…although it was very helpful…it just wasn't enough. (Participant 45)'

	‘there's not enough knowledge, not enough staff (Participant 42)’ ‘the doctors don't know enough about mental health or they haven't got the funding to know more or train more…that's just inadequate. (Participant 42)’ *‘you feel like, you know, far more than they do. They don't have the competence or the understanding…It sounds terrible and I hate saying it, but I don't have any confidence in GPs competence. (Participant 43)’* *‘they're the only one that's available so deal with it. (Participant 14)’* *‘care is provided more on the basis of they're doing the best that they can rather than they're doing the best for the patient. (Participant 14)’* *‘because they're the only one…just put up with it because I need help. And this is the only help I'm going to have. So I've just got to kind of get on with it. (Participant 14)’* *‘I need help right now. If not, I don't know what would happen next, so I decided I can't wait, let me go and seek help. That's how I ended up seeking private help. (Participant 15)’* *‘There was an offer of group therapy…I'll sign up for that then…it would be quicker for me to access…anything would be helpful at the time. (Participant 17)’*

4.4 Symptoms as a barrier	*'Having my condition made it more challenging because I was trying to explain myself and people are not understanding me…end up not getting the best solution. (Participant 15)'* *'when you do have psychosis, you do go through a period of paranoia. And the thing about people listening in or just everyone being aware of your thoughts, things like that. And the fact that you know, it's just another thing to remember. And so they all add to frustrations and when you're on a short fuse anyway because your mental health isn't at its best, then you know it's another thing to kind of add to the mix really, isn't it? (Participant 17)'* *'there's an assumption that somebody would be behaving in the way you'd expect any other person to be acting…it would be reasonable to suggest that there should be a different, sort of base assumption about these sorts of things. (Participant 14)'* *'I was trying to ask her to write information down for me because I'd struggle to remember it and she's looked really unimpressed that I'd asked her to do that. Not very good with the adjustments. (Participant 6)'*
Theme 5: Navigating relapse alone - left to fend for myself	

5.1 Living without a map	*'having a good situational awareness of service provision and issues…having that information does mitigate against uncertainties (Participant 43)'* *'I want to be proactive and I'm trying to be proactive, but then I feel like anytime I've tried to be proactive about my health, I've had doors shut in my face (Participant 2)'* *'I did experience a relapse after being discharged….this made me lose confidence in their services…who should I seek support? How should I handle it…I had no such knowledge with me…it ended up affecting me more as compared to even to the first time (Participant 15)'* *'I have to go to different places for different support…it's quite difficult. So before everything was under one roof, now everything scattered. (Participant 45)'* *'people are kind of like just left on their own devices after they've been discharged, it's really bad. (Participant 45)'* *'had to find out about this service on my own, I've had to sort out myself and I've had to find it myself. (Participant 45)'*
5.2 Erosion of trust and hope in the tiring process of help seeking	*'I just don't have the energy to go through that process again now, even if it is just to make a self-referral. So I'm just thinking you know I can't go through that again. (Participant 45)'*

	'the safest way for me to protect myself is to rely and build on my own resources and have confidence in myself. (Participant 43)' *'I should be getting that help from sort of statutory services because actually I do have like a severe and enduring mental illness…I can't do that. And I've kind of given up and I've lost trust. (Participant 2)'* *'I've kind of given up on…getting anything useful from services (Participant 2)'* *'in general services cannot be relied upon to support you when you most need them in the way you need them to support you (Participant 43)'*
Theme 6: Safer spaces	
6.1 Peer and family support as a refuge	*'But it's not like they're demanding to know, it's very much, you let us know as much as you want. Which I guess you don't always get in services, It's more like we need to know this. Tell us this…So I guess just having that autonomy to share what I want and…when I want. (Participant 6)'* *'They can't section…more reputable…they know your broader story and the context of your life and maybe aren't shy and having difficult conversations. (Participant 1)'* *'Something about needing someone who can relate to kind of how you're feeling and the things that you're*

	going through that makes it more helpful and maybe more kind of desirable to reach out to them for support. (Participant 14)' *'it's that peer contact or that warm contact, that relational contact…that gives you a boost in your own ability to cope and that self-belief…learning from others lived experience and that feeling that you're not alone. (Participant 43)'* *'I just found it a safe space, I really enjoyed it and you can just talk about anything and everything…you're not going to be judged or…ostracised. (Participant 45)'* *'I almost trust that more than services in a way sometimes because it's a bit off the book…people kind of know you in different capacity. (Participant 6)'*
6.2 Humanistic and respectful care	'really good to just be able to be super open about that and like not feel judged. (Participant 14)' 'I felt he just respected my view on things. (Participant 1)' 'I could differentiate between their experiences of illness and them as individuals and that gave me the human validation to recognise I wasn't just an ill entity, I was a human with an illness. (Participant 43)'
6.3 Relational Safety through consistency and trust	*'And if I was unwell then I'd want somebody that knew me rather than a person that you know, has never kind of met me before. (Participant 17)'*

	'He was really down to Earth. We had a very like honest and open conversations…he was really realistic was something I really liked about him…it felt like I was getting the truth, or at least his understanding of the truth…there was no friction between us (Participant 14)' *'The rapport was actually really helpful. Made me feel a bit more confident and empowered. (Participant 1)'* *'a huge part of my Psychosis was I didn't trust people. So yeah, it's really important to have people see that you can trust them. (Participant 1)'* *'If I know the professional themselves that I've met them before…Ill probably open up to them but if hadn't met them before, I probably wouldn't. (Participant 42)'* *'mutual awareness and understanding and relational connection. That's what I find helpful. feeling connected and making new connections which are positive, so that really supports me to be honest. (Participant 43)'* *'it's just vital with mental health that who you're dealing with knows you. (Participant 47)'*

Appendix Y: Guidelines for Schizophrenia Research Journal

About the journal

Aims and scope

An International Multidisciplinary Journal of the Schizophrenia International Research Society

As an official journal of the Schizophrenia International Research Society (SIRS) *Schizophrenia Research* is THE journal of choice for international researchers and clinicians to share their work with the global schizophrenia research community. More than 6000 institutes have online or print (or both) access to this journal - the largest specialist journal in the field, with the largest readership! *Schizophrenia Research*'s time to first decision is as fast as 6 weeks and its publishing speed is as fast as 4 weeks until online publication (corrected proof/Article in Press) after acceptance and 14 weeks from acceptance until publication in a printed issue.

The journal publishes novel papers that really contribute to understanding the biology and treatment of schizophrenic disorders; *Schizophrenia Research* brings together biological, clinical and psychological research in order to stimulate the synthesis of findings from all disciplines involved in improving patient outcomes in schizophrenia.

Manuscripts with a focus on cognition in schizophrenia can be submitted to the journal's open access companion title, *Schizophrenia Research: Cognition*.

Article types

(1) Full-length papers: 4,000 words (excluding tables, figures and references).

(2) Review articles: up to 5,000 words.

(3) Invited comments or hypotheses (no abstract; less than 1,000 words).

(4) Editorials.

(5) Schizophrenia meeting reviews: solicited and/or submitted.

(6) Book reviews (less than 1,000 words).

(7) Letters to the Editor: written in response to recent content in *Schizophrenia Research*, as well as letters with independent content (1,000 words, unstructured (no side headings) and with no abstract. Up to 10 references will be allowed. Additional tables or figures may be included as supplementary material).

Peer review

This journal follows a single anonymized review process. Your submission will initially be assessed by our editors to determine suitability for publication in this journal. If your submission is deemed suitable, it will typically be sent to a minimum of two reviewers for an independent expert assessment of the scientific quality. The decision as to whether your article is accepted or rejected will be taken by our editors.

Read more about peer review.

Our editors are not involved in making decisions about papers which:

- they have written themselves.
- have been written by family members or colleagues.
- relate to products or services in which they have an interest.

Any such submissions will be subject to the journal's usual procedures and peer review will be handled independently of the editor involved and their research group.

Read more about editor duties.

Authors may submit a formal appeal request to the editorial decision, provided it meets all the requirements and follows the procedure outlined in Elsevier’s Appeal Policy. Only one appeal per submission will be considered and the appeal decision will be final.

Special issues and article collections

The peer review process for special issues and article collections follows the same process as outlined above for regular submissions, except, a guest editor may send the submissions out to the reviewers and may recommend a decision to the journal editor. The journal editor oversees the peer review process of all special issues and article collections to ensure the high standards of publishing ethics and responsiveness are respected and is responsible for the final decision regarding acceptance or rejection of articles.

Open access

We refer you to our open access information page to learn about open access options for this journal.

Ethics and policies

Ethics in publishing

Authors must follow ethical guidelines stated in Elsevier's Publishing Ethics Policy.

Submission declaration

When authors submit an article to an Elsevier journal it is implied that:

- the work described has not been published previously except in the form of a preprint, an abstract, a published lecture, academic thesis or registered report. See our policy on multiple, redundant or concurrent publication.
- the article is not under consideration for publication elsewhere.
- the article's publication is approved by all authors and tacitly or explicitly by the responsible authorities where the work was carried out.
- if accepted, the article will not be published elsewhere in the same form, in English or in any other language, including electronically, without the written consent of the copyright-holder.

To verify compliance with our journal publishing policies, we may check your manuscript with our screening tools.

Authorship

All authors should have made substantial contributions to all of the following:

1. The conception and design of the study, or acquisition of data, or analysis and interpretation of data.
2. Drafting the article or revising it critically for important intellectual content.
3. Final approval of the version to be submitted.

Authors should appoint a corresponding author to communicate with the journal during the editorial process. All authors should agree to be accountable for all aspects of the work to ensure that the questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Changes to authorship

The editors of this journal generally will not consider changes to authorship once a manuscript has been submitted. It is important that authors carefully consider the authorship list and order of authors and provide a definitive author list at original submission.

The policy of this journal around authorship changes:

- All authors must be listed in the manuscript and their details entered into the submission system.
- Any addition, deletion or rearrangement of author names in the authorship list should only be made prior to acceptance, and only if approved by the journal editor.

- Requests to change authorship should be made by the corresponding author, who must provide the reason for the request to the journal editor with written confirmation from all authors, including any authors being added or removed, that they agree with the addition, removal or rearrangement.
- All requests to change authorship must be submitted using this form. Requests which do not comply with the instructions outlined in the form will not be considered.
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- Publication of the manuscript may be paused while a change in authorship request is being considered.
- Any authorship change requests approved by the journal editor will result in a corrigendum if the manuscript has already been published.
- Any unauthorized authorship changes may result in the rejection of the article, or retraction, if the article has already been published.

Declaration of competing interests

All authors must disclose any financial and personal relationships with other people or organizations that could inappropriately influence or bias their work. Examples of potential competing interests include:

- Employment
- Consultancies
- Stock ownership
- Honoraria
- Paid expert testimony
- Patent applications or registrations
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- Affiliation with the journal as an Editor or Advisory Board Member

The declarations tool should always be completed.

Authors with a journal affiliation to declare should enter the following text under "Other Activities" within the declarations tool and should inform the journal and publisher prior to completing the submission process:

Given their role as [insert journal role title], [insert your name] had no involvement in the peer-review of this article and has no access to information regarding its peer-

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Authors with no competing interests to declare should select the option "I have nothing to declare".

The resulting Word document containing your declaration should be uploaded at the "attach/upload files" step in the submission process. It is important that the Word document is saved in the .doc/.docx file format. Author signatures are not required.

Funding sources

Authors must disclose any funding sources who provided financial support for the conduct of the research and/or preparation of the article. The role of sponsors, if any, should be declared in relation to the study design, collection, analysis and interpretation of data, writing of the report and decision to submit the article for publication. If funding sources had no such involvement this should be stated in your submission.

List funding sources in this standard way to facilitate compliance to funder's requirements:

Funding: This work was supported by the National Institutes of Health [grant numbers xxxx, yyyy]; the Bill & Melinda Gates Foundation, Seattle, WA [grant number zzzz]; and the United States Institutes of Peace [grant number aaaa].

It is not necessary to include detailed descriptions on the program or type of grants, scholarships and awards. When funding is from a block grant or other resources available to a university, college, or other research institution, submit the name of the institute or organization that provided the funding.

If no funding has been provided for the research, it is recommended to include the following sentence:

This research did not receive any specific grant from funding agencies in the public, commercial, or not-for-profit sectors.

Declaration of generative AI use

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- Ensuring the use of any tools or sources, AI-based or otherwise, is made clear and transparent to readers. If AI Tools have been used, we require a disclosure statement upon submission; please see example below.
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- Statement: *During the preparation of this work the author(s) used [NAME OF TOOL / SERVICE] in order to [REASON]. After using this tool/service, the author(s) reviewed and edited the content as needed and take(s) full responsibility for the content of the published article.*

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Use of inclusive language

Inclusive language acknowledges diversity, conveys respect to all people, is sensitive to differences, and promotes equal opportunities. Authors should ensure their work uses inclusive language throughout and contains nothing which might imply one individual is superior to another on the grounds of:

- age
- gender
- race
- ethnicity
- culture
- sexual orientation
- disability or health condition

We recommend avoiding the use of descriptors about personal attributes unless they are relevant and valid. Write for gender neutrality with the use of plural nouns

("clinicians, patients/clients") as default. Wherever possible, avoid using "he, she," or "he/she."

No assumptions should be made about the beliefs of readers and writing should be free from bias, stereotypes, slang, reference to dominant culture and/or cultural assumptions.

These guidelines are meant as a point of reference to help you identify appropriate language but are by no means exhaustive or definitive.

Reporting sex- and gender-based analyses

There is no single, universally agreed-upon set of guidelines for defining sex and gender. We offer the following guidance:

- Sex and gender-based analyses (SGBA) should be integrated into research design when research involves or pertains to humans, animals or eukaryotic cells. This should be done in accordance with any requirements set by funders or sponsors and best practices within a field.
- Sex and/or gender dimensions of the research should be addressed within the article or declared as a limitation to the generalizability of the research.
- Definitions of sex and/or gender applied should be explicitly stated to enhance the precision, rigor and reproducibility of the research and to avoid ambiguity or conflation of terms and the constructs to which they refer.

We advise you to read the Sex and Gender Equity in Research (SAGER) guidelines and the SAGER checklist (PDF) on the EASE website, which offer systematic approaches to the use of sex and gender information in study design, data analysis, outcome reporting and research interpretation.

For further information we suggest reading the rationale behind and recommended use of the SAGER guidelines.

Definitions of sex and/or gender

We ask authors to define how sex and gender have been used in their research and publication. Some guidance:

- Sex generally refers to a set of biological attributes that are associated with physical and physiological features such as chromosomal genotype, hormonal levels, internal and external anatomy. A binary sex categorization (male/female) is usually designated at birth ("sex assigned at birth") and is in most cases based solely on the visible external anatomy of a newborn. In

reality, sex categorizations include people who are intersex/have differences of sex development (DSD).

- Gender generally refers to socially constructed roles, behaviors and identities of women, men and gender-diverse people that occur in a historical and cultural context and may vary across societies and over time. Gender influences how people view themselves and each other, how they behave and interact and how power is distributed in society.

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- Maps: Readers should be able to locate any study areas shown within maps using common mapping platforms. Maps should only show the area actually studied and authors should not include a location map which displays a larger area than the bounding box of the study area. Authors should add a note clearly stating that "*map lines delineate study areas and do not necessarily depict accepted national boundaries*". During the review process, Elsevier's editors may request authors to change maps if these guidelines are not followed.
- Institutional affiliations: Authors should use either the full, standard title of their institution or the standard abbreviation of the institutional name so that the institutional name can be independently verified for research integrity purposes.

Delayed publication

If you need to delay the publication of your article for any reason, please contact the editorial office of the journal or our Journal Article Publishing Support Center at the earliest possible opportunity. While we will try to ensure that your article is not published before a certain date if you make your request on a timely basis, we cannot guarantee this. Please also note that once the agreed period of delay has expired the article may be published at any time thereafter.

Writing and formatting

File format

We ask you to provide editable source files for your entire submission (including figures, tables and text graphics). Some guidelines:

- Save files in an editable format, using the extension .doc/.docx for Word files and .tex for LaTeX files. A PDF is not an acceptable source file.
- Format Word files in a single-column layout. Double-column formatting is only permitted for LaTeX submissions.
- Remove any strikethrough and underlined text from your manuscript, unless it has scientific significance related to your article.
- Use spell-check and grammar-check functions to avoid errors.

We advise you to read our Step-by-step guide to publishing with Elsevier.

Title page

You are required to include the following details in the title page information:

- Article title. Article titles should be concise and informative. Please avoid abbreviations and formulae, where possible, unless they are established and widely understood, e.g. DNA.
- Author names. Provide the given name(s) and family name(s) of each author. The order of authors should match the order in the submission system. Carefully check that all names are accurately spelled. If needed, you can add your name between parentheses in your own script after the English transliteration.
- Affiliations. Add affiliation addresses, referring to where the work was carried out, below the author names. Indicate affiliations using a lower-case superscript letter immediately after the author's name and in front of the corresponding address. Ensure that you provide the full postal address of each affiliation, including the country name and, if available, the email address of each author.

- Corresponding author. Clearly indicate who will handle correspondence for your article at all stages of the refereeing and publication process and also post-publication. This responsibility includes answering any future queries about your results, data, methodology and materials. It is important that the email address and contact details of your corresponding author are kept up to date during the submission and publication process.
- Present/permanent address. If an author has moved since the work described in your article was carried out, or the author was visiting during that time, a "present address" (or "permanent address") can be indicated by a footnote to the author's name. The address where the author carried out the work must be retained as their main affiliation address. Use superscript Arabic numerals for such footnotes.

Abstract

You are required to provide a concise and factual abstract which does not exceed 250 words. The abstract should briefly state the purpose of your research, principal results and major conclusions. Some guidelines:

- Abstracts must be able to stand alone as abstracts are often presented separately from the article.
- Avoid references. If any are essential to include, ensure that you cite the author(s) and year(s).
- Avoid non-standard or uncommon abbreviations. If any are essential to include, ensure they are defined within your abstract at first mention.

Keywords

You are required to provide 1 to 7 keywords for indexing purposes. Keywords should be written in English. Please try to avoid keywords consisting of multiple words (using "and" or "of").

We recommend that you only use abbreviations in keywords if they are firmly established in the field.

Graphical abstract

You are encouraged to provide a graphical abstract at submission.

The graphical abstract summarizes the contents of your article in a concise, pictorial, professional form, highlighting important aspects of the research. It is designed to appeal to an interdisciplinary audience, and draw more attention to your online article. Some guidelines:

- Ensure you have obtained the necessary permission to include any third party owned material in a graphical abstract.
- Use of generative AI or AI-assisted tools in the production of graphical abstracts must align with Elsevier's GenAI Policies for Journals.
- Submit your graphical abstract as a separate file in the online submission system.
- Ensure the image is 531 x 1328 pixels (h x w) or proportionally more, and is readable at a size of 5 x 13 cm.
- Preferred file types for graphical abstracts are TIFF, EPS, PDF or MS Office files.

More information, examples and a template can be found in the graphical abstract guidelines.

Math formulae

- Submit math equations as editable text, not as images.
- Present simple formulae in line with normal text, where possible.
- Use the solidus (/) instead of a horizontal line for small fractional terms such as X/Y.
- Present variables in italics.
- Denote powers of e by exp.
- Display equations separately from your text, numbering them consecutively in the order they are referred to within your text.

Tables

Tables must be submitted as editable text, not as images. Some guidelines:

- Place tables next to the relevant text or on a separate page(s) at the end of your article.
- Cite all tables in the manuscript text.
- Number tables consecutively according to their appearance in the text.
- Please provide captions along with the tables.
- Place any table notes below the table body.
- Avoid vertical rules and shading within table cells.

We recommend that you use tables sparingly, ensuring that any data presented in tables is not duplicating results described elsewhere in the article.

Figures, images and artwork

Figures, images, artwork, diagrams and other graphical media must be supplied as separate files along with the manuscript. We recommend that you read our detailed artwork and media instructions. Some excerpts:

When submitting artwork:

- Cite all images in the manuscript text.
- Number images according to the sequence they appear within your article.
- Submit each image as a separate file using a logical naming convention for your files (for example, Figure_1, Figure_2 etc).
- Text graphics may be embedded in the text at the appropriate position. If you are working with LaTeX, text graphics may also be embedded in the file.

Figure captions

All images must have a caption. A caption should consist of a brief title (not displayed on the figure itself) and a description of the image. We advise you to keep the amount of text in any image to a minimum, though any symbols and abbreviations used should be explained.

Read how to add captions to your submission here.

Artwork formats

When your artwork is finalized, "save as" or convert your electronic artwork to the formats listed below taking into account the given resolution requirements for line drawings, halftones, and line/halftone combinations:

- Vector drawings: Save as EPS or PDF files embedding the font or saving the text as "graphics."
- Color or grayscale photographs (halftones): Save as TIFF, JPG or PNG files using a minimum of 300 dpi (for single column width: min. 1063 pixels, full page width: 2244 pixels).
- Bitmapped line drawings: Save as TIFF, JPG or PNG files, using a minimum of 1000 dpi (for single column width: min. 3543 pixels, full page width: 7480 pixels).
- Combinations bitmapped line/halftones (color or grayscale): Save as TIFF, JPG or PNG files using a minimum of 500 dpi (for single column: min. 1772 pixels, full page width: 3740 pixels).

Please do not submit:

- Files that are too low in resolution.

- Disproportionally large images compared to font size, as text may become unreadable.

Color artwork

If you submit usable color figures with your accepted article, we will ensure that they appear in color online.

Please ensure that color images are accessible to all, including those with impaired color vision. Learn more about color and web accessibility.

Generative AI and Figures, images and artwork

Please read our policy on the use of generative AI and AI-assisted tools in figures, images and artwork, which can be found in Elsevier's GenAI Policies for Journals.

This policy states:

- We do not permit the use of Generative AI or AI-assisted tools to create or alter images in submitted manuscripts.
- The only exception is if the use of AI or AI-assisted tools is part of the research design or methods (for example, in the field of biomedical imaging). If this is the case, such use must be described in a reproducible manner in the methods section, including the name of the model or tool, version and extension numbers, and manufacturer.
- The use of generative AI or AI-assisted tools in the production of artwork such as for graphical abstracts is not permitted. The use of generative AI in the production of cover art may in some cases be allowed, if the author obtains prior permission from the journal editor and publisher, can demonstrate that all necessary rights have been cleared for the use of the relevant material, and ensures that there is correct content attribution.

Supplementary material

We encourage the use of supplementary materials such as applications, images and sound clips to enhance research. Some guidelines:

- Supplementary material should be accurate and relevant to the research.
- Cite all supplementary files in the manuscript text.
- Submit all supplementary materials at the same time as your manuscript.
- Include a concise, descriptive caption for each supplementary file, describing its content.
- After submission supplementary files can only be added or replaced in the revision stage of the editorial process.

- Be aware that all supplementary materials provided will appear online in the exact same way as received. These files will not be checked, formatted or typeset by the production team.

Video

This journal accepts video material and animation sequences to support and enhance your scientific research. We encourage you to include links to video or animation files within articles. Some guidelines:

- When including video or animation file links within your article, refer to the video or animation content by adding a note in your text where the file should be placed.
- Clearly label files ensuring the given file name is directly related to the file content.
- Provide files in one of our recommended file formats. Files should be within our preferred maximum file size of 150 MB per file, 1 GB in total.
- Provide "stills" for each of your files. These will be used as standard icons to personalize the link to your video data. You can choose any frame from your video or animation or make a separate image.
- Provide descriptive text in your manuscript to refer to the video content. This text helps ensure accessibility for visually impaired readers who rely on descriptive information. For journals publishing in print this is also essential, as video and animation files cannot be embedded in the print version.

We publish all video and animation files supplied in the electronic version of your article.

For more detailed instructions, we recommend that you read our guidelines on submitting video content to be included in the body of an article.

Research data

We are committed to supporting the storage of, access to and discovery of research data, and our research data policy sets out the principles guiding how we work with the research community to support a more efficient and transparent research process.

Research data refers to the results of observations or experimentation that validate research findings, which may also include software, code, models, algorithms, protocols, methods and other useful materials related to the project.

Please read our guidelines on sharing research data for more information on depositing, sharing and using research data and other relevant research materials.

Research data deposit and citation

For this journal, Option A instructions from our research data guidelines apply. This means that you are encouraged to:

- Deposit your research data in a relevant data repository.
- Cite this dataset in your article.

Data linking

Linking to the data underlying your work increases your exposure and may lead to new collaborations. It also provides readers with a better understanding of the described research.

If your research data has been made available in a data repository there are a number of ways your article can be linked directly to the dataset:

- Provide a link to your dataset when prompted during the online submission process.
- For some data repositories, a repository banner will automatically appear next to your published article on ScienceDirect.
- You can also link relevant data or entities within the text of your article through the use of identifiers. Use the following format: Database: 12345 (e.g. TAIR: AT1G01020; CCDC: 734053; PDB: 1XFN).

Learn more about linking research data and research articles in ScienceDirect.

Research Elements

This journal enables the publication of research objects (e.g. data, methods, protocols, software and hardware) related to original research in Elsevier's Research Elements journals.

Research Elements are peer-reviewed, open access journals which make research objects findable, accessible and reusable. By providing detailed descriptions of objects and their application with links to the original research article, your research objects can be placed into context within your article.

You will be alerted during submission to the opportunity to submit a manuscript to one of the Research Elements journals. Your Research Elements article can be prepared by you, or by one of your collaborators.

Co-submission of related data, methods or protocols

You are encouraged to publish a description of your research data, methods, or protocols related to your regular article as a co-submission article in *Data in Brief* or *MethodsX*.

This co-submission can be submitted at the same time as your regular manuscript submission to this journal. If both your regular and co-submitted manuscripts are accepted for publication, they will be linked together on ScienceDirect, thereby promoting research reproducibility, interoperability, and open science.

- Prepare a separate manuscript describing your research data, methods, or protocols using the mandatory templates from *Data in Brief* or in *MethodsX*.
- Submit this co-submission alongside your regular manuscript as a separate submission item; on the 'Attach files' page in Editorial Manager, after which it will be automatically forwarded to the *Data in Brief* or *MethodsX* and assigned an editor.
- For associated Article Processing Charge (APC) details, please visit:
    - MethodsX
    - Data in Brief

Please note: Due to the automated process of submitting to *Data in Brief* or *MethodsX*, only after acceptance will you be presented with a personalized OA Article Publishing Charge based on your individual context (your country, institutional affiliation, and any society membership for example).

Please visit co-submission Researcher Support page for more information on how to submit a co-submission.

Article structure

Article sections

- Divide your article into clearly defined and numbered sections. Number subsections 1.1 (then 1.1.1, 1.1.2, ...), then 1.2, etc.
- Use the numbering format when cross-referencing within your article. Do not just refer to "the text."
- You may give subsections a brief heading. Headings should appear on a separate line.
- Do not include the article abstract within section numbering.

Theory and calculation

The theory section should lay the foundation for further work by extending the background you provided in the introduction to your article. The calculation section should represent a practical development from a theoretical basis.

Footnotes

We advise you to use footnotes sparingly. If you include footnotes in your article, ensure that they are numbered consecutively.

You may use system features that automatically build footnotes into text. Alternatively, you can indicate the position of footnotes within the text and present them in a separate section at the end of your article.

Acknowledgements

Include any individuals who provided you with help during your research, such as help with language, writing or proof reading, in the acknowledgements section. Acknowledgements should be placed in a separate section which appears directly before the reference list. Do not include acknowledgements on your title page, as a footnote to your title, or anywhere else in your article other than in the separate acknowledgements section.

Author contributions: CRediT

Corresponding authors are required to acknowledge co-author contributions using CRediT (Contributor Roles Taxonomy) roles:

- Conceptualization
- Data curation
- Formal analysis
- Funding acquisition
- Investigation
- Methodology
- Project administration
- Resources
- Software
- Supervision
- Validation
- Visualization
- Writing – original draft
- Writing – review and editing

Not all CRediT roles will apply to every manuscript and some authors may contribute through multiple roles.

We advise you to read more about CRediT and view an example of a CRediT author statement.

Appendices

We ask you to use the following format for appendices:

- Identify individual appendices within your article using the format: A, B, etc.
- Give separate numbering to formulae and equations within appendices using formats such as Eq. (A.1), Eq. (A.2), etc. and in subsequent appendices, Eq. (B.1), Eq. (B. 2) etc. In a similar way, give separate numbering to tables and figures using formats such as Table A.1; Fig. A.1, etc.

References

References within text

Any references cited within your article should also be present in your reference list and vice versa. Some guidelines:

- References cited in your abstract must be given in full.
- We recommend that you do not include unpublished results and personal communications in your reference list, though you may mention them in the text of your article.
- Any unpublished results and personal communications included in your reference list must follow the standard reference style of the journal. In substitution of the publication date add "unpublished results" or "personal communication."
- References cited as "in press" imply that the item has been accepted for publication.

Linking to cited sources will increase the discoverability of your research.

Before submission, check that all data provided in your reference list are correct, including any references which have been copied. Providing correct reference data allows us to link to abstracting and indexing services such as Scopus, Crossref and PubMed. Any incorrect surnames, journal or book titles, publication years or pagination within your references may prevent link creation.

We encourage the use of Digital Object Identifiers (DOIs) as reference links as they provide a permanent link to the electronic article referenced.

Reference style

All citations in the text should refer to:

- Single author: the author's name (without initials, unless there is ambiguity) and the year of publication.
- Two authors: both authors' names and the year of publication.
- Three or more authors: first author's name followed by 'et al.' and the year of publication.

Citations can be made directly (or parenthetically). Groups of references can be listed either first alphabetically, then chronologically, or vice versa. Examples: "as demonstrated (Allan, 2020a, 2020b; Allan and Jones, 2019)" or "as demonstrated (Jones, 2019; Allan, 2020). Kramer et al. (2023) have recently shown".

The list of references should be arranged alphabetically and then chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.

Abbreviate journal names according to the List of Title Word Abbreviations (LTWA).

Examples:

Reference to a journal publication:

Van der Geer, J., Handgraaf, T., Lupton, R.A., 2020. The art of writing a scientific article. J. Sci. Commun. 163, 51–59. https://doi.org/10.1016/j.sc.2020.00372.

Reference to a journal publication with an article number:

Van der Geer, J., Handgraaf, T., Lupton, R.A., 2022. The art of writing a scientific article. Heliyon. 19, e00205. https://doi.org/10.1016/j.heliyon.2022.e00205.

Reference to a book:

Strunk Jr., W., White, E.B., 2000. The Elements of Style, fourth ed. Longman, New York.

Reference to a chapter in a book:

Mettam, G.R., Adams, L.B., 2023. How to prepare an electronic version of your article, in: Jones, B.S., Smith, R.Z. (Eds.), Introduction to the Electronic Age. E-Publishing Inc., New York, pp. 281–304.

Reference to a website:

Cancer Research UK, 2023. Cancer statistics reports for the UK. http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/ (accessed 13 March 2023).

Reference to a dataset:

Oguro, M., Imahiro, S., Saito, S., Nakashizuka, T., 2015. Mortality data for Japanese oak wilt disease and surrounding forest compositions [dataset]. Mendeley Data, v1. https://doi.org/10.17632/xwj98nb39r.1.

Reference to software:

Coon, E., Berndt, M., Jan, A., Svyatsky, D., Atchley, A., Kikinzon, E., Harp, D., Manzini, G., Shelef, E., Lipnikov, K., Garimella, R., Xu, C., Moulton, D., Karra, S., Painter, S., Jafarov, E., & Molins, S., 2020. Advanced Terrestrial Simulator (ATS) v0.88 (Version 0.88) [software]. Zenodo. https://doi.org/10.5281/zenodo.3727209.

Web references

When listing web references, as a minimum you should provide the full URL and the date when the reference was last accessed. Additional information (e.g. DOI, author names, dates or reference to a source publication) should also be provided, if known.

You can list web references separately under a new heading directly after your reference list or include them in your reference list.

Data references

We encourage you to cite underlying or relevant datasets within article text and to list data references in the reference list.

When citing data references, you should include:

- author name(s)
- dataset title
- data repository
- version (where available)
- year
- global persistent identifier

Add [dataset] immediately before your reference. This will help us to properly identify the dataset. The [dataset] identifier will not appear in your published article.

Preprint references

We ask you to mark preprints clearly. You should include the word "preprint" or the name of the preprint server as part of your reference and provide the preprint DOI.

Where a preprint has subsequently become available as a peer-reviewed publication, use the formal publication as your reference.

If there are preprints that are central to your work or that cover crucial developments in the topic, but they are not yet formally published, you may reference the preprint.

Reference management software

Most Elsevier journals have their reference template available in popular reference management software products. These include products that support Citation Style Language (CSL) such as Mendeley Reference Manager.

If you use a citation plug-in from these products, select the relevant journal template and all your citations and bibliographies will automatically be formatted in the journal style. We advise you to remove all field codes before submitting your manuscript to any reference management software product.

If a template is not available for this journal, follow the format given in examples in the reference style section of this Guide for Authors.

Submitting your manuscript

Submission checklist

Before completing the submission of your manuscript, we advise you to read our submission checklist:

- One author has been designated as the corresponding author and their full contact details (email address, full postal address and phone numbers) have been provided.
- All files have been uploaded, including keywords, figure captions and tables (including a title, description and footnotes) included. This includes any supplementary materials and videos.
- Spelling and grammar checks have been carried out.
- All references in the article text are cited in the reference list and vice versa.
- Permission has been obtained for the use of any copyrighted material from other sources, including the Web.
- For open access articles, all authors understand that they are responsible for payment of the article publishing charge (APC) if the manuscript is accepted. Payment of the APC may be covered by the corresponding author's institution, or the research funder.

After receiving a final decision

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If your manuscript is more suitable for an alternative journal published by Elsevier, you may receive an email asking you to consider transferring your manuscript via the Elsevier Article Transfer Service.

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Authors will be asked to complete a publishing agreement after acceptance. The corresponding author will receive a link to the online agreement by email. We advise you to read Elsevier's policies related to copyright to learn more about our copyright policies and your, and your employer's/institution's, additional rights for subscription and open access articles.

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Authors will be offered open access user license options which will determine how you, and third parties, can reuse your open access article. We advise that you review these options and any funding body license requirements before selecting a license option.

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Corresponding authors will be sent an email which includes a link to our online proofing system, allowing annotation and correction of proofs online. The environment is similar to Word. You can edit text, comment on figures and tables and answer questions raised by our copy editor. Our web-based proofing service ensures a faster and less error-prone process.

You can choose to annotate and upload your edits on the PDF version of your article, if preferred. We will provide you with proofing instructions and available alternative proofing methods in our email.

The purpose of the proof is to check the typesetting, editing, completeness and correctness of your article text, tables and figures. Significant changes to your article at the proofing stage will only be considered with approval of the journal editor.

Share Link

A customized Share Link, providing 50 days free access to the final published version of your article on ScienceDirect, will be sent by email to the corresponding author. The Share Link can be used to share your article on any communication channel, such as by email or on social media.

A Share Link will not be provided if your article is published open access. The final published version of your open access article will be openly available on ScienceDirect and can be shared through the article DOI link.

Responsible sharing

We encourage you to share and promote your article to give additional visibility to your work, enabling your paper to contribute to scientific progress and foster the exchange of scientific developments within your field. Read more about how to responsibly share and promote your article.

Resources for authors

Language and editing services

We recommend that you write in American or British English but not a combination of both.

If you feel the English language in your manuscript requires editing to eliminate possible grammatical or spelling errors and to conform to correct scientific English, you may wish to use the English Language Editing service provided by Elsevier's Author Services.

Getting help and support

Author support

We recommend that you visit our Journal Article Publishing Support Center if you have questions about the editorial process or require technical support for your submission. Some popular FAQs:

- How can I track the status of my submitted article?
- When will my article be published?

APPENDIX Z: Journal Guidelines for Psychosis

Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements.

We offer a range of editing, manuscript preparation and post publication services to assist you in preparing your manuscript for submission, increase your chance of acceptance, or broaden the readership of your article. General guidance on every stage of the publication process is available at our Author Services website.

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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, First Person Accounts, Brief Reports, Registered Reports, Opinion Pieces, Letters to Editor and Book Reviews.

Open Access

You have the option to publish open access in this journal via our Open Select publishing program. Publishing open access means that your article will be free to access online immediately on publication, increasing the visibility, readership and impact of your research. Articles published Open Select with Taylor & Francis typically receive 35% more citations* and over 5 times as many downloads** compared to those that are not published Open Select.

Your research funder or your institution may require you to publish your article open access. Visit our Author Services website to find out more about open access policies and how you can comply with these.

You will be asked to pay an article publishing charge (APC) to make your article open access and this cost can often be covered by your institution or funder. Use our APC finder to view the APC for this journal. Please note that only the corresponding author is eligible to request funding from their institution, and it is not possible to change the corresponding author to achieve eligibility after submission. For further information, please see details here.

Please visit our Author Services website if you would like more information about our Open Select Program.

*Citations received up to 7th August 2024 for articles published in 2019-2023. Data obtained on 7th August 2024, from Digital Science's Dimensions platform, available at https://app.dimensions.ai

**Usage in 2021-2023 for articles published in 2019-2023.

Peer Review and Ethics

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be double blind peer reviewed by independent, anonymous expert referees. If you have shared an earlier version of your Author’s Original Manuscript

on a preprint server, please be aware that anonymity cannot be guaranteed. Further information on our preprints policy and citation requirements can be found on our Preprints Author Services page. Find out more about what to expect during peer review and read our guidance on publishing ethics.

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.

Word limits include everything, i.e abstract, tables and references.

The journal does not publish supplementary material.

- **Research Article or a Literature Review**
  - The maximum word length this journal is 6000 words.
- **First Person Account**
  - The maximum word length is 3500 words.
- **Brief Report**
  - The maximum word length is 1500 words.
- **Opinion Piece**
  - The maximum word length is 1500 words.
- **Letters to Editor**
  - The maximum word length is 400 words.
- **Book Review**
  - The maximum word length is 1000 words.
- **Registered Report**
  - Should be written with the following elements in the following order: title page; abstract; keywords; main text introduction, materials and

methods, results, discussion; acknowledgements; data availability statement; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

- Should be no more than 3500 for Stage 1 reports and no more than 5000 words for Stage 2, inclusive of the abstract, tables, references, figure captions, footnotes, endnotes.
- Should contain an unstructured abstract of 250 words.
- Should contain no more than 6 keywords. Read making your article more discoverable, including information on choosing a title and search engine optimization.
- Registered reports – are a form of empirical article in which the methods and proposed analyses are pre-registered and reviewed prior to the research being conducted. High quality protocols are then provisionally accepted for publication before data collection commences. Acceptance in principle indicates that the article will be published pending successful completion of the study according to the pre-registered methods and analytic procedures, as well as inclusion of a defensible and evidence-based interpretation of the results. Full details on the registered reports workflow and policies can be found here.

Format-Free Submission

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