Pathways to Care in At-Risk Mental States and First Episode Psychosis

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Thesis Portfolio Abstract

Background: People with early psychotic symptoms often experience treatment delays, which can exacerbate distress and lead to poorer outcomes, with significant personal and financial costs. Delays can occur in both people with an At-Risk Mental State (ARMS) for psychosis and in First Episode Psychosis (FEP). The thesis aimed to explore treatment delays and help-seeking using the paradigm of Pathways to Care (PtC).

Methods: A systematic review of PtC in ARMS was conducted which synthesised quantitative and qualitative studies. A qualitative study was carried out exploring PtC in participants with ARMS and FEP using semi-structured one-to-one interviews, analysed using thematic analysis.

Results: Ten studies met inclusion criteria for the systematic review. There was significant heterogeneity, with varying countries, screening tools and PtC instruments adopted. Overall, mental health professionals and General Practitioners (GPs) were found to have a key role in PtC, with family also identified as important in several studies. In the empirical study, eleven participants were interviewed about their experiences of PtC and barriers and facilitators to earlier help-seeking. Many participants had complex PtC and difficult experiences. Themes identified for experiences of PtC were “onset” and “unheard”; for barriers and facilitators themes were “gate keepers”, “personal” and “societal”. Overall the empirical paper also identified the key role of GPs and family, as well as stigma and culture.

Conclusions: The role of both GPs and family in help-seeking in both ARMS and FEP renders the need for service-level and public health interventions to raise awareness of psychotic experiences and available services. These may have the potential to shorten the PtC and improve outcomes. Clinical implications, including for GPs and Early Intervention in Psychosis services are given. Further research is required to triangulate and extend the findings.

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I wish to dedicate this thesis to Claudia and Julia.

Chapter One

Introduction

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Chapter One

Introduction

The following introduction aims to provide context for the thesis by outlining models of psychosis (including the At-Risk Mental State), help seeking, and pathways to care. Aims and a rationale for the thesis will be presented, as well as an overview of the chapters the thesis will consist of.

Models of Psychosis

Psychotic experiences such as hallucinations and delusions are relatively common in the general population. For instance, a recent meta-analysis found a mean lifetime prevalence of 9.6% for auditory hallucinations, which was higher for children and adolescents than for adults and older adults (Maijer, Begemann, Palmen, Leucht, & Sommer, 2018). One large (*n* = 31 261) study from 18 countries found psychotic experiences had a 5.8% mean lifetime prevalence, with hallucinations being more common than delusions (McGrath et al., 2015). Nevertheless, a recent systematic review found a 3% minimum reported prevalence of delusional beliefs in the general population (Heilskov, Urfer-Parnas, & Nordgaard, 2020).

Given this, increasing attention has been given to a continuum model of psychosis, with subjectively mild experiences that are not distressing on one side, and those with a greater severity that require intervention on the other (Van Os, Linscott, Myin-Germeys, Delespaul, & Krabbendam, 2009). The continuum paradigm is not without controversy. Its utility and indeed very existence have been extensively debated (David, 2010; Kaymaz & Van Os, 2010; Lawrie, Hall, McIntosh, Owens, & Johnstone, 2010; Shevlin, McElroy, Bentall, Reininghaus, & Murphy, 2016).

The continuum approach to psychotic experiences contrasts with a categorical medical model where psychotic experiences are either diagnosable as mental disorders or not (Linscott & Os, 2010). Indeed, people who come to the attention of mental health services (either by actively help seeking or involuntary treatment) seem to have a different quality of psychotic experiences to those in non-clinical samples. Compared to the general population, people with psychotic experiences which necessitate access to mental health services are likely to have more persistent symptoms, a greater level of functional impairment, and experience more distress (Van Os et al., 2009). In addition, clinical populations of those who hear voices tend to have more distressing and frequent voices than their non-clinical voice hearing counterparts (Baumeister, Sedgwick, Howes, & Peters, 2017). Given this, it is important to provide evidence-based treatment for this group.

At-Risk Mental States

An important distinction in the field of psychosis is that of the At-Risk Mental State (ARMS), also known as (ultra) high risk for psychosis. For the purposes of this thesis, ARMS will be classified according to Yung's definition: "a state that confers high, but not inevitable risk of development of psychotic disorder in the near future" (2005, p. 965). The ARMS paradigm emerged in the 1990s in response to growing evidence that the vast majority of people who develop a diagnosable psychotic illness have a prodromal phase prior to their psychotic episode (Yung & McGorry, 1996). The prodromal period was generally acknowledged to consist of psychotic symptoms of lesser duration or intensity than in “frank” psychosis, or other less specific symptoms such as anxiety or low mood, together with a drop in social functioning (Yung et al., 2005). This was an important consideration given the extensive evidence of the impact of the duration of untreated psychosis (DUP) in predicting outcomes including psychotic symptoms, social functioning and quality of life (Marshall et al., 2005; Penttilä, Jääskeläinen, Hirvonen, Isohanni, & Miettunen, 2014). It was proposed that intervening in the prodromal period would enable shortening DUP or even preventing the psychotic episode itself, thus improving outcomes (Fusar-Poli et al., 2013)

While it was not originally anticipated that everyone experiencing an ARMS would make transition to psychosis (Yung et al., 1996), it has since been found that a relatively small number of people experiencing ARMS transition to psychosis. For instance, Simon and colleagues’ systematic review found a mean transition rate of 24% (2011), which may be declining over time (Hartmann et al., 2016; Yung et al., 2007). This challenges the notion that ARMS is synonymous with prodromal psychosis. Nevertheless the ARMS population have high levels of distress, significant number of co-morbid conditions, and poor outcomes regardless of whether they transition to psychosis or not (Addington et al., 2011; Brandizzi et al., 2015; Lin et al., 2015). The argument for intervening earlier in the ARMS phase and thus reducing the Duration of Untreated Illness (DUI) or Duration of Attenuated Psychotic Symptoms (DUAPS) has growing support (e.g. Burton et al., 2019; Carrión et al., 2016; Gebhardt et al., 2019; Zhang et al., 2019).

Identifying those presenting with ARMS is not without challenges, as people can often seek help for non-specific symptoms such as anxiety or depression in the first instance (Fusar-Poli et al., 2013; Strelchuk et al.,, 2020), and thus be undetected by services. This has led to calls for screening of ARMS in primary care and schools although this also poses complexities , as well as ethical issues (e.g. whether there are sufficient resources to treat those identified as ARMS); Howie et al., 2020; Kline & Schiffman, 2014).

Help Seeking and Pathways to Care

Help seeking is an important consideration in both ARMS and FEP as gaining access to the right support has the potential to reduce DUP in FEP and DUI/DUAPS in ARMS, thus improving outcomes. A number of psychological models inform the help-seeking literature, including the theory of planned behaviour, health belief model, and cycle of avoidance (Gulliver, Griffiths, Christensen, & Brewer, 2012). The theory of planned behaviour (Ajzen, 1991) posits that consequences or attributes of behaviour, others' subjective norms and factors that may advance or hinder performance shape how one behaves (Ajzen, 2002). This may affect the decision about whether or not to help seek. The health belief model (Rosenstock, 1974) views appraisal of the threat of illness and readiness to take specific action to change health behaviour to be key to health behaviour change (Rosenstock, 2005). In help seeking for psychotic experiences this is relevant to the perceived stigma that may be identified as threatening for the person when deciding whether or not to seek help. Finally, the cycle of avoidance (Biddle, Donovan, Sharp, & Gunnell, 2007), taken from data on young people's experiences of help seeking, classifies help seeking as a circular procedure where public understandings of mental illness, social meanings of seeking help, and actions of individuals are central. Again this relates to stigma of psychotic experiences and the impact help seeking may have on an individual's identity.

Within the help seeking literature, Pathways to Care (PtC) is defined as:

> "The sequence of contacts with individuals and organisations prompted by the distressed person's efforts, and those of his or her significant others, to seek help as well as the help that is supplied in response" (Rogler & Cortes, 1993, p. 555)

The PtC paradigm is a useful addition to the help seeking literature, as it also encompasses how agencies respond to the individual or family's attempts to seek help (Rogler & Cortes, 1993; Singh & Grange, 2006). This is important because treatment delays have a significant impact on recovery rates. It also points to where intervention is required to reduce time – whether it is the responsibility of services (service level approaches needed) or individuals (public health approach needed). PtC can be measured in terms of the number of contacts from initial help seeking to the appropriate service, and the duration that this pathway lasts for in months or years. The care pathway can also be drawn diagrammatically (e.g. as presented by Hodgekins et al., 2017).

Treatment and Care for ARMS and FEP

The "care" referred to in Pathways to Care is, for the purposes of this thesis, treatment recommended by the National Institute for Health and Care Excellence (NICE) provided by an Early Intervention in Psychosis (EIP) service. For ARMS, this is individual Cognitive Behavioural Therapy (CBT), with or without family intervention (NICE, 2014). For FEP, NICE-concordant care includes antipsychotic medication combined with psychological interventions (individual CBT and family intervention; NICE, 2014). In EIP, individual psychological therapy is generally delivered by a Clinical Psychologist or Cognitive Behavioural Therapist; family intervention by members of the Multi-Disciplinary Team (usually with pairs of therapists). Significant investment in English EIP services has taken place over recent years (NICE & NHS England, 2016), in response to growing concerns about the costliness (both personal and financial) of treatment delays, although many services continue to experience challenges in fully implemented NICE-concordant care (National Clinical Audit of Psychosis, 2020). The NICE-recommended therapies both both ARMS and FEP require engagement with services if they are to be effective, but unfortunately disengagement from treatment is common in both groups (Leanza et al., 2020; Mascayano et al., 2020).

Thesis Aims and Overview

In summary, the thesis aims to extend the literature in the area of PtC in ARMS and FEP. This is particularly important due to increased attention paid to the importance of early detection, both in United Kingdom health policy (NICE & NHS England, 2016) and in research more generally. The thesis portfolio takes a critical realist ontological stance, positing that concepts such as ARMS and FEP exist in reality but that they are mediated by social experiences (Fletcher, 2017; see chapter five for a more detailed discussion of this.)

To the author’s knowledge, while systematic reviews of PtC in FEP have been conducted (Anderson, Fuhrer, & Malla, 2010; Singh & Grange, 2006), no such investigation has been undertaken for the ARMS population. Thus, chapter two presents a systematic review of PtC in ARMS. A bridging chapter follows which outlines the rationale for comparing PtC in ARMS and FEP. The empirical study (chapter 4) adopts a qualitative approach to explore the experiences of participants with either ARMS or FEP. Chapter five provides additional methodology. Finally, a concluding chapter critically appraises the portfolio, and details the implications of the research for clinical services, policy makers and future research. Plans for dissemination are also given.

Chapter Two

Systematic Review

Pathways to Care in At-Risk Mental States: a systematic review

Prepared for submission to 'Early Intervention in Psychiatry'[1]

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[1] See Appendix A for author guidelines. For ease of reading, figures and tables are provided within the main body of the text.

Pathways to Care in At-Risk Mental States: a systematic review

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Abstract

Aim: Pathways to care are well studied in the First Episode Psychosis field, but At-Risk Mental States or prodromal psychosis has been given less attention. This is important because accessing appropriate help at the earliest opportunity is likely to improve outcomes, particularly for those who transition to psychosis. This systematic review aimed to synthesise the available literature on pathways to care in ARMS or prodromal psychosis.

Methods: CINAHL Complete, EMBASE, Medline Complete, PsycINFO and PubMED databases were searched. Studies were included if they were published in English between 1985 and 2019, where reported data came exclusively from an At-Risk Mental State population, and the study described or related to pathways to care.

Results: Ten studies met the inclusion criteri (8 quantitative, two qualitative). Screening tools and pathways to care instruments varied. Mental health professionals and general practitioners played a key role in help seeking. Family involvement was also an important factor.

Conclusions: Pathways to care research in At-Risk Mental States is more scarce than in the field of First Episode Psychosis. More research is warranted, especially concerning the role of patient-level characteristics on pathways to care. A validated measure of pathways to care may also be of benefit.

Keywords: At Risk Mental States, help seeking behaviour, high risk, pathways to care, prodromal psychosis, treatment delays

Introduction

Psychosis is associated with high levels of disability and suffering (Rössler, Salize, van Os, & Riecher-Rössler, 2005), but outcomes are improved the earlier pharmacological or psychological intervention is initiated (Penttilä, Jääskeläinen, Hirvonen, Isohanni, & Miettunen, 2014). The concept of an At-Risk Mental State (ARMS; also known as clinical high risk and ultra-high risk) for psychosis emerged in the 1990s in response to growing calls that psychotic disorders had a prodromal period that lay undetected by services (Yung & McGorry, 1996). It was originally posited that positive psychotic symptoms of a lesser severity or duration than in psychosis, together with a drop in social functioning, would be indicative of transition to a first episode of psychosis (FEP; Fusar-Poli et al., 2013), and that intervening at this time would prevent transition.

Since then, whether ARMS is synonymous with prodromal psychosis has been intensely debated (van Os & Guloksuz, 2017). Conservative estimates find only 25% of people with ARMS transition to psychosis (Simon et al., 2011), a figure which appears to be reducing over time (Fusar-Poli et al., 2013; Hartmann et al., 2016). One study found only 4% of their sample with FEP came from an ARMS service (Ajnakina et al., 2017). Nevertheless, those who fail to make transition have poor trajectories, with high levels of comorbid conditions and substance use; impairments in quality of life; and poor social functioning in general (Addington et al., 2011; Beck et al., 2019; Brandizzi et al., 2015; Fusar-Poli et al., 2015; Lin et al., 2015; Rietdijk et al., 2013). As a result there is a growing school of thought that ARMS should be viewed through a transdiagnostic lens (Ajnakina, David, & Murray, 2019; McGorry, Hartmann, Spooner, & Nelson, 2018; Perez & Jones, 2019).

Evidence shows that intervening in the ARMS phase appears to be advantageous and cost effective whether or not transition to psychosis is made (Ising et al., 2017; Ising et al., 2015; Van der Gaag, Nieman, & Van den Berg, 2013; Wijnen et al., 2019). In those that transition to psychosis, being treated in an ARMS service has the benefit of already being engaged with services, thus reducing the Duration of Untreated Psychosis (Valmaggia et al., 2015) and improving treatment adherence (Van der Gaag et al., 2013). Intervening in the ARMS stage can also prevent decline in social exclusion (Van der Gaag et al., 2013). Cognitive Behavioural Therapy in ARMS reduces transition rates; lessens severity and distress associated with psychotic symptoms; and improves quality of life (Devoe, Farris, Townes, & Addington, 2019; Hutton & Taylor, 2014; Ising et al., 2015; Van der Gaag et al., 2013; Wilson, Shryane, Yung, & Morrison, 2019).

Given the effectiveness of intervention in the ARMS population, and the poorer outcomes for ARMS patients if left untreated, the question arises whether earlier detection in the ARMS phase is warranted (Dimitrakopoulos, Kollias, Stefanis, & Kontaxakis, 2015). The time between psychotic symptom onset and treatment in ARMS is described variously as the Duration of Untreated Attenuated Psychotic Symptoms (DUAPs), Duration of Untreated Illness (DUI), and Duration of Untreated Prodromal Symptoms (DUPrS). A growing body of research suggests longer DUAPs are predictive of less favourable outcomes, including increased transition rates (Nelson et al., 2016), reduced scores on the Global Assessment of Functioning (Fusar-Poli et al., 2009; Zhang et al., 2019), poorer social functioning (Burton et al., 2019; Carrión et al., 2016), and, in those who transition, increased risk of negative symptoms (Gebhardt et al., 2019).

The “pathways to care” (PtC) paradigm is used to measure delays in help seeking and treatment, which is important for understanding how people can access services at an earlier stage. Defined as “the sequence of contacts with individuals and organisations prompted by the distressed person's efforts, and those of his or her significant others, to seek help as well as the help that is supplied in response" (Rogler & Cortes, 1993, p. 555), PtC encompasses help seeking by individuals, carers and organisations, and how agencies respond (Singh & Grange, 2006). PtC generally measures the time between symptom onset, first professional contact and the initiation of appropriate treatment, which gives a proxy timescale of help seeking and treatment delay. This has the potential to identify whether public health or service level intervention would be most of benefit. Given the growing body of evidence pointing to the importance of intervening early in ARMS, PtC seems a useful paradigm in which to explore this further. For the purposes of this review, "care" is defined as that provided by an Early Intervention in Psychosis service or programme, which in the UK should provide evidence based psychological interventions including Cognitive Behavioural Therapy, with or without family intervention (NICE, 2014).

To our knowledge, no systematic review exploring PtC in ARMS alone has been conducted to date. This is surprising given PtC have been given consideration in FEP (Anderson, Fuhrer, & Malla, 2010; Singh & Grange, 2006) and in youth mental health (MacDonald, Fainman-Adelman, Anderson, & Iyer, 2018). Gronholm and colleagues (2017) examined the role of stigma in PtC in FEP and those at risk of psychotic disorders, where nine papers out of forty were found for the latter. The lack of research may be an indication of the complexities of PtC in an ARMS population. As previously discussed, the ARMS population are a heterogeneous group and those who present in the "true" prodrome may have different characteristics to those who don't make transition (Cannon et al., 2008; Nelson, Yuen, & Yung, 2011; Yung et al., 2003). In contrast to FEP there is a lack of clarity about when the ARMS period starts, especially given the high levels of psychotic experiences in the general population (Hanssen, Bak, Bijl, Vollebergh, & Van Os, 2005).

The present systematic review is therefore warranted due to the growing evidence base of early intervention in DUAPS, and the implications this may have on whether service or population interventions are required in order to reduce treatment delays. This is important because while service interventions are in place, evidence for population level interventions are lacking in ARMS compared to those for FEP (Ajnakina et al., 2019). The systematic review aimed to examine what care pathways people with ARMS take, and what the barriers and facilitators to receiving care from an ARMS service are.

Methods

The systematic review protocol was developed according to Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA; Moher, Liberati, Tetzlaff, & Altman, 2009). It was registered with the International Prospective Register of Systematic Reviews (PROSPERO, https://www.crd.york.ac.uk/prospero, registration number CRD42019120243).

Search Strategy and Procedure

The CINAHL Complete, EMBASE, Medline Complete, PsycINFO and PubMED databases were searched, with additional searches carried out on Google Scholar. Search terms were as follows: (“at risk mental state*” or “at risk” or “high risk” or “ultra high risk” or “clinical high risk” or prodrom* or attenuated) and (“pathway* to care” or “pathway* to mental health care” or “pathway* to health care” or “pathway* to services” or “pathway* to mental health services” or “pathway* to health services” or “pathway* to psychiatric services”). Search terms were identified from other systematic reviews, in the field of PtC and ARMS (e.g. Anderson, Fuhrer, & Malla, 2010; Cotter et al., 2014), and finalised in supervision discussions.` Searches were carried out on 23rd January 2018 for papers published between 1985 and 2018, with an additional search on 26th February 2020 for papers published in 2019.

Inclusion and Exclusion Criteria

The following inclusion criteria were adopted: 1) primary papers published in English between 1985 and 2019, 2) sample where available data reported is exclusively from an at-risk mental state, at high risk for psychosis, or prodromal psychosis population (not necessarily using a validated screening tool), 3) describes or relates to PtC. Both qualitative and quantitative studies were included.

Screening

Abstracts and full texts from the database searches were screened by SA. Twenty percent of full text articles screened for eligibility (*n* = 6) were checked independently by SP, with one discrepancy resolved following discussions with SO and PB. A further five full-text articles were discussed in consensus meetings with SO and PB.

Quality Appraisal

Methodological quality of the studies was measured using the Mixed Methods Appraisal Tool (MMAT; Hong et al., 2018). Papers were assessed by SA, with twenty per-cent (*n* = 2) independently checked by SP, with 78.57% agreement . Discrepancies were resolved by discussion with SO and PB. The MMAT is a well-established checklist for studies using qualitative, quantitative, mixed or randomised control trial methodologies, and consists of two generic core measures of quality, and a further five questions tailored to the methodology adopted. The scoring system used was that adopted by Gronholm and colleagues (2017), where points were added together to give a total score, which was converted to a percentage (0% no criteria met to 100% all criteria met), with a higher percentage indicating better quality studies.

Data Extraction and Narrative Synthesis

Data extracted from studies meeting the inclusion criteria included aims, study design, country, screening tool used, information about the sample (*n*, genders, ages), and PtC (definition of PtC, instrument, key pathway agents, among others). A narrative synthesis was carried out according to guidelines by Popay and colleagues (2006). This involved developing a preliminary synthesis based on common patterns across the studies (similar to a thematic analysis type process), exploring relationships between the data and assessing the robustness of the synthesis by going back to the full texts. In accordance with the guidance, quality appraisal was conducted before the narrative synthesis.

Results

Database searches yielded 4 510 papers (3 263 without duplicates; see Fig. 1). Of these, 26 full texts were screened for eligibility, with ten meeting the inclusion criteria, with a combined sample size of 720 (Boydell, Volpe, Gladstone, Stasiulis, & Addington, 2013; Chung et al., 2010; Cocchi et al., 2013; Fridgen et al., 2013; Gronholm, Thornicroft, Laurens, & Evans-Lacko, 2017; Platz et al., 2006; Shin et al., 2010; Stowkowy, Colijn, &

Addington, 2013; von Reventlow et al., 2014; Wiltink, Velthorst, Nelson, McGorry, & Yung, 2015).

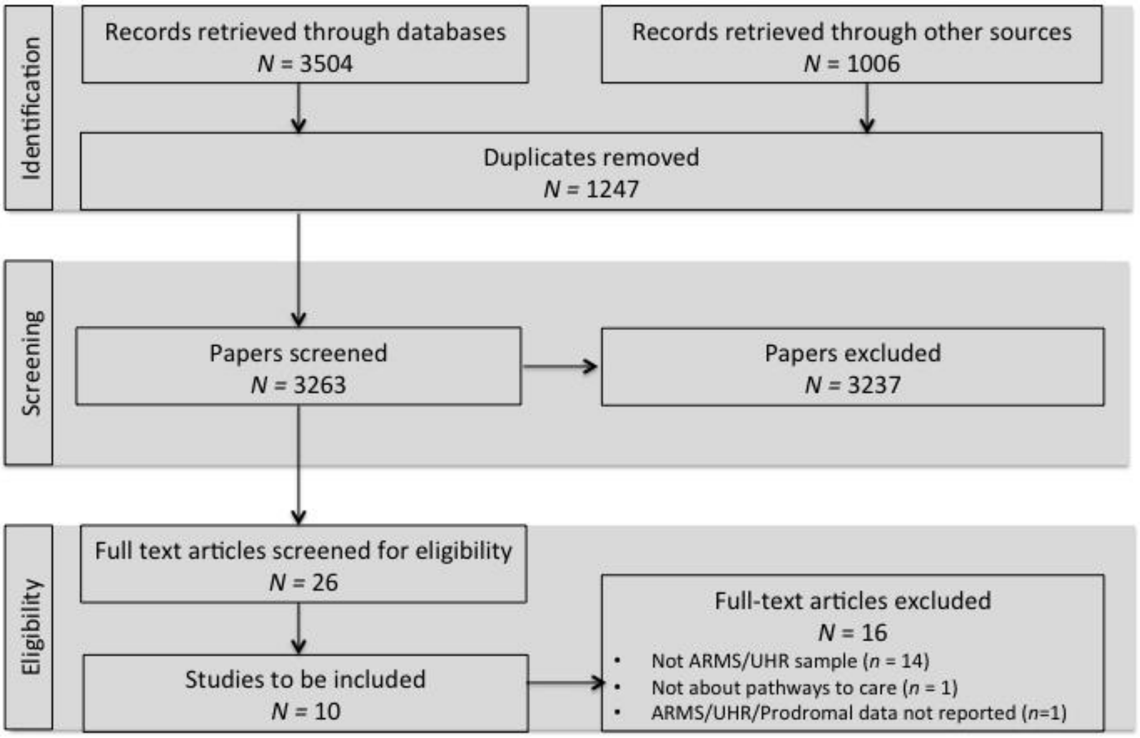

Figure 1. PRISMA Diagram.

Study Characteristics

Study characteristics are given in Table 1. All but two studies (Boydell et al., 2013; Gronholm et al., 2017) were quantitative. Research came from a wide variety of countries, with two each from Canada, South Korea and Switzerland, and one each from Italy, the United Kingdom and Australia. One study (von Reventlow et al., 2014) took place across four European countries. Screening tools varied, but the Comprehensive Assessment of At-Risk Mental States (CAARMS; Yung et al., 2005) was the most frequently used (*n*=3), followed by the Structured Interview for Prodromal Symptoms (SIPS; McGlashan, Miller, Woods, Hoffman, & Davidson, 2001; n=2).

Seven papers consisted of samples from an ARMS population only, with the remaining three (Cocchi et al., 2013; Fridgen et al., 2013; Platz et al., 2006) having samples consisting of ARMS and FEP populations. These three were included in the study because they analysed their ARMS and FEP data separately. Sample sizes for ARMS populations ranged from 10 (Boydell et al., 2013) to 233 (von Reventlow et al., 2014), with a mean of 73. Mean ages of participants were generally in the late teens or early twenties (range=15.7-26.8 years). Percentages of male participants were a mean of 56.67% (range=20-81.6%). Ethnicities were reported in one third of papers (*n*=3): of those reported, most participants were White or European (Table 1). No studies reported whether their participants lived in urban or rural locations.

Pathways to Care Information

PtC information is given in Table 2.

Instruments and data sources.

Instruments used to measure PtC varied considerably between studies (Table 2). Of those papers that measured PtC (all but Boydell et al., 2013; Gronholm et al., 2017; n=8), most used an interview designed for the purposes of the research (*n*=5). Two studies (Stowkowy et al., 2013; von Reventlow et al., 2014) used the Pathways to Care Interview (Perkins, Nieri, Bell, & Lieberman, 1999), although the latter used an adapted version of the instrument. No studies reported information about their measure's psychometric properties, but Fridgen's (2013) chosen measure, the Basel Interview for Psychosis, has since been shown to have good inter-rater reliability (Riecher-Rossler et al., 2015). All papers collected data using face-to-face interviews, either with the participant alone or with the participant and their significant other(s) (Table 2).

Table 1. Characteristics of included studies.

Study	Study objectives	Country	Population	Setting	Screening tool	*N*	Mean age (SD)	% Male	Ethnicity
Boydell et al. (2013)	Identify ways which UHR youth access mental health services and factors that advance/delay help seeking. Elaborate and refine Revised Network Episode Model	Canada	UHR	Early Intervention Clinic	Criteria of Prodromal Symptoms, Bonn Scale for the Assessment of Basic Symptoms	10	17.0	20.0	60% European 3% Chinese 1% Mixed Race
Chung et al. (2010)	To investigate the help-seeking behaviours, Duration of Untreated Attenuated Psychotic Symptoms, and baseline clinical characteristics in individuals at HR for psychosis.	South Korea	HR	Early Psychosis Centre	Comprehensive Assessment of At-Risk Mental States (CAARMS)	38	24.24 (6.43)	81.6	Not reported
Cocchi et al. (2013)	To investigate patterns of referral in UHR patients	Italy	UHR	Early Detection and Early Intervention team	Early Recognition Inventory Retrospective Assessment of Symptoms Checklist, Brief Psychiatric Rating Scale	96†	22.1 (3.6)	67.0	Not reported

Study	Study objectives	Country	Population	Setting	Screening tool	*N*	Mean age (SD)	% Male	Ethnicity
Fridgen et al. (2013)	To investigate duration of untreated illness/psychosis and help-seeking contacts for referrals to specialist clinic	Switzerland	ARMS	Early Detection Clinic	Basel Screen Instrument for Psychosis	61†	26.8 (8.7)	59.0	Not reported
Gronholm et al. (2017)	To explore stigma and discrimination in relation to initial pathways to care from the perspective of young people putatively in an early stage of increased risk of developing psychotic disorders	UK	HR "Putatively at risk of developing psychotic disorders"	Participants from London Child Health and Development Study	Psychotic-like experiences questionnaire, Strengths and Difficulties Questionnaire	29	15.7 (1.6)	34.5	65.5% White 31% Black 3.4% Asian
Platz et al. (2006)	To obtain information on help seeking pathways for patients at putative risk for psychosis, including type of health professionals contacted, number of contacts, symptom, interval between initial contact and referral to specialist service	Switzerland	ARMS	Prodromal clinic	Schizophrenia Prediction Instrument Adult Version, Scale of Prodromal Symptoms, Positive and Negative Syndrome Scale	50†	21.0	62.0	Not reported
Shin et al. (2010)	To examine help seeking contacts	South Korea	UHR	Early Psychosis Centre	CAARMS	18	16.78 (1.99)	72.2	Not reported

Study	Study objectives	Country	Population	Setting	Screening tool	*N*	Mean age (SD)	% Male	Ethnicity
Stowkowy et al. (2013)	To prospectively investigate the pathways to care of those at CHR of developing psychosis	Canada	CHR	Prodromal clinic	Structured Interview for Prodromal Syndromes (SIPS)	35	21.0 (4.2)	71.43	57% White 23% Asian 14% Mixed Race 6% Black
Von Reventlow et al. (2014)	To acquire accurate knowledge about pathways to care and delay in obtaining specialised high risk care	Finland Germany Netherlands England	HR	Various, including university-based hospital and specialist early intervention in psychosis services	SIPS (version 3.0), Schizophrenia Proneness Instrument Adult Version	233	23.0 (5.3)	54.9	Not reported
Wiltink et al. (2015)	To compare changes in referral patterns in an UHR clinic with a previous study, and investigate if this may account for a drop in the rate of transition to psychosis	Australia	HR	ARMS Clinic	CAARMS	150	18.3 (3.2)	44.0	Not reported

Abbreviations: UHR = Ultra High Risk, HR = High Risk, ARMS = At Risk Mental State, CHR = Clinical High Risk.
† Studies contained mixed samples. *N* reported here refers to participants who met the systematic review inclusion criteria.

Table 2. Pathways to Care information

Study	PtC definition	PtC Instrument	Mean number PtC (SD), range	Mean months duration PtC (SD)	DUI definition	Mean months DUI (SD)	Key pathway agents	Common first help seeking contacts
Boydell et al. (2013)	The specific path that individuals experiencing psychosis use to access treatment	Interview developed for the study (participant and significant other)	Not reported	Not reported	Not defined	Not reported	Family, community, school	Not reported
Chung et al. (2010)	Not defined	Interview developed for the study (participant and significant other)	Not reported	Not reported	Onset of attenuated psychotic symptoms to first visit to psychiatric services	22.0 (28.59)	Family	Family, psychiatrist
Cocchi et al. (2013)	The range of contacts made by distressed people and their relatives with individuals and organisations to seek help	Interview developed for the study (participant and significant other)	Not reported	Not reported	Onset of anxiety, depression and/or social withdrawal to start of psychotherapy treatment	30.7 (22.3)	Mental health professional, public or private mental health centre, family	Mental health professional, psychiatrist

Study	PtC definition	PtC Instrument	Mean number PtC (SD), range	Mean months duration PtC (SD)	DUI definition	Mean months DUI (SD)	Key pathway agents	Common first help seeking contacts
Fridgen et al. (2013)	Difficulties in finding the right help- seeking contact	Basel Interview for Psychosis	8.57 (8.42)	30	Time between first self-perceived signs or symptoms of a change in well-being and first contact with specialised early detection clinic.	66.2 (76.9)†	Family, friends	Family, friends, psychiatrist
Gronholm et al. (2017)	Help seeking and support from informal (e.g. family, friends) and formal (e.g., primary care, school-based support, specialist services) sources	Not measured	Not reported	Not reported	Not defined	Not reported	Someone with a close relationship to the person (not a specific group)	Not reported
Platz et al. (2006)	Help seeking pathways	Interview developed for the study (participant)	2.38 (1.42) 1-8	28.5 (49.91)	Not defined	Not reported	Psychiatric outpatient services, private psychiatrists/psychologists, GPs	GP

Study	PtC definition	PtC Instrument	Mean number PtC (SD), range	Mean months duration PtC (SD)	DUI definition	Mean months DUI (SD)	Key pathway agents	Common first help seeking contacts
Shin et al. (2010)	The contact process during the period of time from when the illness is suspected until the first psychiatric treatment	Interview developed for the study (participant and significant other)	1.83	Not reported	Not defined (term DUI used)	13.31 (12.57)	Psychiatrists, family, teachers	Family
Stowkowy et al. (2013)	The number of attempts individuals make to obtain help and who is most likely to ensure appropriate treatment is obtained	Pathways to Care Interview	1.7 1-4	Not reported	Not defined	Not reported	GP	GP

Study	PtC definition	PtC Instrument	Mean number PtC (SD), range	Mean months duration PtC (SD)	DUI definition	Mean months DUI (SD)	Key pathway agents	Common first help seeking contacts
Von Reventlow et al. (2014)	Number of help-seeking events, initial help-seeking delay (time from onset of at-risk criteria to first help-seeking contact), and treatment delay (time between first help-seeking contact and receiving appropriate treatment)	Adapted version of the Pathways to Care Interview	2.9 (1.4) 1-9	25.29 (36.78)	Duration of unrecognised risk for psychosis: delay between help-seeking and treatment	41.70 (56.28)	Primary care, mental health care centre, private practice	Not reported
Wiltink et al. (2015)	Not defined	Interview designed for research projects in the clinic	1.93 (1.15) 0-6	1.49 (3.08)	Not defined	Not reported	Emergency/crisis response team	Emergency/ crisis response team, GP, teacher

Abbreviations: PtC = Pathways to Care, DUI = duration of untreated illness
† reported for FEP and ARMS but difference not statistically significant

All instruments asked participants to identify the people and or institutions they approached to seek help. Fridgen's Basel Interview for Psychosis specifically asked about the involvement of a number of different social, professionals and community contacts, including family, friends, health professionals and religious leaders, rather than relying on the person's recollection alone, which may have provided greater accuracy of reporting. In four papers (Platz et al., 2006; Stowkowy et al., 2013; von Reventlow et al., 2014; Wiltink et al., 2015) information was requested about the type of symptom leading to each contact.

Number and duration of Pathways to Care.

All but four studies (Boydell et al., 2013; Chung et al., 2010; Cocchi et al., 2013; Gronholm et al., 2017) reported the mean number of PtC between initial help seeking and successful referral. Caution should be adopted in pooling the data as a whole, as differences in findings may be reflective of variability in data collection instruments and healthcare contexts. Taken together, the number of PtC ranged between 0 and 9, with a pooled mean of 3.22. Duration of PtC (the time between help seeking is initiated and acceptance to an appropriate service; reported by five studies) was much more variable, ranging from 1.49 to 30 months (Table 2).

The pathway to care and Duration of Untreated Illness.

DUI (definitions and mean months) are given in Table 2. DUI or equivalent were reported in five studies (Chung et al., 2010; Cocchi et al., 2013; Fridgen et al., 2013; Shin et al., 2010; von Reventlow et al., 2014). Definitions of DUI varied greatly. Only one of the five papers reporting DUI gave attenuated psychotic symptoms as indicative of illness onset (Chung et al., 2010). The remainder mostly gave less specific indicators of

ARMS onset, including "first self-perceived signs or symptoms in a change in wellbeing" (Fridgen et al., 2013), and onset of anxiety, depression or social withdrawal (Cocchi et al., 2013). Taken together, DUI or equivalent ranged between 13.31 and 66.2 months, with a mean of 34.78.

Key pathway agents and first help seeking encounter.

Table 2 presents the key pathway agents and first help seeking encounter. Key pathway agents (the people or agency involved in help seeking across the whole pathway to care) were most frequently identified as mental health professionals (*n*=6), followed by family (*n*=4) and General Practitioners (GPs) or primary care (*n*=3). School was given as important in the care pathway in two studies. Other key pathway agents identified by one study each include friends, the community, private practice and the emergency/crisis team.

Findings for first help seeking encounters were similar to key pathway agents, with psychiatrists or mental health professionals identified by four studies, and family and GPs by three. Friends, emergency/crisis team, and teachers were given as first help seeking encounters in one study each.

Factors influencing the pathway to care.

Family involvement was identified as important in half of studies meeting the review criteria (Boydell et al., 2013; Chung et al., 2010; Cocchi et al., 2013; Fridgen et al., 2013; Shin et al., 2010). More specifically, family played a key role in initial help seeking (Chung et al., 2010; Fridgen et al., 2013), and in initiating referrals to the appropriate ARMS service (Cocchi et al., 2013). Studies that identified the importance of family involvement tended to be of higher quality than those who did not (Table 3).

The importance of family involvement was not a universal finding. This may perhaps be reflective of the cultural differences in the role of the family, given the variety of countries in which the studies took place, as well as study quality. Wiltink and colleagues (2015) identified that a greater proportion of first contacts in the care pathway were with emergency or crisis response teams , General Practitioners and school counsellors rather than family. School employees were also found to play a more important role than family by Boydell et al. (2013), who report that young people are more likely to take an active role in the help seeking process. Stowkowy and colleagues (2013) found only 1% of reported contacts prior to acceptance at the CHR service were by family. The remaining three studies Gronholm et al., 2017; Platz et al., 2006; von Reventlow et al., 2014) did not report any influence of family on PtC. The importance of primary care professionals, in particular General Practitioners, was identified by three studies (Platz et al., 2006; Stowkowy et al., 2013; von Reventlow et al., 2014), however these were generally lower quality studies (all 42.86%; see Table 3).

Emergency services involvement (including police, ambulance, or attendance at accident and emergency) was reported by four studies (Cocchi et al., 2013; Fridgen et al., 2013; Stowkowy et al., 2013; von Reventlow et al., 2014; Wiltink et al., 2015). Results presented a mixed picture. Wiltink and colleagues' (2015) found the most common source of referral was the emergency or crisis team. Von Reventlow (2014) found 6.6% of participants had used emergency hospital but this figure also took into account admissions to general hospital. Cocchi (2013) reported that 2 participants (2% of the sample) used the "emergency room" during the PtC, but that no police authority, legal authority or ambulance service were involved. One contact (1.6% of contacts) was with "emergency services" by Stowkowy and colleagues (2013).

One study, which was of relatively high quality, reported on compulsory admission on the PtC (Chung et al., 2010), who reported one participant (1% of sample) was detained prior to admission to the service. Compulsory admissions were not reported to occur in the PtC by the remaining studies. No studies commented on the role of ethnicity in the PtC.

Three studies (Platz et al., 2006; Stowkowy et al., 2013; Wiltink et al., 2015) found that patients presenting with positive psychotic symptoms (e.g. hallucinations, delusions) were more likely to have a shorter care pathway to the appropriate ARMS service. These studies were of medium quality.

Quality Appraisal

Methodological quality of studies varied (see Table 3). Percentages calculated using the MMAT ranged between 28.57% and 100%, with a mean of 64.29% (see Supplementary Information for justification of MMAT ratings). Both qualitative studies gained a score of 100%. Generally, the quantitative studies used suitable measurements and appropriate statistical analyses. Limitations were generally due to a lack of information given in papers, especially sampling strategies and whether the samples were representative of the target population. Some studies lacked clear research aims or objectives.

Discussion

Main Findings

This systematic review found that PtC in ARMS is a much more neglected area than FEP. Our review found 10 studies meeting the inclusion criteria, whereas a systematic review of PtC in FEP published ten years ago included 30 papers (Anderson et al., 2010). While the ARMS field is a more recent concept than FEP, it is well out of its infancy, thus the lack of research in this area is concerning. The paucity of research may be in part due to difficulties in defining the onset of illness in ARMS, as evidenced by the varying definitions for illness onset in the papers included in this review.

Interpretation of Findings

The fact that the papers originate from different countries which have varying healthcare contexts mean taking findings together should be undertaken cautiously.

The review has highlighted that variability in the measurement of PtC continues to be a concern. A key limitation of the studies identified is that none used a measure that was validated at the time of the paper's publication, and the majority used a measure designed for the purposes of the study. The need for a validated measure of PtC was recommended in the FEP population over a decade ago (Singh & Grange, 2006), and also, more recently, by MacDonald and colleagues in the field of youth mental health (MacDonald et al., 2018). A psychometrically sound measure of PtC in ARMS appears warranted too. Development of such an instrument is likely to bring its own complexities due to the variation in definitions and terminologies in the field of ARMS, as well as differences in healthcare systems across countries and healthcare systems.

The pooled mean for the numbers of PtC was 3.22 contacts, which was similar to MacDonald's finding of 2.9 across mental health services for young people (2018). DUI ranged between 13.31 and 66.2 months (pooled mean = 34.78 months). This is shorter than an equivalent study of DUI in FEP, where the median was 44.89 months (Anderson, Fuhrer, Schmitz, & Malla, 2013), which is to be expected given people with FEP are likely to present at a later stage.

The importance of family involvement, while not a universal finding, echoes the literature in both youth mental health services and FEP (Del Vecchio et al., 2015; MacDonald et al., 2018). It seems that a public health approach to educate parents may be warranted in this area. The important role of family in PtC raises the question of whether treatment delays may occur in people who are socially isolated and those who do not have family to turn to, as is the case in FEP (Anderson et al., 2010).

Emergency services involvement was generally found to be a small percentage of PtC contacts. One paper found that compulsory admissions did not play a significant role in PtC in ARMS, with mental health professionals and GPs more likely to be first help seeking contacts. This is in common with Valmaggia and colleagues' findings (2015) that patients presenting in the prodromal phase who went on to transition to psychosis were less likely to be compulsorily admitted compared to those who did not present prodromally. These findings are somewhat contrary to findings in the FEP literature, where contacts with police, emergency services and compulsory admissions are much more frequent (Anderson et al., 2010). This makes sense given those presenting during the ARMS phase tend by their very nature to have less severe presentations than those with FEP. Interestingly, Anderson and colleagues (2010) point out that more frequent contacts with emergency services can lead to disengagement with treatment (so-called "negative" PtC). This reinforces the importance of intervening during the prodromal stage before contact with emergency services occurs, as this may be a more optimal stage to engage patients in treatment.

The impact of ethnicity on PtC was a neglected area in the studies meeting the review's criteria. Only three of the ten studies reported their participants' ethnicities. No studies reported on the effects of ethnicity on PtC, which is surprising as this is a well-researched area in FEP. The literature generally finds those of Black ethnicity are likely to have longer and more negative PtC in psychosis (Anderson, Flora, Archie, Morgan, & McKenzie, 2014), thus this is an area worthy of further consideration. Similarly, no studies in this review compared PtC in rural and urban populations, which warrants further examination considering the evidence that living in a rural community impacts on treatment delays in the field of FEP (Boonstra et al., 2012; Kvig et al., 2017).

Positive symptoms as being indicators of shorter care pathways is understandable given that negative symptoms have higher overlap with other conditions, such as depression, and are associated with social withdrawal. Indeed, in the first episode psychosis samples Anderson (2010) found that people presenting with delusions, hallucinations, depression, suicidal ideation tended to have more successful treatment contacts.

Limitations

The findings are limited by the relatively small number of papers meeting the criteria for this review. In retrospect it may have been beneficial to add additional search terms, for instance “psychosis” and “access”, although all ten papers originated from database searches rather than other sources. The fact that papers originated from countries with different healthcare systems, used various non-validated screening tools and used different PtC instruments mean results must be interpreted with caution. In addition, having a second rater for all papers rather than 20% would have been preferable if resources allowed for this. The fact that the MMAT does not recommend cut offs for quality rating renders it difficult to objectively judge the quality of the studies.

Implications for Research and Treatment

Mental health professionals, family and primary care were found to be key pathway agents. Family involvement in help seeking was also identified as extremely important for half of studies meeting the inclusion criteria. This points to the importance of developing evidence-based interventions to improve early detection of ARMS for both health professionals and the general public. Education of general practitioners in both those at high risk for psychosis and FEP has been shown to be efficacious in improving referral rates and referral quality (Perez et al., 2015), however more research is required in this area. The case for public health interventions is an emerging field in ARMS (Ajnakina et al., 2019; Anderson, 2019); this review appears to support the development of such interventions.

The findings in our review also point to the need for a validated measure of PtC. This was recommended in a review published 13 years ago in the area of FEP (Singh & Grange, 2006). More research is required in the role of ethnicity for PtC in ARMS and the role of emergency services.

Future studies in the field of PtC in ARMS should use a validated screening tool (e.g. the CAARMS) prior to collecting PtC data. Research questions should be clear. Attention should be given to the reporting of sampling strategies, in particular whether the sample is representative of the target population, for studies to be considered higher quality.

Recommendations for Clinicians

Recommendations must be given with caution given the heterogeneity of the papers, including the countries and different healthcare settings that they originate from. Nevertheless, based on the finding that family play an important role in the PtC, it is important for clinicians (both General Practitioners and specialist mental health services) to actively involve family in the assessment process in order to build an accurate picture of the patient's presentation. Patients with positive psychotic symptoms tended to have shorter PtC compared to those whose symptoms were less specific (e.g. decline in social functioning, depression or anxiety). Professionals, in particular general practitioners, should be mindful that those patients presenting with symptoms other than attenuated psychotic symptoms may be in the early stages of ARMS, and to refer to appropriate services as soon as possible.

Future Directions

More research is required in the area of PtC in ARMS in general. More specifically, the impact of ethnicity and urbanicity is recommended. Studies exploring the role of intervening earlier in ARMS and the impact reducing DUI has on outcomes are also warranted.

Conclusion

In summary, this review found evidence is lacking in this area, especially considering the body of PtC research in FEP. The papers meeting the criteria found that family involvement and presentations of attenuated psychotic symptoms were key factors at play. More research into ethnicity and the differences between rural and urban populations may be warranted. Finally, future studies should examine the means of streamlining care pathways in ARMS, with further exploration of whether reducing DUI results in improved outcomes for this population.

Table 3. Quality Appraisal

Domain	Quality criteria	Quality assessment of included studies									
		Boydell et al. (2013)	Chung et al. (2010)	Cocchi et al. (2013)	Fridgen et al. (2013)	Gronholm et al. (2017)	Platz et al. (2006)	Shin et al. (2010)	Stowkowy et al. (2013)	Von Reventlow et al. (2014)	Wiltink et al. (2015)
Screening Questions	Are there clear research questions[†]?	+	+	+	+	+	+	-	-	-	+
	Do the collected data allow to address the research questions[†]?	+	+	+	+	+	+	+	+	+	+
Qualitative Studies	Qualitative approach appropriate to answer research question[†]?	+	n/a	n/a	n/a	+	n/a	n/a	n/a	n/a	n/a
	Qualitative data collection methods adequate to address the research question[†]?	+	n/a	n/a	n/a	+	n/a	n/a	n/a	n/a	n/a
	Findings adequately derived from the data?	+	n/a	n/a	n/a	+	n/a	n/a	n/a	n/a	n/a
	Interpretation of results sufficiently substantiated by data?	+	n/a	n/a	n/a	+	n/a	n/a	n/a	n/a	n/a
	Coherence between qualitative data sources, collection, analysis and interpretation?	+	n/a	n/a	n/a	+	n/a	n/a	n/a	n/a	n/a
Quantitative Descriptive Studies	Sampling strategy relevant to address the research question[†]?	n/a	?	+	?	n/a	?	?	?	?	+
	Sample representative of the target population?	n/a	?	+	?	n/a	?	?	?	?	?
	Measurements appropriate?	n/a	+	+	+	n/a	?	?	+	+	+
	Risk of nonresponse bias low?	n/a	+	+	?	n/a	?	?	?	?	-
	Statistical analysis appropriate to answer the research question?	n/a	+	+	+	n/a	+	+	+	+	+
Total percentage		100	71.43	100	57.14	100	42.86	28.57	42.86	42.86	57.14

[†] also taken to mean research objectives and aims (confirmed by P. Pluye, MMAT developer, personal communication 16.04.19). + yes, - no, ? can't tell

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Data Availability Statement

Data sharing is not applicable to this article as no new data were created or analysed in this study.

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Chapter Three

Bridging Chapter

Word Count: 939

Chapter Three

Bridging Chapter

This chapter aims to summarise the findings of the systematic review, and provide a background and rationale to the empirical paper.

Systematic Review Findings

The systematic review identified a paucity of evidence in the area of pathways to care (PtC) in ARMS, with only ten papers meeting the inclusion criteria. Of these, the majority (*n*=8) were quantitative. Papers meeting the inclusion criteria came from varying countries and healthcare systems. Only one paper originated from the United Kingdom (Gronholm et al., 2017), and this focused on stigma in relation to PtC, not help seeking and PtC in general. Most participants had White ethnicity. It seems additional research in the United Kingdom health context adopting a qualitative approach would be pertinent in order to address these gaps.

In addition, the review found significant variation in screening tools and PtC instruments, which limits the validity of amalgamating the numerical findings on numbers and duration of PtC. Nevertheless, the Duration of Untreated Illness was found to be less than equivalent measures in First Episode Psychosis (Anderson, Fuhrer, Schmitz, & Malla, 2013), which is perhaps unsurprising given people with ARMS access support at an earlier stage of their psychotic illness. Mental health professionals and General Practitioners seemed to play key role in the help seeking pathway, with the role of family identified as important in half the studies that met the review criteria. In general, emergency services accounted for few PtC contacts. Three studies identified that participants who disclosed their "positive" psychotic symptoms (e.g. hallucinations, delusions) led to shorter care pathways. Only three studies reported their participants' ethnicities; none addressed whether ethnicity impacted on PtC. This is surprising given considerable attention has been given to this in First Episode Psychosis (FEP; e.g. Anderson, Flora, Archie, Morgan, & McKenzie, 2014).

Background and Rationale for the Empirical Paper

Reducing the Duration of Untreated Psychosis (DUP) for people with FEP has been given increasing attention in recent years, due to the potential benefits this may have on a variety of recovery outcomes, including psychotic and affective symptoms, as well as social and overall functioning (Marshall et al., 2005; Penttilä et al., 2014). This has the potential to reduce the significant financial and personal costs of psychosis (Andlin-Sobocki & Rössler, 2005; Chong et al., 2016). This could manifest itself in savings from decreased health and social care service use, reduced spending required on benefits, as well as a reduction in the significant suffering that psychosis can cause (Andlin-Sobocki & Rössler, 2005; Chong et al., 2016).

Despite the evidence suggesting significant benefits to reducing DUP, evidence on interventions that do so is relatively limited. Lloyd-Evans' systematic review (2011) found Early Intervention in Psychosis (EIP) services alone are insufficient to reduce DUP. There is mixed evidence about the effectiveness of GP education on reducing service delays (Lester, Birchwood, Freemantle, Michail, & Tait, 2009; Perez et al., 2015; Power et al., 2007). However, these interventions assume people with psychotic symptoms will attend the GP during their PtC, which is not always the case (Anderson et al., 2010). It seems likely that ARMS services may be effective to reducing DUP, but given one study finding 96% of people on an EIP FEP caseload did not reach prodromal services (Ajnakina et al., 2017), ARMS services alone are unlikely to provide the only solution.

Given more effective interventions for reducing DUP are needed, it seems evidence exploring the experiences of the PtC are warranted. Examining the experiences of those with ARMS and FEP seems pertinent in order to explore the overlap and differences between those who were able to access help prodromally (ARMS) and those who did not access EIP until they became psychotic (FEP). This could inform the development of an intervention to reduce DUP in ARMS, and indeed reduce DUI in ARMS.

Despite the clear rationale for examining PtC in ARMS and FEP, existing literature that does this is very limited. Three quantitative papers included in the above systematic review compared ARMS and FEP (Cocchi et al., 2013; Fridgen et al., 2013; Platz et al., 2006). To the authors' knowledge there is no other research in this area, including no qualitative research, nor any research conducted in the UK National Health Service context. Findings from comparisons with ARMS and FEP are outlined in the empirical paper, but in brief, people with ARMS are less likely to be compulsorily admitted to psychiatric hospital (Cocchi et al., 2013). Family and friends seem to play a more significant role in help-seeking for people with FEP than ARMS (Cocchi et al., 2013; Fridgen et al., 2013). In general, quantitative research can yield insights at more of a macro level but is by its nature somewhat reductionist. In addition, quantitative data cannot capture the minutiae of experience and journey to EIP services in so much detail. A qualitative approach may address this gap, giving insights into individual journeys and the barriers and facilitators thereof. It seems there is an urgent need for qualitative evidence in the UK context in this area. This has the advantage of adopting a more critical realist stance, where the reality of ARMS and FEP as concepts are considered mediated by the experience of those who meet that criteria (Fletcher, 2017; Maxwell, 2012).

The following empirical paper thus examines PtC in ARMS and FEP, adopting a qualitative methodology to explore service users' experiences in detail in order to add to the research evidence in this area, and to prepare for a larger-scale quantitative study on the topic. This has the potential to inform the development of interventions to reduce DUP, thus significantly improving outcomes for those experiencing psychotic symptoms.

Chapter Four

Empirical Paper

"Jumping from place to place": Service User Perspectives on Pathways to care in At-Risk Mental States and First Episode Psychosis

Prepared for submission to 'Clinical Psychology and Psychotherapy'[2]

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[2] See Appendix B for author guidelines. For ease of reading, figures and tables are provided within the main body of the text.

“Jumping from place to place”: Service User Perspectives on Pathways to care in At-Risk Mental States and First Episode Psychosis

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Abstract

Objectives: It is important for people with early psychotic symptoms to access treatment at the earliest opportunity, but only a small proportion of people with First Episode Psychosis access help in the prodromal stage. The study aimed to explore perspectives of people with an At-Risk Mental State (ARMS) or First Episode Psychosis (FEP) to understand 1) the experiences of pathways to care and 2) barriers and facilitators encountered.

Methods: Qualitative, semi-structured interviews took place with eleven participants (5 ARMS, 6 FEP). Data were analysed using inductive thematic analysis.

Results: Many participants interviewed had complex pathways to care; the majority had negative experiences. Themes under experiences of pathways to care were “onset”, and “unheard”. Barriers and facilitators were divided into gate keepers, personal and societal levels.

Conclusions: Most participants experienced significant challenges in accessing Early Intervention in Psychosis services, often leading to significant treatment delays. Population and service level interventions are required to reduce the Duration of Untreated Illness and Duration of Untreated Psychosis. Recommendations for future research are given.

Keywords: Pathways to care, psychosis, early intervention, help seeking, high risk, thematic analysis

Key Practitioner Message

- It is important that people with first episode psychosis get help at the earliest opportunity, but treatment delays often occur, which lead to poorer outcomes. This study aimed to examine the pathways to Early Intervention in Psychosis (EIP) care from the perspectives of patients who had experienced a first psychotic episode (FEP), compared to those who had sought help in their prodromal period (At-Risk Mental State (ARMS) group).
- Eleven patients were interviewed about their experiences. Most reported challenging journeys to EIP, with difficulties accessing the right support, and a general sense of feeling unheard. Family and friends were an important facilitator.
- Overall, significant barriers are faced by people experiencing early psychotic symptoms. Services need to be as accessible as possible to account for this if people are to get help at the earliest opportunity. The paper recommends staff training, particularly for GPs, and measures to make services as accessible as possible.

Introduction

People with first episode psychosis (FEP) have better outcomes the earlier treatment begins (Marshall et al., 2005), but delays often occur in their “pathway to care” (PtC): the time between symptom onset, help seeking, and acceptance to appropriate services (Rogler & Cortes, 1993; in this case treatment refers to that provided by an Early Intervention in Psychosis (EIP) service. Delays occur despite help seeking attempts during the psychosis prodrome (Addington, Van Mastrigt, Hutchinson, & Addington, 2002; Rietdijk et al., 2010). Examining reducing treatment delays is important due to their significant financial and personal costs.

The At-Risk Mental State (ARMS) paradigm heralded an opportunity for earlier detection of people with psychotic experiences. People with ARMS have psychotic symptoms which are shorter in duration or frequency than FEP, and a deterioration in social functioning (Yung et al., 2005). Despite recent expansion of ARMS services, effects on FEP pathway lengths are unclear. One study found 4% of FEP patients accessed ARMS services before transitioning to psychosis (Ajnakina et al., 2017), raising the question why 96% were not identified prodromally. Contrasting PtC in FEP to those who reached EIP services in the prodromal phase may provide insight into this, and elucidate factors associated with people with FEP not being identified early enough.

Having White ethnicity, good social support, presenting with “positive” psychotic symptoms (hallucinations, delusions) or suicidal ideation, and living in urban environments are associated with shorter PtC in FEP (Anderson, Flora, Archie, Morgan, & McKenzie, 2014; Anderson, Fuhrer, & Malla, 2010; Anderson, Fuhrer, Schmitz, &

Malla, 2013; Boonstra et al., 2012). People with ARMS seem most likely to first help seek for affective symptoms (Falkenberg et al., 2015), although delusions and paranoia may facilitate successful referrals to ARMS services (Stowkowy et al., 2013). Help seeking appears more frequently initiated by others in FEP and self-initiated in ARMS (Del Vecchio et al., 2015; Fridgen et al., 2013). Cocchi (2013) found more people with FEP were admitted to psychiatric inpatient units involuntarily than ARMS.

To the authors' knowledge, no qualitative research specifically exploring similarities and differences in PtC in ARMS and FEP has taken place to date. This approach may yield richer insights than quantitative methodologies. Learning in depth about individuals' experiences affords a fuller exploration of contributing factors to treatment delays, and perhaps greater insight into reducing them.

The study aimed to explore the experiences of PtC in ARMS and FEP in the United Kingdom (UK) using an exploratory, qualitative approach. For the purposes of the study, the "end point" of the PtC was acceptance by the Cambridgeshire EIP service. Research questions were: 1) 'what are the experiences of PtC in people accessing services for ARMS and FEP?'; 2) 'what do people with ARMS and FEP feel are the barriers and facilitators to more timely treatment in EIP services?'; 3) 'are there common themes or variation in the experience of PtC between people with ARMS and FEP?'.

Methods[3]

Design and Epistemology

A qualitative design was adopted using semi-structured interviews. A critical realist stance was adopted, within a social constructionist epistemological position.

Expert by Experience Involvement

A Lived Experience Advisory Panel (LEAP) consisting of five people with lived experience of psychosis was formed from an early stage in the study's development. The LEAP contributed to the study by identifying that individual interviews were the most appropriate methodology, co-writing the interview topic guide with SA, as well as amending wording of study documentation to make the language more straightforward and recommending the voucher payment amount (£15).

Study Context

CAMEO (Cambridgeshire Assessing, Managing and Enhancing Outcomes) South team is an EIP service for people aged 14-35 presenting with FEP or ARMS in Cambridgeshire, UK. It covers a population of approximately 450 000, including the city of Cambridge and rural Cambridgeshire (Cambridgeshire & Peterborough CCG, 2013). The majority of the caseload are White British (Clay et al., 2018).

CAMEO's FEP acceptance criteria are: 1) experiencing psychotic symptoms for the first time; 2) <6 months' antipsychotic medication treatment. ARMS patients must:

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[3] See chapter five for additional methodology that for space reasons were omitted from this section. This includes further information about the philosophical position, ethics, procedure, and data analysis.

1) score minimum 5 (“severe”) on a positive psychotic symptom subscale of the Comprehensive Assessment of At-Risk Mental States (Yung et al., 2005); 2) have 30% drop in social functioning (measured by the Social and Occupational Functioning Scale; Morosini, Magliano, Brambilla, Ugolini, & Pioli, 2000). Referrals are accepted from anyone. CAMEO treatment is free at the point of use. Patients receive 3 years’ treatment.

Participants

Participants (*n*=11) were CAMEO South patients in the ARMS (*n*=5) or FEP (*n*=6) pathways, accessing ongoing treatment. Demographic information for each participant given in Table 1. All participants lived in cities; seven were of White British heritage. Inclusion criteria were: 1) aged 16-35 inclusive; 2) have capacity to consent; 3) able to speak conversational level English. Participants were not known to the interviewer (SA) prior to their involvement in the study. They were informed that the study was part of a clinical psychology doctorate thesis, with the aim of building understanding of how service users can be helped to access support at an earlier stage.

Ethics

NHS Research Ethic Committee approval was granted prior to the study commencing (reference 19/LO/0398; Appendix C). See Appendices D-F for study documentation, including the Participant Information Sheet (PIS) and written consent forms. Following the interview, participants were given a debriefing sheet (Appendix G) which listed professionals to contact if they became distressed, although all denied distress.

Table 1
Participant Demographic Information

Participant ID	ARMS or FEP	Age	Gender	Pathway length	No. of different agencies contacted on pathway
A01	ARMS	19	Male	< 6 months	3
F02	FEP	20	Female	> 6 months	5
F03	FEP	21	Male	> 6 months	5
A04	ARMS	23	Male	> 6 months	5
F05	FEP	34	Male	> 6 months	5
F06	FEP	33	Other	< 6 months	3
A07	ARMS	20	Female	< 6 months	4
F08	FEP	21	Male	< 6 months	2
A09	ARMS	22	Female	> 6 months	10
A10	ARMS	22	Female	> 6 months	4
F11	FEP	22	Female	> 6 months	7

Note. ARMS = At Risk Mental State, FEP = First Episode Psychosis

Procedure

See Appendix H for study procedure diagram. Patients were approached by a CAMEO clinician to give written consent to be contacted. The researcher then contacted them to arrange a visit to explain the PIS and answer questions. Participants were given minimum 24 hours after the PIS visit to decide whether to take part. Interviews took place on CAMEO premises or participants' homes and were audio recorded. Participants were paid a £15 shopping voucher as a thank you.

Interviews

Interviews took place between July 2019 and February 2020 and were conducted by SA, a female Trainee Clinical Psychologist studying for a doctorate in clinical psychology with experience of working with people with psychosis, as well as lived experience in this area. Interviews lasted between 19 and 47 minutes. The interview schedule (Appendix I) was written jointly by SA and two of the study's LEAP. Topics included discussion of the agencies the participant accessed before EIP, what was (un)helpful about their experience, and general reflections. The number and duration of PtC were also elicited.

Analysis

Inductive thematic analysis (Braun & Clarke, 2006) was chosen as it was the most suitable method for the epistemological position. No pre-existing codes were used. Interviews were transcribed verbatim by SA and SR. All transcripts were analysed by SA, with the remaining authors analysing two transcripts each (one ARMS and one FEP; 6 total). Analysis took place in accordance with Braun and Clarke's six stages (2006; see Table 2). Data were analysed on NVivo and paper.

Reflexivity

A reflective diary was kept throughout the study. Reflections included the implications SA's lived experience and role as a therapist may have on study objectivity. SA's reflexive position is in line with the critical realist approach that psychosis and psychotic experiences exist in reality but are mediated by how they are viewed by society. This is informed by her own lived experience.

Table 2

Thematic Analysis Process

Analysis stage	Procedure*
1. Data familiarisation	Transcripts read through twice and annotated with notes and initial reflections
2. Coding	Transcripts annotated with initial codes e.g. *'I told my mum I was feeling a bit weird'* -> family
3. Searching for themes	Putting codes together to start to identify themes e.g. family, friends -> personal barrier/facilitator (family and friends)
4. Reviewing themes	Thematic maps drawn. Themes identified compared with initial codes identified in stage 2. Some themes discarded (e.g. "life before, life after")
5. Defining and naming themes	Researcher went back to the data from each theme and constructed a narrative around it
6. Writing up findings	Findings written up in format suitable for journal publication

* further details are given in Chapter 5.

Credibility and Rigour

The study was conducted in accordance with the Consolidated Criteria for Reporting Qualitative Research guidelines (Tong, Sainsbury, & Craig, 2007) in order to maintain credibility and rigour. Steps taken included attention paid to reflexivity, multiple coding, and using NVivo to establish an audit trail.

Results

Pathway to Care Background Information and Context

Table 1 shows participants' PtC lengths (this is divided into long (>6 months) and short (<6 months) in accordance with existing PtC literature (e.g. Birchwood et al., 2013), and for confidentiality purpose). Overall, ARMS participants contacted slightly more agencies than FEP. PtC durations averaged around two years for both groups. See Figure 2 for PtC diagrams (for confidentiality purposes these are combinations of cases).

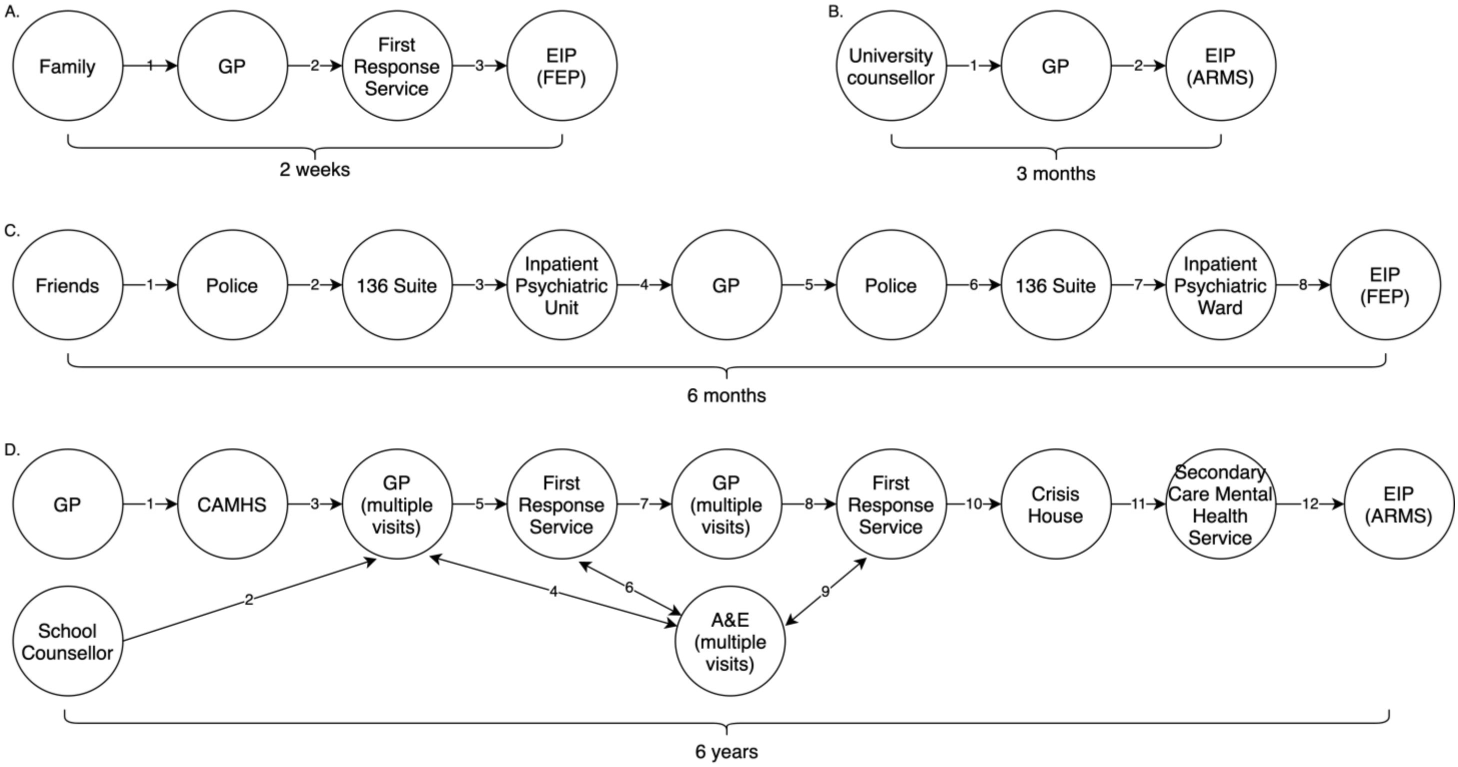

Figure 2. *Example pathways to care diagrams.*

A = FEP shorter pathway; B = ARMS shorter pathway; C= FEP longer pathway; D= ARMS longer pathway. GP=General Practitioner, EIP=Early Intervention in Psychosis, FEP=First Episode Psychosis, ARMS=At-Risk Mental State. First Response Service = crisis mental health support service. 136 Suite = Mental Health Act place of safety.

Eight participants' PtC occurred exclusively in the UK; three sought help in either Denmark, Switzerland or Australia prior to accessing UK services. In terms of services accessed, all but one participant saw a General Practitioner (GP) on their PtC, which included for reasons other than for psychosis (physical and mental health). Six participants accessed one or more non-statutory services, including three from counsellors, three from education, and two with an employment charity.

Four participants (1 ARMS, 3 FEP) had used the First Response Service, a local NHS mental health crisis telephone support line. Only FEP participants had been admitted to inpatient units, accessed community crisis resolution teams, or had police contact prior to accessing the support of EIP services. Three participants (2 ARMS, 1 FEP) attended Emergency Departments (ED) on their PtC.

Experiences of Pathways to Care

A diagram of themes for research question 1 is given in Figure 3. Quotations in italics are verbatim; participants are identified by their ID number (A denotes ARMS and F FEP).

Summary.

Participants' experiences of their PtC varied in terms of duration and services accessed. Three participants described their PtC experience as almost entirely positive:

'[Treatment was] *really good actually'* A01

'*I've had amazing care'* F03

'The transition from no help to help, was really…smooth...and quick' F08

Those who had positive experiences described feeling more hopeful about their journey less alone, reassured by others, and more engaged with services.

The remaining participants expressed more difficult and lengthy journeys to EIP (e.g. ‘*a battle’* A09*,* ‘*willfully obtuse* [systems]*’* A03*, ‘there’s not enough help until it’s too late’* F02*)*. Consequences of negative experiences included feeling rejected, isolated, frustrated, and disempowered and, for some, disengagement. One participant remarked they may not have needed EIP treatment if they received appropriate support earlier:

> *‘I don’t know if there would have been at all journey to [EI team] if I would have got help earlier, like years ago.’* F11

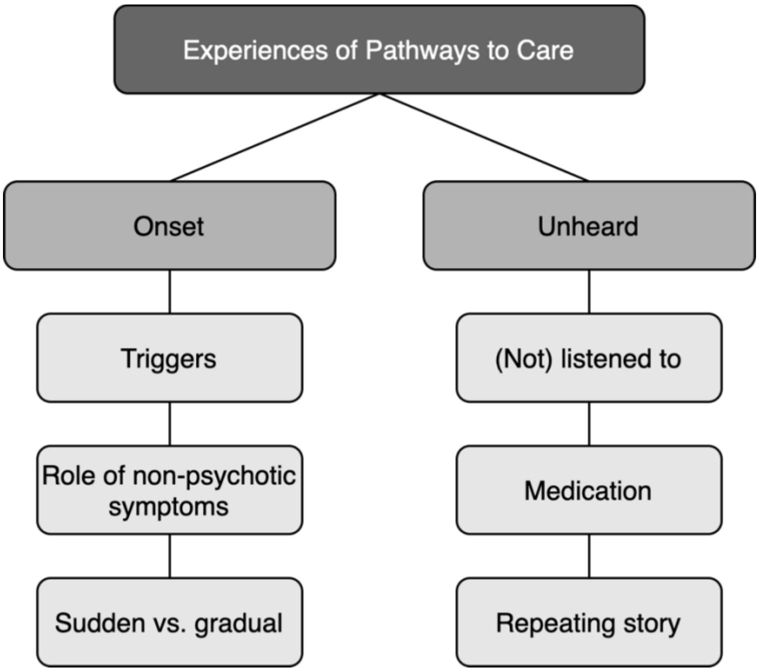

Figure 3. Themes and subthemes for research question 1: experiences of Pathways to Care.

Onset.

Triggers.

This first theme of triggers signifies the beginning of the participants' PtC. Triggers refers to precipitating factors for becoming unwell (including noticeable changes in functioning and behaviour, as well as symptoms), and points leading participants to seek help. Both participant groups identified triggers, including starting university, travelling, and work difficulties. Several ARMS participants identified a *'pushing factor'* (A07) which gave impetus to seek help. This was often when their depression or anxiety escalated. Conversely, many participants with FEP did not identify a point when they actively sought help:

> *'I kind of didn't seek help, that's just it…it got to a stage where…they deemed it necessary to section me'* F05

This was often related to awareness of being unwell (see personal barriers).

Role of non-psychotic symptoms.

Six participants experienced symptoms other than psychotic symptoms prior to seeking help, most commonly depression and anxiety:

> *'I'd been dealing with quite bad anxiety'* A04
>
> *'It started with just depression'* F02

Some people's symptoms included physical health presentations, particularly amongst ARMS participants:

> '*I thought it was sort of like a heart attack erm similar to that'* A01
>
> *'I started kind of like low-level shaking'* A04

Sometimes these experiences were difficult to describe (see personal barriers).

Sudden vs. gradual onset.

Five participants described a sudden onset of psychosis (*'I went bang…it all exploded'* F06, *'suddenly I just kind of snapped'* F03). All but one participant with a sudden onset had FEP. Others, particularly ARMS participants, described more gradual build-ups (*'I'd always felt unwell to a certain extent'* A07, *'bubbling under the surface'* F06). Participants with more positive experiences tended to have more rapid onset of symptoms.

Four participants tended to initially "brush off" what was happening, e.g. by attributing symptoms to a different factor:

'[I] *thought…it'll kind of tail off eventually'* A01

'At the time I assumed it was because of the work-related break down' F05

This was particularly the case for those with gradual onset. The "brushing off" of these experiences often led participants not to seek help.

(Un)heard.

Seven participants felt unheard by professionals. Two participants had the opposite experience, feeling heard and listened to.

(Not) listened to.

Across almost every service accessed by participants (both ARMS and FEP) was a clear sense of not feeling listened to, particularly by General Practitioners. This was associated with not being taken seriously. Not being listened to led participants to feel unheard, misunderstood, frustrated and rejected. For several this experience occurred across several services:

> *'It was another case of he didn't seem like he was really listening to me or cared what I was saying'* A04

Not being listened to was also directly affected participants' subsequent service use: either by disengaging with that service (mostly FEP participants), or making repeated attempts to access services (almost exclusively ARMS participants):

> *'I tend not to go to the doctor because I feel like they don't listen to me'* F06
>
> *'I've wasted many GP's time…because I was desperately trying to get help'* A09

For many, not being listened to led to treatment delays:

> '*I think it takes so long to get the support you need and for someone to actually listen'* F02.

Some participants *did* feel listened to, which made them more likely to engage with services. This was particularly the case for the First Response Service:

> *'They [FRS] knew exactly what to do…they were very nice…understanding…I feel like they knew what I was going through'* F08

For one participant the fact they were listened to was the highlight of their experience of the service: '*that was probably the best thing about it, he listened*' (F05).

Medication.

ARMS and FEP participants felt unheard about medication. Some participants felt pressurised to take medication, when they would have preferred psychotherapy:

> *'It was very "medicate her as soon as possible"…I just feel that people are too quick to put people on medication'* A09
>
> *'If they would have talked more instead of like just medicating you'* F11

One (FEP) participant had the opposite experience and wanted to be put onto medication at an earlier stage:

> *'I think they want you to try so many things before even trying medication so it takes a long process to get there'* F02

Repeating story.

A related theme to (not) being listened to was participants needing to repeat their story. This was identified by ARMS participants in particular, two of whom stated this was the most challenging aspect of their PtC. One participant stated repeating their story about a traumatic event was particularly challenging as it triggered difficult memories:

> *'It was very hard…you're reliving the worst bits but nothing positive's ever said'* A09

Two participants felt that repeating their stories meant they felt detached from their own experiences:

> *'I guess repeating it took something away from it because it felt like I was just telling a story at some point and so…it was…detaching'* A07

For some repeating their experiences was so distressing it led them to disengage.

Barriers and Facilitators

See Figure 3 for a diagram of themes for research question 2. Participants faced significant barriers. Many themes were both barriers and facilitators, as they had either positive or negative effects on experiences.

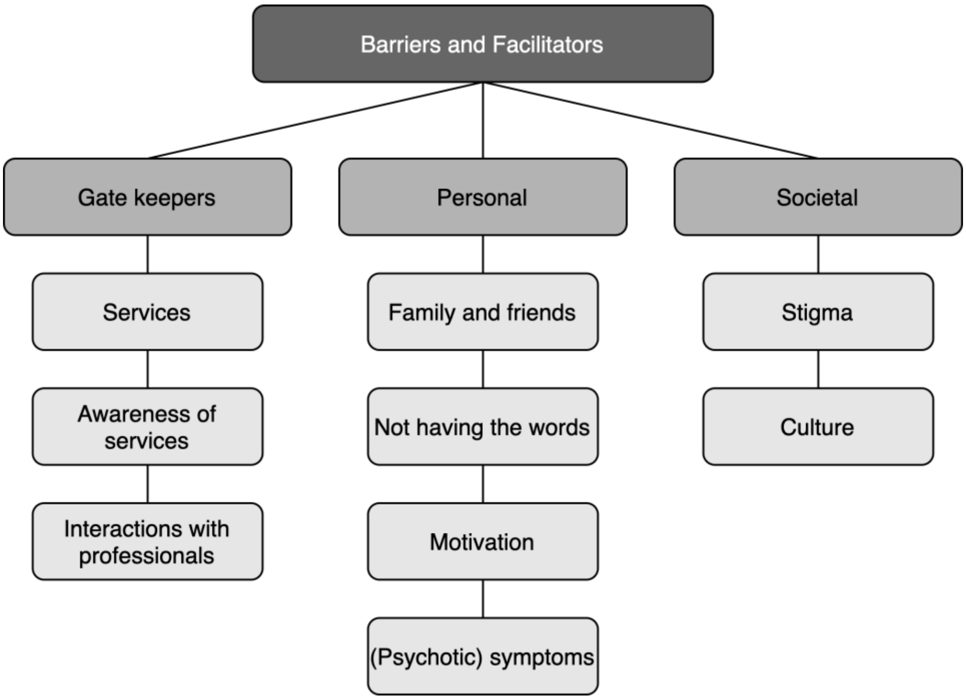

Figure 4. Themes and subthemes for research question 2: barriers and facilitators to accessing Early Intervention in Psychosis services.

Gate keepers.

Services.

Service level barriers included waiting lists, continuity of care, and financial constraints. Treatment delays sometimes led to participants reaching crisis point before gaining appropriate help:

> *'To get my help it felt like I had to go completely insane...before anyone actually listened'* F02
>
> *'You know even with several attempts at trying to kill myself, you know it's not working, what can I do'* A09

Waiting lists were identified as a barrier by ARMS participants. One participant described this as being *'left on hold'* (A07).

There was a general sense of services being disconnected from each other, e.g. staff going on holiday and not following up referrals, resulting in a 6-week delay (A04); services disagreeing who would provide support inpatient discharge (F02); and seeing different staff at each crisis team visit, leading to having to repeat their story (F03). This led to frustration and feeling rejected. For FEP participants this lack of continuity tended to lead to disengagement from services; ARMS participants seemed better able to persevere and be more pro-active, e.g. making follow up telephone calls.

A significant service level barrier was finance and lack of resources. Many people, particularly ARMS participants, experienced their appointments being cancelled due to services having funding cut:

> *'They told me would take 18 months for me to get my first appointment. So I was dropped and left…they emailed me to say the funding had been cut and it wouldn't happen'* A09

Cuts to finances left participants unable to access the help they needed, often leading to worsening of symptoms. Finance was a particular barrier outside the UK: two participants could not have psychotherapy due to insufficient insurance. Once again this led to participants being missed bv services, resulting in deterioration in their mental health. This often meant more treatment was required from specialist services later on.

Awareness of services.

Lack of awareness of services was another factor in not reaching the right help:

> *'I didn't know what sort of help I was looking for, I just knew that I needed intervention'* A07
>
> *'It's knowing who to reach out to at what point'* F05

This led to people being unsure of where to go to get help, which was associated with treatment delays. For some participants, this lack of awareness extended to psychosis itself:

> *'I mean before having psychosis, I'd never heard of that, so let alone knowing where to go to get help'* F05

Participants recommended that EIP services promote themselves more, especially to GPs.

Interactions with professionals.

Participants had mixed experiences with individual staff members. Some participants felt heard and understood by professionals:

> *'They [FRS] were really like gentle and kind with me'* (F08)
>
> *'He [GP] was…very calm and listened to me… so I found it quite easy to be quite honest with him.'* (A09)

A09 felt able to speak openly about their symptoms as a direct consequence of the GP's manner. Positive staff interactions led to feeling accepted and meant participants felt able to "open up" about their symptoms, perhaps leading to quicker EIP referrals.

Difficult experiences included feeling patronised and unheard:

> *'…Completely ignoring everything I was telling him and was just like kind of dismissing it and like being quite patronising'* A04

Two participants had a particularly challenging experience with ED staff:

‘The doctor walked in and said “what are you doing on the bed, you don’t need the bed, you’re here for your head aren’t you”. And it was that terminology that was so isolating that I actually found myself…going “yeah I am here for my head, ok I’ll go’ A09

‘She seemed a bit disapproving….like I was being stupid and wasting her time’ F03

This experience led to A09 leaving ED prior to an assessment being carried out. Negative interactions led to feelings of rejection and frustration, and either repeated help seeking elsewhere (ARMS), or sometimes disengagement (FEP).

Personal.

Family and friends.

Significant others were key facilitators of timely treatment in both participant groups. Nine participants contacted family or friends on their PtC. Many attended appointments accompanied by significant others. Sometimes family sought help from services on the person’s behalf: in some cases, the person would not otherwise have sought help:

‘She [participant’s mother] *wanted me to see the GP…I didn’t want to do that, because I felt like nothing was wrong with me…but then I said fine, I’ll do it’* F08

Sometimes family and friends were barriers to appropriate treatment:

‘I remember my cousin said to me don’t talk to them, don’t tell them anything’ F08

‘When I did try to tell my mum…that I’m struggling… she obviously got worried and she spoke to my uncle...and my uncle just sort of you know said that I’m homesick and it…undermined what I was feeling’ A07

The latter participant identified that their mother's reaction was linked to their cultural background, where mental health was often viewed as shameful (see "culture").

Not having the words.

Many participants struggled to express their symptoms, especially psychotic experiences. Not having the language limited how they could communicate with others, leading to treatment delays, e.g. one participant was discharged from ED because they were not able to express the extent of their psychotic symptoms:

> *'Not because I didn't want to tell him but because I just didn't know how to'* A01

This led to a readmission to ED later on due to their symptoms worsening.

For some, not having the right words added to a sense of not being listened to:

> *'I thought that I had, I tried to explain to him, so it's kind of like, what am I meant to do in this situation?'* A04
>
> *'I try to use my words very carefully, I mean very specific things, but very often I feel when people listen, they don't take the meaning of what I'm actually trying to get across'* F06

This led to further frustration and additional help-seeking attempts (mostly ARMS participants), or disengagement (mostly FEP participants).

Motivation.

The need for motivation in help-seeking was identified in ARMS participants, who were more likely to actively seek help. Many ARMS participants needed to persevere with rejection from services prior to acceptance from EIP. For instance, participants needed motivation to telephone services to chase referrals, and attend multiple appointments with different agencies. One participant remarked:

> *'I think there definitely needs to be an easier way of individuals who have the strong will that are fighting against everything'* A09

(Psychotic) symptoms.

Four participants had symptoms that were barriers to seeking help, including paranoia (*'I just felt quite guarded'* (A10) and hallucinations. Non-psychotic symptoms included mania (*'Because why would you want to get with something if you're feeling really good?'* (F08)), poor concentration, confusion and disorientation.

Several FEP participants did not seek help because their psychotic symptoms were associated with a lack of awareness that they were unwell. Two participants felt that in hindsight they were acting differently:

> *'I didn't think anything was wrong but clearly looking back…it was obvious'* F08
> *'I didn't really recognise whereas now I can look back and go…I should've done something or seek somebody but I just didn't'* F05

Societal.

Stigma.

The influence of stigma on help-seeking was identified by five participants (mostly FEP). This manifested itself as worries of being seen as weak, different, or a failure:

> *'I didn't obviously want to kind of let on that I was any different because I didn't want people to kind of erm to think I was like weird…I didn't want to make it like a sign of weakness'* A01

These concerns led to this participant not disclosing the extent of their psychotic symptoms in ED. This resulted in being discharged, which necessitated a re-admission shortly afterwards.

Some participants conflated mental health difficulties with failure:

> *'I have a lot of pride and it's hard for me to think I was failing…so I didn't really want to reach out to her'* F02

A fear of being perceived as a failure led to this participant not accessing support from a family member.

Culture.

The impact of culture on mental health PtC was identified by one ARMS participants, who was of Asian heritage. This was a significant part of their narrative. Culture was linked to talking about feelings and language use:

> '*I think it's culture that we're not that ready to talk about our feelings…It's the….linguistic capacity. We don't use that language in our daily conversations and therefore a lot of the terms that we use to describe our mental states aren't…used in everyday conversation…That's why I wasn't telling anyone.'* A07

This led them not to discuss their psychotic symptoms with their family.

Another participant felt a change in culture was necessary for mental health to have parity of esteem with physical health:

> Interviewer*: 'So maybe it's a perception that it seems, that physical health seems more important than mental health?'*
>
> Participant: *'Yeah, yeah definitely and I think that needs to change and that's a shift in culture'* F05

They suggested public education about mental health and psychosis was needed.

Discussion

The study revealed the perspectives of 11 EIP patients accessing an EIP service in Cambridgeshire, UK. It aimed to investigate their experience of accessing services, barriers and facilitators, and commonality of themes between ARMS and FEP participants. Overall, most participants had negative experiences, with significant treatment delays which often exacerbated distress. Key barriers and facilitators included service structures, individual care professionals, personal factors and societal barriers. Most themes applied to ARMS and FEP participants. While further research is required, it seems service-level interventions are warranted, particularly for General Practitioners, if people with psychotic experiences are to access treatment earlier.

Many participants sought help before developing psychotic symptoms (mostly depression and anxiety). These non-specific symptoms are typical of the psychosis prodrome (Yung & McGorry, 1996), but are associated with less successful help-seeking compared to "positive" psychotic symptoms (Anderson, Fuhrer, & Malla, 2010; Stowkowy et al., 2013). This poses challenges for services given how many people with anxiety and affective symptoms do not develop ARMS or FEP. Participants struggled to articulate their "positive" psychotic symptoms, which contributed to a sense of not feeling heard or understood, as well as being missed by services. Screening tools in primary care, or educational settings (e.g. the Community Assessment of Psychic Experiences; Mossaheb et al., 2012) may be warranted so that the right questions are asked in order to facilitate a helpful dialogue.

The literature deems inpatient units, crisis teams, and police as "negative" PtC (Anderson et al., 2013). While some participants undoubtedly had very difficult experiences in these settings, others described these more positively. This study highlights the importance of subjective experience, and of not making assumptions.

Across almost every service accessed by participants was a clear sense of not feeling listened to. There is some evidence to suggest shared decision making (SDM) leads to improved outcomes (Joosten et al., 2008). Lack of SDM led to repeated healthcare contacts or disengagement, both of which are costly for healthcare services.

Participants identified that staff attitudes have a significant impact on service engagement. Lack of awareness about services for psychosis was also apparent. Staff training is known to increase referral rates to EIP services (Power et al., 2007; Reynolds et al., 2015), and was suggested by participants themselves. The significant numbers of personal barriers to treatment mean that services need to be as accessible as possible.

In common with existing research, stigma was a barrier to help seeking (Gronholm, Thornicroft, Laurens, & Evans-Lacko, 2017; Hardy et al., 2020; Uttinger et al., 2018), including for those accessing mental health support in general acute healthcare settings (Perry, Lawrence, & Henderson, 2020). Further anti-stigma campaigns (e.g. Connor et al., 2016) may be warranted. Given the role of culture in help seeking, it is important for these interventions to be culturally appropriate. Other healthcare areas such as HIV have adapted public healthcare interventions for ethnic minorities (Fish et al., 2016).

Common Themes and Variations

Conclusions about the overlap of themes between ARMS and FEP participants must be cautious due to small sample sizes and the nature of qualitative methodology. The majority of themes overlapped between ARMS and FEP. This reinforces the need to examine why so few FEP patients access prodromal services (Ajnakina et al., 2017). It also points to the fact that PtC should be improved for both groups.

Nevertheless, patterns emerged which require further exploration. Unlike ARMS participants, some FEP participants lacked insight into their difficulties, and relied on significant others to seek help for them. FEP participants seemed to have a prodromal phase but either did not seek help then or their prodromal psychosis was overlooked by professionals. Indeed, social isolation and not being in a relationship are associated with longer care pathways in FEP (Anderson, Fuhrer, & Malla, 2010; Heslin et al., 2011). This reinforces the importance of public health interventions about psychosis so families are aware of EIP services. Perhaps as a consequence of lacking in insight, only FEP participants were used inpatient psychiatric care or crisis teams, or saw police. This too chimes with existing research showing participants with ARMS are less likely to be compulsorily detained than in FEP (e.g. Cocchi et al., 2013; Valmaggia et al., 2015). This is perhaps to be expected given ARMS patients are by their nature presenting with less severe symptoms than FEP.

ARMS participants in this study tended to show higher levels of motivation to seek help than FEP, describing needing to fight to get appropriate help. High levels of motivation seemed to facilitate being taken more seriously by healthcare professionals and perhaps a greater rate of onward referrals. Conversely, lack of motivation was a barrier to achieving appropriate support for many people with FEP, in keeping with literature that “negative” psychotic symptoms are associated with longer PtC (Anderson et al., 2010).

Strengths and Limitations

The study is, to the authors’ knowledge, the first research of its kind in the UK. It therefore provides important preliminary findings into the experiences of patients with ARMS and FEP about accessing support prior to EIP teams, as well as barriers and facilitators. There are important implications for NHS service development and commissioning. The study benefitted from the perspectives of several patients from ethnic minority backgrounds, which was a strength given the majority of the CAMEO South caseload is White British (Clay et al., 2018). The fact that the interview was co-produced by experts by experience is also positive.

The study is limited by interviews being from people who were actively engaged with the service, giving a partial perspective about PtC in ARMS and FEP as a whole. Participants access one EIP service only, meaning that any extrapolation of findings should be cautious. Interviews were relatively short; additional interviews were planned but not possible due to COVID-19. PtC information should be viewed with caution as a standardised tool was not used. While every attempt was made by the researchers to “bracket” their pre-existing assumptions and experiences (Fischer, 2009), these were inevitably an influence on the study design and analysis.

Clinical and Research Implications

Clinicians should be aware that the person they are seeing with ARMS or FEP will likely have encountered significant barriers to being seen, including being rejected by other services and concerns about stigma. They should listen to the person’s concerns and refer to the appropriate EIP service at the earliest opportunity. Practitioners should specifically ask questions about the presence of “positive” psychotic symptoms to people presenting with symptoms of depression and anxiety, as psychotic experiences may be difficult to articulate.

Further research in the NHS context with larger samples would be advisable using clinical interviews (e.g. the Pathways to Care Interview; Perkins, Nieri, Bell, & Lieberman, 1999) or medical records. Adopting a quantitative approach to these is likely to yield insights for a greater number of participants that may be more generalisable for the ARMS and FEP population.

An exploration of healthcare staff perceptions on the topic may be beneficial to triangulate findings and to explore how services could be improved. Further intervention studies (both service and population-level) are needed to examine how Duration of Untreated Illness (DUI) and DUP can be reduced, as recommended in recent systematic reviews (Allan et al., 2020; Oliver et al., 2018).

In summary, people with ARMS and FEP face significant obstacles in accessing appropriate treatment, despite timely treatment being cost-effective. Further research is required if DUI and DUP are to be reduced and people to be treated at the earliest opportunity.

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Chapter Five

Additional Methodology

Word Count: 3 645

Chapter Five

Additional methodology for the Empirical Study

This chapter provides supplementary information about the methodology for the empirical study, in order to provide additional context to the empirical paper. It covers more information about the background to the study (rationale for qualitative framework and for thematic analysis, philosophical position), extended methods, and section expanding on the data analysis part of the empirical paper. Personal reflections (indicated in italics and written in the first person) are based on extracts from the researcher's reflective journal.

Introduction

Rationale for qualitative framework.

Pathways to Care (PtC) in early psychosis has been studied both quantitatively and qualitatively. Systematic reviews in the field have focused exclusively on quantitative studies (Anderson et al., 2010; MacDonald, Fainman-Adelman, Anderson, & Iyer, 2018; Singh & Grange, 2006; Volpe, Mihai, Jordanova, & Sartorius, 2015), due to the focus on measuring the lengths and duration of PtC. The systematic review in this thesis (Allan, Hodgekins, Beazley, & Oduola, 2020; chapter 2) found two qualitative papers of the total ten. It seems qualitative research has been a relatively neglected area in the field.

Studying PtC quantitatively using a positivist epistemology has the advantage of larger sample sizes and ease of group comparison, perhaps leading to findings that are more generalisable (Yilmaz, 2013). However, there are several methodological limitations of current quantitative approaches in the PtC literature, including that studies have varying definitions of PtC, come from countries with different healthcare systems, and rarely use standardised tools for measuring PtC (Allan et al., 2020; Singh & Grange, 2006). This renders generalisability difficult, perhaps limiting the utility of the research. While quantitative approaches can give information about the broad nature of the PtC (long, short etc.), they cannot ascertain what the experience of the individual's PtC was like, nor the implications that positive or negative experiences have at an individual level. A qualitative approach allows for the experience of the participant's pathway to be understood with a greater level of complexity. It also allows for detailed discussion about individual factors (such as staff reactions or attitudes) that may have led to a more straightforward pathway. Gaining information at this level of detail may have important implications for planning services and informing further quantitative work.

Philosophical position.

It is important for qualitative research to take a philosophical position, which includes ontological and epistemological perspectives. Ontology refers to the nature of reality; epistemology the nature of knowledge (Merriam & Tidsell, 2015). The portfolio took a critical realist ontological stance, within a social constructionist epistemological position. A critical realist approach combines positivist and constructivist positions, and posits that there is an objective reality that exists, but this is mediated by our own perspectives, experiences, and world views, thus we cannot be certain about the world (Fletcher, 2017; Maxwell, 2012). In critical realism, data can tell us about reality but is not a direct mirror of it (Harper, 2011). So for instance, the researcher believes there is such a thing as the objective concept of the diagnoses of At-Risk Mental States (ARMS) and First Episode Psychosis (FEP), but this is constructed by participants according to what they considered was important and how they interpreted the concept. This fits with a social constructionist epistemological position, where knowledge is situated within a wider historical, social and cultural context, and what is said in the interviews reflects this (Harper, 2011).

Rationale for Thematic Analysis.

Thematic analysis was chosen as it was deemed to fit best with the epistemological position and in order to answer the research questions. Interpretive Phenomenological Analysis (IPA) was considered but IPA's phenomenological epistemology stance means any sort of objective reality is rejected. Similarly, grounded theory was not compatible with a critical realist ontology and was also not appropriate due to the lack of existing research in the field (Fletcher, 2017; Tweed & Charmaz, 2011). Thematic analysis is also a method well suited to early stage qualitative researchers due to its accessibility (Braun & Clarke, 2006).

Service user involvement.

A Lived Experience Advisory Panel (LEAP) was formed for the purposes of the study. This consisted of five experts by experience (3 male, 2 female), who all had lived experience of psychosis. The LEAP were paid £10 an hour for their time, funded by the Cambridgeshire and Peterborough NHS Foundation Trust Research & Development department. Meetings were held in Cambridge and Peterborough. During the meetings the LEAP contributed to the design of the study, commented on study documentation, and assisted with decision making about payment (e.g. the study originally planned to give participants a £10 voucher for their time; the LEAP felt it was more appropriate to pay £15 in order to cover travel expenses). At a separate meeting two of the panel wrote the interview schedule with the researcher (the three others were invited to this meeting but were not able to attend). One member of the LEAP contributed to and approved the interview schedule via email. A summary of the results of the study were sent to the LEAP members by email.

Methods

Ethical considerations.

The study was conducted in accordance with British Psychological Society ethical guidelines (British Psychological Society, 2014, 2018). The study was approved by the Health Research Authority prior to commencing (Reference 19/LO/0398; Appendix C). The University of East Anglia acted as the sponsor for the research. The research took place in Cambridgeshire and Peterborough NHS Foundation Trust (CPFT), who confirmed they had capacity and capability for the study to take place (Appendix J).

Capacity and consent.

Participants were only approached about the study if the clinician approaching the patient deemed them to have capacity to consent according to the Mental Capacity Act (2005). Participants gave written consent to be contacted about the research (Appendix D), which was taken by a Cameo South clinician who was known to them.

The Participant Information Sheet (PIS; Appendix E) gave sufficiently detailed information about the study in order for participants to gain full informed consent to participate. The wording of the PIS was amended and approved by the study's Lived Experience Advisory Panel prior to being submitted for ethical approval. At the PIS visit participants were given the opportunity to ask questions about the study. Participants were given a minimum of 24 hours after the PIS visit in which to decide whether they would take part in the study or not, and were encouraged to discuss their participation with friends or family, as well as their care team. Written consent was gained prior to the interview taking place (Appendix F).

At all times during the consent process it was emphasised that taking part in the study was entirely optional, was confidential (see below), and taking part (or not) would not affect their clinical care, including if they withdrew from the study.

Deception.

There was no deception associated with this study. Participants were informed from the outset the full rationale for and purpose of the study.

Location of the interviews.

Interviews took place in clinical bases used by the Cameo team and at participants' homes. Home visits were conducted in accordance with the Trust lone working policy (CPFT, 2018) and the Cameo local policy. This included writing the name of the participant and estimated return time on a whiteboard in the Cameo South office and phoning the duty worker to confirm the interview had taken place. Interviews only took place at a participant's home when it was confirmed this was safe to do so by a member of the clinical team who knew the participant and their home environment well.

Confidentiality and data storage.

Participants were informed that taking part in the study would be confidential, including in written information (PIS) and verbally, with the only exception being if the researcher was concerned that there was risk of harm to the participant or a third party. There were no instances where confidentiality needed to be broken during the study.

All written information containing participants' names (e.g. consent forms) were stored in a locked filing cabinet in the Cameo South office in a separate folder for each participant. They will be destroyed after 10 years. Any electronic identifying information, for instance a recruitment log which included participants' names, was saved on a password protected NHS computer accessible only to SA. Participants were allocated an identification number which was used in all other documentation and to identify the audio recordings. Interviews were recorded on an NHS-issued Dictaphone and transferred onto a password protected NHS computer as soon as possible after the interview. During transcription any identifying characteristics (e.g. family members' names) were removed.

Confidentiality was carefully considered during the writing of the empirical paper. It was decided by the research team that a table containing participants' demographic information would not be included in order not to identify them. Similarly, PtC diagrams were combinations of cases.

Potential risks and benefits to the study.

The potential risks and benefits to the study were presented in the PIS (Appendix E). The only identified risk to taking part in the study was the chance of a participant becoming distressed by recounting the details of when they first became unwell. Several steps were taken to mitigate this (see 'Distress'). There was no direct benefit to participants for taking part, except for a £15 shopping voucher given as a token of appreciation of the participants' time and to cover any travel expenses. This sum was chosen by the Lived Experience Advisory Panel.

Distress.

When planning the study it was anticipated there would be a low likelihood of participants becoming distressed during the interview, based on the opinion of senior clinicians in the Cameo South team and research evidence (e.g. Jorm, Kelly, & Morgan, 2007). The possibility of distress occurring as a result of the study was documented in the Participant Information Sheet (PIS; Appendix E) and discussed at the time of the PIS visit. No participants anticipated distress occurring as a result of the study during the PIS visit, but had they done so they would have been encouraged to think carefully about participating in the study, or consider not taking part. No participants appeared distressed during the interviews and all denied being distressed at the end of the interviews. However had they become distressed they would have been given the option to have a break or terminate the interview. As a precaution, a debriefing sheet (Appendix G) was provided to all participants after the interview. This included the contact details for the Cameo team and out of hours emergency telephone numbers.

Supervision.

It was important to use supervision to reflect on the interviews, as well as to process reactions to hearing potentially emotive accounts of help-seeking. Allowing space for reflection in supervision was necessary given the potential for countertransference, which may have had an impact both emotionally on the trainee and in the process of conducting subsequent interviews (Holmes, 2014). This ensured that the process was carried out safely for both the researcher and participant. Thus a discussion of the personal impact of the research was a regular supervision agenda item.

Rationale for number of participants chosen.

The study aimed to recruit between 8 and 12 participants for the research. This was in line with existing qualitative studies in the field (Boydell, Stasiulis, Volpe, & Gladstone, 2010), guidelines for data saturation in qualitative research (Guest, Bunce, & Johnson, 2006), as well as what was feasible in the time available to conduct the thesis.

It was originally anticipated that interviews would last approximately one hour. However in reality they were shorter than this, with a mean interview length of 30 minutes. In hindsight it may have been beneficial to pilot the interview. Further interviews were planned to address this limitation but were not possible due to COVID-19 and resulting university restrictions adopted. Nevertheless, the interviews generated a significant amount of data and subjectively it appeared that data saturation had occurred.

Personal reflections on the interviews.

Overall, I enjoyed the interviews. It was a privilege to hear the participants' stories. I was impressed by the bravery they showed in recounting often difficult experiences to a stranger. Many participants stated they wanted to take part in order to make things better for other people seeking help for psychotic experiences, which I felt humbled by. I hope that this piece of research will have as tangible impact as possible in order to fulfil their hopes.

The interviews were challenging because they were an experience of being one-to-one in a room with a patient but not delivering therapy. This became particularly apparent when I joined the service I was recruiting from as a specialist placement. This conflict left me unsure about my therapeutic style of interviewing. I wanted to make participants feel as comfortable as possible, and found myself unwittingly commenting on their experiences and offering validation (e.g. "that sounds scary", "what a long journey you've been on"). I wondered if this was appropriate and as a researcher I should have been taking a more "objective" stance. Was I making the interviews a therapeutic encounter? Was I being "too much of a therapist?" Was it even possible to "bracket" my therapy experiences as a trainee clinical psychologist (Fischer, 2009)?

I came to the conclusion that I was bringing my authentic self to the interviews, which included my experiences of delivering therapy and conducting research. I realised that it was positive that I recognised the tension between being a therapist and researcher/interviewer, and the impact this may have both on the interview and the participant's experience of being interviewed. I was able to engage participants in the *interview process and hope that by bringing my skills of building rapport and being empathic I was able to put participants at ease.*

Transcription.

Data were transcribed verbatim onto a Microsoft Word document. Six were transcribed by the researcher (SA), and five by the CAMEO Assistant Psychologist (SR). Any identifying details (e.g. names) were removed from the transcripts.

Data Analysis

Stages of analysis.

In accordance with Braun and Clarke (2006), the data analysis took part of six broad stages: data familiarisation, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and writing up findings.

1. Data familiarisation.

The first stage of analysis took place on paper. Transcripts were read through twice and annotated with ideas and notes. ARMS transcripts were read first, followed by FEP to help inform the answers to research question three (whether there were overlapping themes or differences between ARMS and FEP participants. This was an important step even though the researcher had conducted the interviews and thus was familiar with the content of them (Braun & Clarke, 2006).

2. *Generating initial codes.*

Coding took place on NVivo version 12 as this enabled common codes to be identified more easily than on paper, and to have a clearer audit trail of the process. Transcripts from ARMS participants were coded separately to FEP. Coding was conducted as broadly as possible, with 90 codes initially generated. Examples of codes are given in Table 1.

Table 1
Initial coding examples

Participant	Data extract	Initial Code
A01	*'Not because I didn't want to tell him but because I just didn't know how to'*	Not being able to find the words
F03	*'I told my mum I was feeling a bit weird'*	Role of family
A04	*'And then in February it pretty much all came at once'*	Came on quickly

3. *Searching for themes.*

Given the amount of codes, it felt more manageable to conduct this stage of analysis on paper. This method is recommended by Braun and Clarke (2006). At this stage codes were put together to start to form themes. This was an active and iterative process rather than themes simply "emerging" (Braun & Clarke, 2012). Post-it notes were used on large sheets of paper, with one piece of paper for each of the first two research questions. Different coloured post-it notes were used to indicate whether the theme related to ARMS, FEP or both (see Figure 1). Notes were kept throughout the process, both in the researcher's reflective journal and on the pieces of paper themselves.

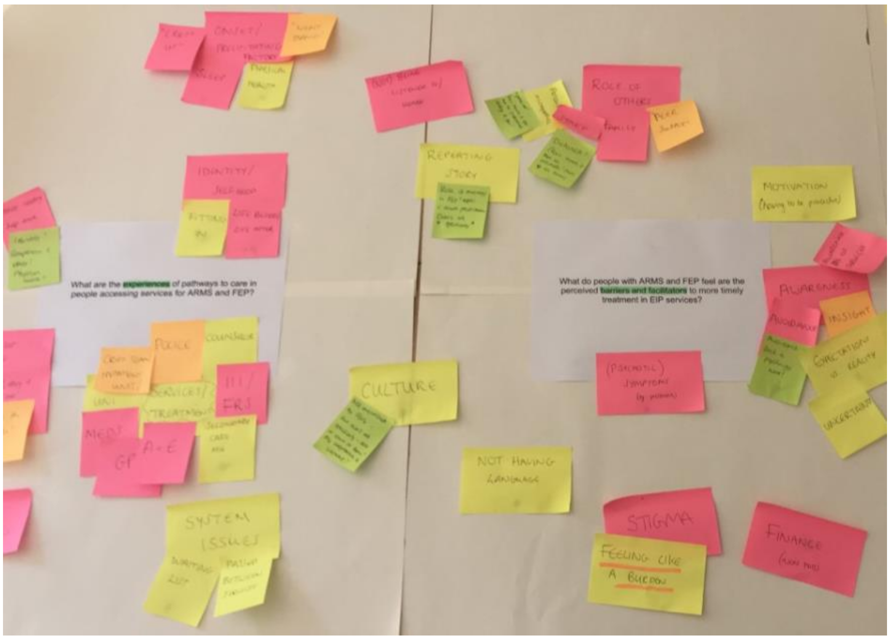

Figure 1. Pen and paper analysis: searching for themes.

Figure two shows a preliminary diagram that was developed during this phase in order to help shape ideas. After discussions in supervision and further examination of the research questions, it was agreed the coding structure should be divided into two parts (one for each research question).

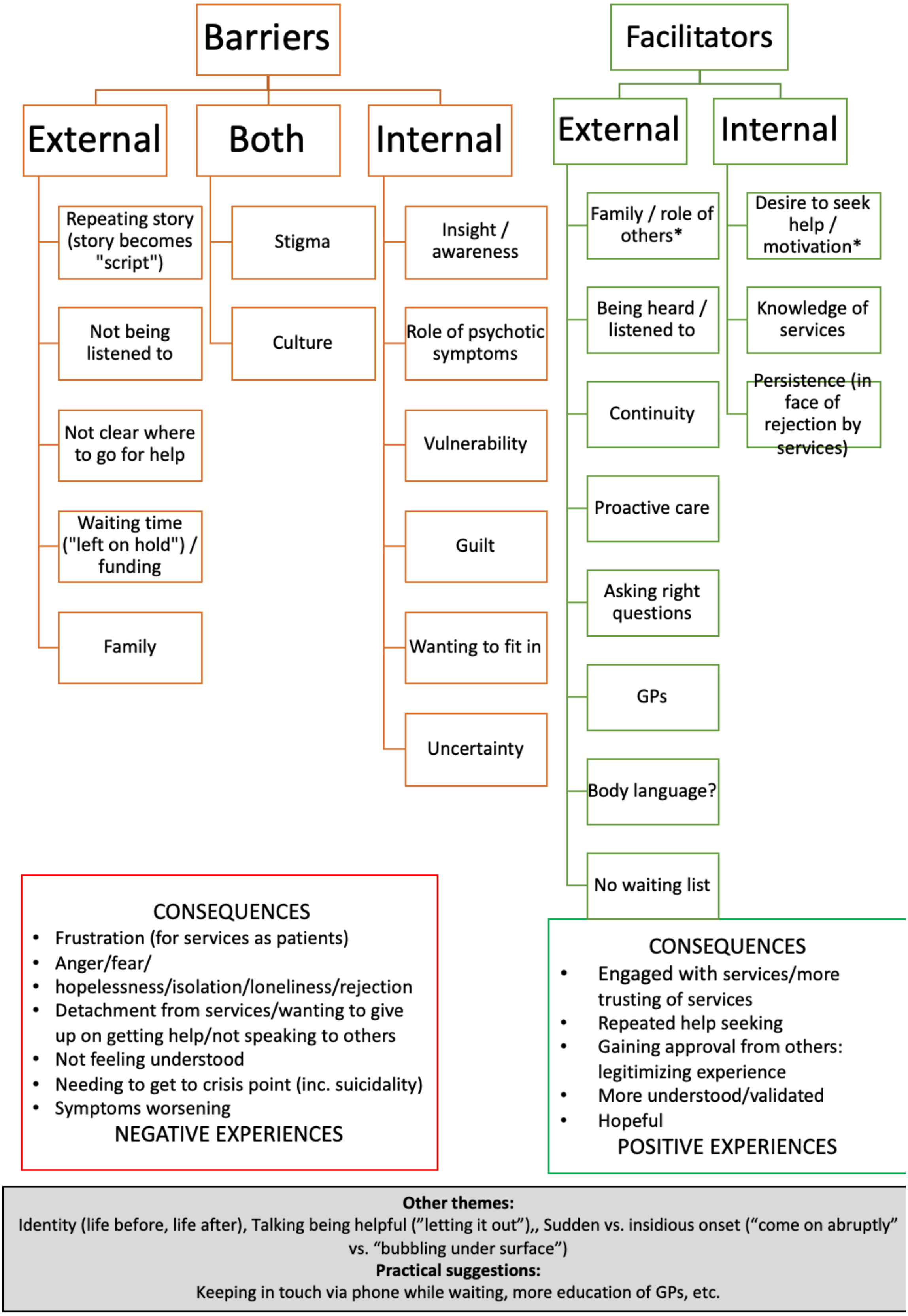

Figure 2. Preliminary diagram.

4. *Reviewing themes.*

Themes that had been identified so far were compared against the initial coding of the data by going back through each transcript on NVivo. This led to some themes being discarded. For instance, the theme of "identity"/"life before, life after" was omitted as this seemed to refer to the experience of becoming unwell rather than an experience of the PtC. At stage discussions about the proposed themes were had both in supervision and with trainee colleagues in order to clarify thinking about the themes. This led to several themes being shifted around and renamed: for instance, "external" barriers was divided into "gatekeepers" and "societal" barriers. After this stage two maps of themes was drawn, representing answers to research questions one and two (Figures 3 and 4).

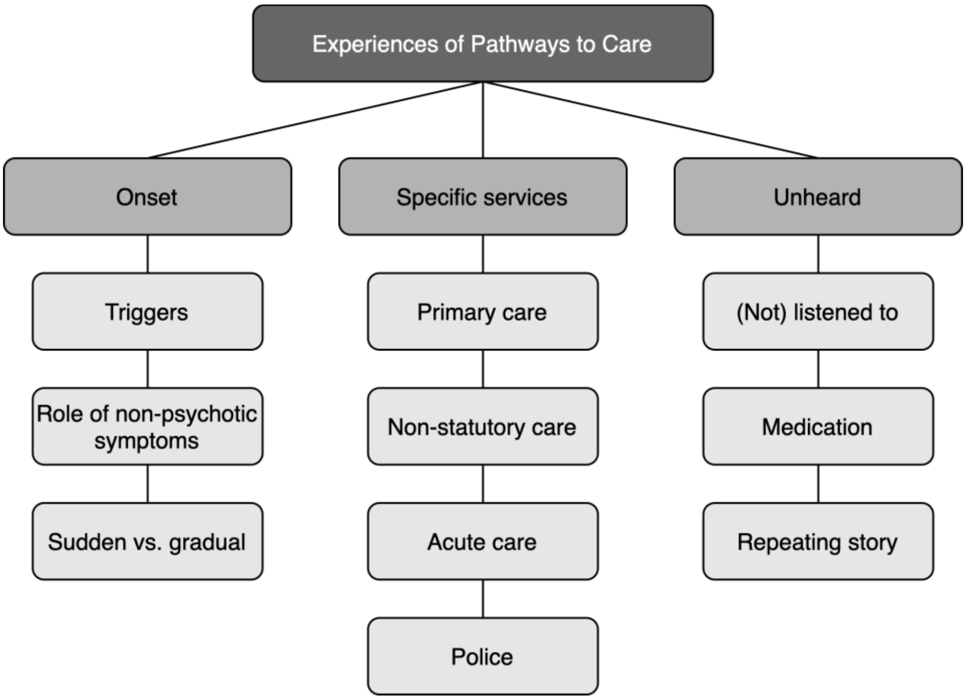

Figure 3. Themes and subthemes for research question 1: experiences of Pathways to Care.

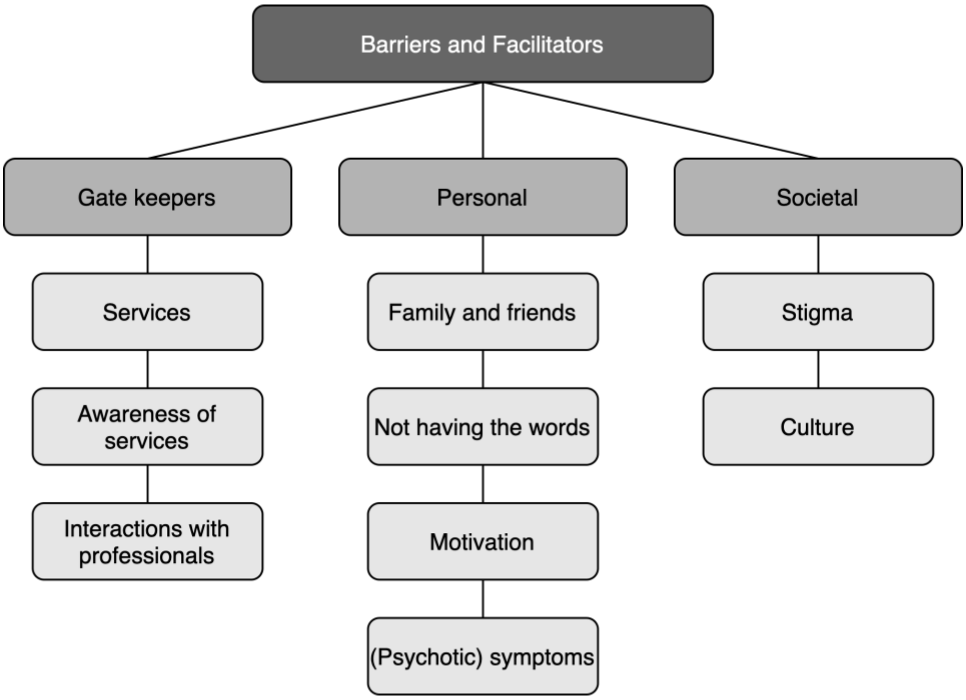

Figure 4. Themes and subthemes for research question 2: barriers and facilitators to accessing Early Intervention in Psychosis services.

5. *Defining and naming themes.*

Defining the themes that were given on the thematic maps was conducted by going back to the data from each theme and constructing a narrative around it. The researcher had further discussions to ensure each theme could be described concisely. This process was refined as the results were written up: Braun and Clarke (2012) identify that stages five and six often overlap.

6. *Writing up findings.*

Findings were written up in journal article format. First of all the results were written without paying attention to the word count in order to ensure nothing was missed. Quotations were used for each theme in order to provide evidence of it (Braun & Clarke, 2006). Following the full writing of the results, the section was cut down to conform to the word count allocated by the journal.

Personal reflections on analysis.

I found the process of analysis extremely rewarding at the end but at times overwhelming. I felt especially overwhelmed when at an early stage in the analysis I had 90 codes! Given how much data there was I wondered how I could possibly do justice to my participants' experiences. I felt in an extremely powerful position to be the person responsible for reducing their stories into themes, and this made me feel uncomfortable. It reminded me of the days of first-order days when participants were known as "subjects" to be experimented on. I had originally planned to involve the Lived Experience Advisory Group in the data analysis but there wasn't time to do this and I felt this may have been helpful. On the 18th May I wrote the following in my reflective journal:

> *"I'm feeling overwhelmed by all the codes. How can I do my participants' stories justice given there is so much data that I am going to have to reduce into a few pages of writing or a couple of thousand words? Am I doing this 'right'? I don't want to miss anything, and am wary of reducing the richness of the stories and denying people of their lived experience. I feel in a powerful position and this makes me uncomfortable. But if their stories are going to be heard by others they will have to be reduced. I've just got to do my best."*

I later found out from speaking to other qualitative researchers that feeling overwhelmed was a very common experience during data analysis. I managed to reframe this experience as a sign of my conscientiousness and commitment to my participants.

Here I reflect on the rationale for keeping the theme of "culture" as a barrier and the implications of doing so (21.05.20). At the time this theme only related to one participant's experience:

> *"Role of culture was only suggested by one participant but this was a significant part of their narrative. It feels important to include. I'm also aware it's an important part of the literature (e.g. people of Black ethnicity having longer PtC) – but if I included purely because of this isn't inductive thematic analysis? Culture also came up despite me not asking about it explicitly during the interview – maybe if I'd had a question about it more participants may have reflected on it? I don't want to subjugate this person's story: it was a powerful part of their experience. It feels particularly wrong to cut it out as a person of White ethnicity when the participant came from an ethnic minority background – this goes back again to the power I have as a researcher…"*

As a result of these reflections I decided that I should keep the sub-theme of "culture" within the barriers and facilitators theme. I later identified another participant talked about changes in culture being necessary if physical health is to be taken as seriously as mental health, so also included this as part of the sub-theme.

Transparency and Quality

The study was conducted and written up in accordance with the Consolidated Criteria for Reporting Qualitative Research guidelines (Tong, Sainsbury, & Craig, 2007). This led to a number of procedures being adopted to maximise the transparency and credibility of the work. Reflexivity was given key attention throughout the study, for instance by keeping a reflective diary and reflective discussions in supervision. Multiple coding was used in order to provide a more rigorous approach. Coding the interviews on NVivo meant there was an audit trail of how themes were developed (Rodgers & Cowles, 1993). Quotations illustrating themes were provided encompassing all participants (Tong et al., 2007).

Chapter Six

Discussion and Critical Evaluation

Word Count: 1 714

Chapter 6

Discussion and Critical Evaluation

This chapter presents a summary of the findings from both the systematic review and empirical paper, a critical evaluation, implications, and strengths and limitations.

Summary of Findings

The systematic review of Pathways to Care (PtC) in At-Risk Mental States (ARMS) found ten papers meeting the inclusion criteria, across a wide variety of healthcare contexts. Screening tools and PtC data collection tools varied considerably. Overall, mental health professionals and General Practitioners (GPs) played a significant role in the PtC. Family involvement was identified as important in half of the studies that met the review criteria. In general, attendance at Emergency Departments, contact with the police and ambulance use accounted for relatively few PtC contacts. Three studies found that presenting with “positive” psychotic symptoms led to a shorter care pathway. No studies addressed the role of ethnicity or urbanicity in the PtC.

The empirical paper explored the experiences of PtC according to 11 patients with ARMS or First Episode Psychosis (FEP), as well as barriers and facilitators. It also made preliminary steps to explore the overlaps between the two groups of participants. The empirical study found that many participants had long PtC, with a mean pathway length of around two years. Experiences of low mood and anxiety prior to developing psychotic symptoms were common. Participants with positive experiences and quick referrals to EIP tended to have rapid onset of symptoms. In terms of services accessed, ten participants had contact with a GP on their PtC. Only FEP participants had been admitted to inpatient psychiatric units, used community crisis resolution/home treatment teams, or had contact with the police. Two ARMS participants had used an ED, as well as one participant with FEP. It was clear from the transcripts that many participants felt unheard, not listened to and not taken seriously. Barriers and facilitators included services being disconnected from each other, the manner and attitudes of individual healthcare staff, the role of family and friends, and societal barriers of stigma and culture.

Taken together, the findings of the papers broadly fit with one another in several respects. First of all, both the systematic review empirical paper identified the key role that General Practitioners have on the PtC. Family was identified as important in several systematic review papers, and also played a significant role in the empirical paper's participants. In addition, the finding that people from an ARMS population tend to use fewer acute services and the police was in part identified in the empirical paper, although conclusions drawn about this findings must be adopted with caution due to the small sample size.

Implications

Clinical implications.

The main hope for the thesis was that the findings may provide insight for the development of interventions that may shorten the PtC, thus reducing the Duration of Untreated Psychosis in FEP, and Duration of Untreated Illness in ARMS, and improving outcomes (Marshall et al., 2005). Given the significant roles of both GPs and family identified in both the systematic review and empirical paper, as well as in previous studies, the results suggest that both service-level and public health interventions are required. These kinds of interventions are undoubtably complex to implement and evaluate. Nevertheless there is a precedent for intervention targeting GPs in increasing referrals and timeliness to EIP services (Perez et al., 2015; Power et al., 2007), as well as for public health interventions in reducing stigma and DUP (Connor et al., 2016; Sampogna et al., 2017). Given the role of culture in PtC identified in the empirical paper, interventions need to be culturally appropriate. This may be in part facilitated by interventions being co-produced by experts by experience from diverse backgrounds.

The extensive range of service level, personal, and societal barriers facing young people with early psychotic symptoms to accessing care, as well as the finding that patients often presented to GPs with affective symptoms, raises the question of whether universal screening for psychotic symptoms should be adopted, for instance in schools or primary care. Universal screening using self-report questionnaires may facilitate quicker referrals to EIP and reduce treatment delays (Howie, Potter, Shannon, Davidson, & Mulholland, 2019; Kline & Schiffman, 2014). It is also important to screen for psychotic experiences because even those patients with anxiety or depression who do not meet criteria for ARMS have poorer response to psychological therapy (Knight et al., 2020). Screening is undoubtably complex, and is likely to attract a significant number of ARMS false positives (Howie et al., 2019; Savill, D'Ambrosio, Cannon, & Loewy, 2018). There are also considerable implications for identifying large numbers of people on services that may already be under-resourced, and ethical issues for those who cannot be taken on for treatment (Levitt, Saka, Romanelli, & Hoagwood, 2007).

The findings clearly have implications for commissioning, as additional training and public health campaigns are likely to attract significant costs. However, there is a possibility that costs may be offset by service level savings, given the expense of treatment delays. Perhaps an additional mandatory measure of, or requirement of reduction to, PtC in the EIP Access and Waiting Time Standards (NICE & NHS England, 2016) may assist with measuring this.

Research implications.

The thesis adds to a limited evidence base and corroborates existing research, for instance in findings that people with “negative” symptoms are less likely to be detected, the role of GPs and family in the PtC, and people with ARMS being less likely to have inpatient or police involvement (Anderson et al., 2010; Anderson, Fuhrer, Schmitz, & Malla, 2013; Valmaggia et al., 2015). The systematic review found more research is needed into a validated measure of PtC, which was also identified by Singh and Grange (2006). Additional study of the role of ethnicity and urbanicity in PtC in ARMS is warranted. Research comparing PtC in ARMS and FEP quantitatively may be of benefit, for example using clinical interviews or anonymised medical records (e.g. Cambridgeshire and Peterborough NHS Foundation Trust’s ‘Clinical Records Anonymisation and Text Extraction’; Cardinal, 2017). Gaining staff and commissioners’ perspectives about shortening PtC in ARMS and FEP may be beneficial to implement the findings of this research.

Theoretical implications.

The research has theoretical implications for both models of psychosis and models of help-seeking. The fact that ARMS and FEP participants had overlapping experiences of PtC fits with the continuum model of psychosis, where there is less of a divide between diagnostic categories. Findings about the role of stigma also fit with the importance societal norms place on help-seeking in the theory of planned behaviour (Ajzen, 1991), as well as the social meanings of seeking help identified in the cycle of avoidance model (Biddle et al., 2007). Stigma may also contribute to psychotic illness being seen as threatening, thus reducing the likelihood of seeking help, in accordance with the health belief model (Rosenstock, 1974).

Strengths and Limitations

In terms of strengths, the thesis portfolio adds to a growing area of research. It provides important information for service providers about PtC in ARMS and FEP and understanding of treatment delays. The systematic review updated the evidence base of PtC in ARMS, which had been lagging behind the more extensive literature in PtC in FEP, where several systematic reviews had already been conducted (Anderson, Flora, Archie, Morgan, & McKenzie, 2014; Anderson et al., 2010; Singh & Grange, 2006). The empirical study was the first of its kind to take place in the UK. It benefitted from expert by experience involvement in the study design, interview questions, and wording of study documentation. Participants were recruited from different cultural backgrounds, which was a particular positive given the demographics of the caseload (Clay et al., 2018).

The thesis must be interpreted with several limitations in mind. The systematic review is limited in its generalisability due to the small number of papers meeting the inclusion criteria. Perhaps it would have been advisable to search for papers in languages other than English. Due to resource constraints screening was conducted by a single person, with 20% data extraction being conducted by an additional person. The empirical paper could have benefitted from more participants and interviews of longer duration. Additional interviews were planned but were not possible due to COVID-19 restrictions. Nevertheless, subjectively the researchers felt that data saturation had occurred. The empirical study only represents the views of those who were engaged with the service and the study took place only in one EIP service, thus results cannot be generalised to the ARMS and FEP populations as a whole. Indeed, the participants may have been among the most engaged in the service as they were deemed most "suitable" to approach by clinicians. Particular care must be drawn to the overlapping and diverging themes between ARMS and FEP participants due to the qualitative methodology and small numbers of participants.

Dissemination

In number of steps have been taken to disseminate the findings. A summary of the results was sent by email to all participants who wished to receive a copy (as indicated on their consent form). The Lived Experience Advisory Panel also received a summary of the results to close the "feedback loop". Both of these groups were given an opportunity to read the completed thesis. A presentation at a CAMEO South Multi-Disciplinary Team meeting is planned. The study team will also consider sending summaries of results to other relevant services, for instance GPs and the First Response Service.

The systematic review was published in *Early Intervention in Psychiatry* in October 2020 (Allan et al,, 2020). The empirical paper will also be submitted for publication. Both papers will be submitted for conference presentation, for instance the IEPA Early Intervention in Mental Health annual conference.

Overall Conclusion

In conclusion, the thesis provides important insights into treatment delays in ARMS and FEP. There is limited research in the area of PtC in ARMS, with studies varying in the screening tools and PtC instruments adopted. Most empirical study participants tended to have complex PtC with significant treatment delays, and had difficult experiences on their journeys to EIP support. They reported significant service level, personal and societal barriers to accessing EIP. Further research is required to triangulate findings, and especially to develop population and service-level interventions. This may reduce treatment delay, shorten DUP and DUI, and improve outcomes for those experiencing effects of distressing and potentially devastating psychotic experiences.

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Appendices

List of Appendices

Appendix A. Early Intervention in Psychiatry Author Guidelines

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Author Guidelines

1. SUBMISSION

Thank you for your interest in *Early Intervention in Psychiatry*. Authors should kindly note that submission implies that the content has not been published or submitted for publication elsewhere except as a brief abstract in the proceedings of a scientific meeting or symposium.

Once the submission materials have been prepared in accordance with the Author Guidelines, manuscripts should be submitted online at **http://mc.manuscriptcentral.com/eip**

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2. AIMS AND SCOPE

Early Intervention in Psychiatry publishes original research articles and reviews dealing with the early recognition, diagnosis and treatment across the full range of mental and substance use disorders, as well as the underlying epidemiological, biological, psychological and social mechanisms that influence the onset and early course of these disorders. The journal provides comprehensive coverage of early intervention for the full range of psychiatric disorders and mental health problems, including schizophrenia and other psychoses, mood and anxiety disorders, substance use disorders, eating disorders and personality disorders. Papers in any of the following fields are considered: diagnostic issues, psychopathology, clinical epidemiology, biological mechanisms, treatments and other forms of intervention, clinical trials, health services and economic research and mental health policy. Special features are also published, including hypotheses, controversies and snapshots of innovative service models.

In contrast with mainstream healthcare, early diagnosis and intervention has come late to the field of psychiatry. *Early Intervention in Psychiatry* creates a common forum for researchers and clinicians with an interest in the early phases of a wide range of disorders to share ideas, experience and data. This journal not only fills a gap, but also creates a new frontier in academic and clinical psychiatry.

3. MANUSCRIPT CATEGORIES AND REQUIREMENTS

Articles reporting original work that embodies scientific excellence in psychiatry and advances in clinical research (maximum word count for text 3000; abstract 250);

Reviews which synthesize important information on a topic of general interest to early intervention in psychiatry. (maximum word count for text 5000; abstract 250);

Brief Reports which present original research that makes a single point, or negative studies of important topics (maximum word count for text 1500; abstract 150);

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vii. Acknowledgements;
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ix. References;
x. Tables (each table complete with title and footnotes);
xi. Figure legends;
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All articles must have a structured abstract that states in 250 words (150 words for Brief Reports) or fewer the purpose, basic procedures, main findings and principal conclusions of the study. Divide the abstract with the headings: Aim, Methods, Results, Conclusions. The abstract should not contain abbreviations or references.

Five key words, for the purposes of indexing, should be supplied below the abstract, in alphabetical order, and should be taken from those recommended by the US National Library of Medicine's Medical Subject Headings (MeSH) browser list at **http://www.nlm.nih.gov/mesh/meshhome.html**.

Text

Authors should use the following subheadings to divide the sections of their manuscript: Introduction, Methods, Results and Discussion.

Acknowledgments

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Authors will be asked to provide a conflict of interest statement during the submission process. For details on what to include in this section, see the section 'Conflict of Interest' in the Editorial Policies and Ethical Considerations section below. Submitting authors should ensure they liaise with all co-authors to confirm agreement with the final statement.

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References should be prepared according to the Publication Manual of the American Psychological Association (6th edition). This means in text citations should follow the author-date method whereby the author's last name and the year of publication for the source should appear in the text, for example, (Jones, 1998). The complete reference list should appear alphabetically by name at the end of the paper.

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Book

Bradley-Johnson, S. (1994). *Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school* (2nd ed.). Austin, TX: Pro-ed.

Internet Document

Norton, R. (2006, November 4). How to train a cat to operate a light switch [Video file]. Retrieved from **http://www.youtube.com/watch?v=Vja83KLQXZs**

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

Figure Legends

Legends should be concise but comprehensive – the figure and its legend must be understandable without reference to the text. Include definitions of any symbols used and define/explain all abbreviations and units of measurement.

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Author Guidelines updated 18 March 2019

Appendix B. Clinical Psychology and Psychotherapy Author Guidelines

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Enter an abstract of no more than 250 words containing the major keywords. An abstract is a concise summary of the whole paper, not just the conclusions, and is understandable without reference to the rest of the paper. It should contain no citation to other published work.

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Reference examples follow:

Journal article
Beers, S. R. , & De Bellis, M. D. (2002). Neuropsychological function in children with maltreatment-related posttraumatic stress disorder. *The American Journal of Psychiatry, 159,* 483–486.
doi: **10.1176/appi.ajp.159.3.483**

Book
Bradley-Johnson, S. (1994). *Psychoeducational assessment of students who are visually impaired or blind: Infancy through high school* (2nd ed.). Austin, TX: Pro-ed.

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Norton, R. (2006, November 4). How to train a cat to operate a light switch [Video file]. Retrieved from *http://www.youtube.com/watch?v=Vja83KLQXZs*

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Endnotes should be placed as a list at the end of the paper only, not at the foot of each page. They should be numbered in the list and referred to in the text with consecutive, superscript Arabic numerals. Keep endnotes brief; they should contain only short comments tangential to the main argument of the paper.

Tables

Tables should be self-contained and complement, not duplicate, information contained in the text. They should be supplied as editable files, not pasted as images. Legends should be concise but comprehensive – the table, legend, and footnotes must be understandable without reference to the text. All abbreviations must be defined in footnotes. Footnote symbols: †, ‡, §, ¶, should be used (in that order) and *, **, *** should be reserved for P-values. Statistical measures such as SD or SEM should be identified in the headings.

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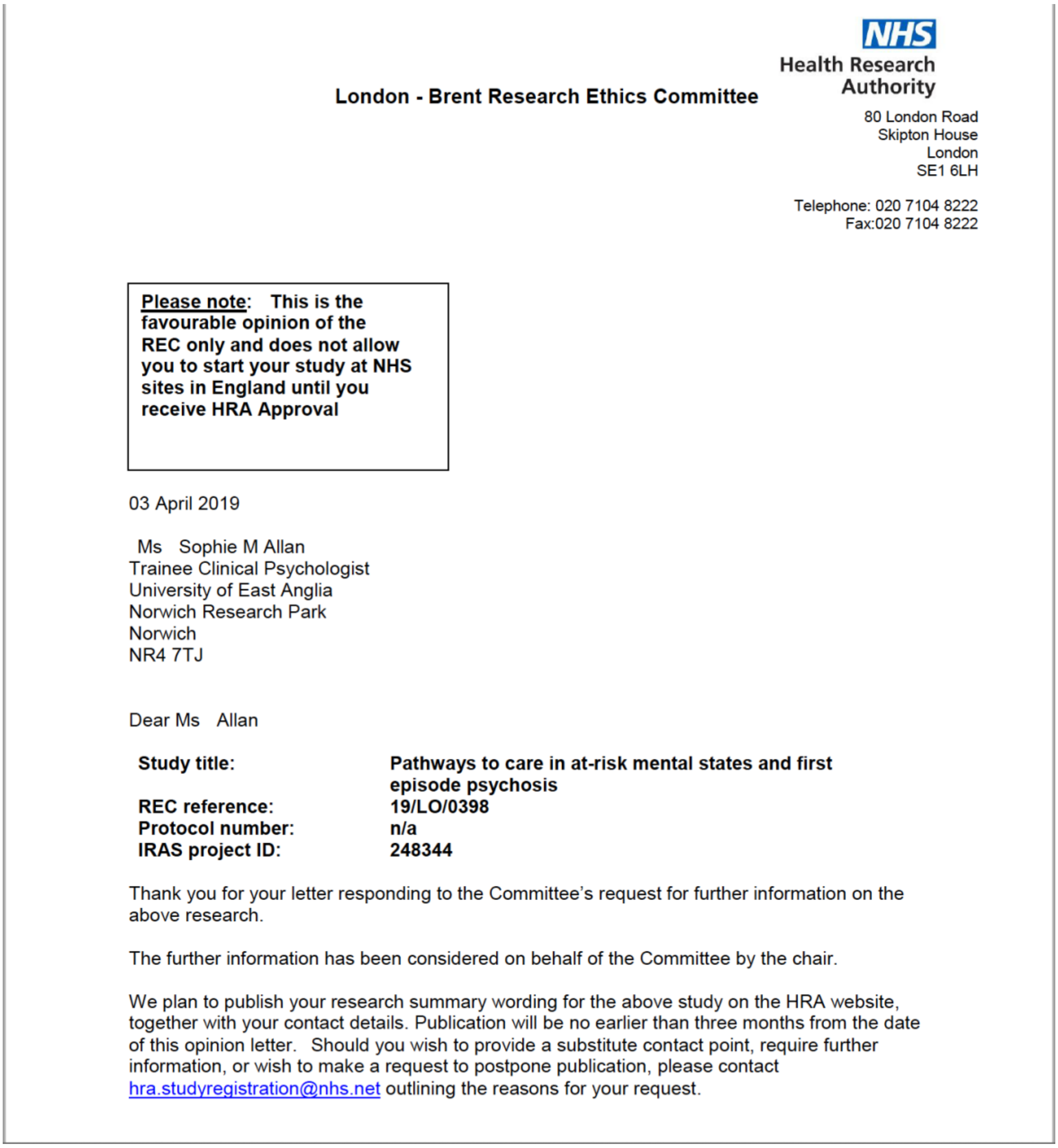
8. EDITORIAL OFFICE CONTACT DETAILS

Email: **CPPedoffice@wiley.com**

Author Guidelines updated 18th April 2018

Appendix C. REC ethical approval



NHS
Health Research
Authority

London - Brent Research Ethics Committee

80 London Road
Skipton House
London
SE1 6LH

Telephone: 020 7104 8222
Fax:020 7104 8222

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

03 April 2019

Ms Sophie M Allan
Trainee Clinical Psychologist
University of East Anglia
Norwich Research Park
Norwich
NR4 7TJ

Dear Ms Allan

Study title:	**Pathways to care in at-risk mental states and first episode psychosis**
REC reference:	**19/LO/0398**
Protocol number:	**n/a**
IRAS project ID:	**248344**

Thank you for your letter responding to the Committee's request for further information on the above research.

The further information has been considered on behalf of the Committee by the chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

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

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System, at www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor Insurance]	1	07 May 2018
GP/consultant information sheets or letters [Study 2 Letter to Healthcare Team]	1.0	16 November 2018
Interview schedules or topic guides for participants [Study 2 Interview Schedule]	2.0	24 November 2018
IRAS Application Form [IRAS_Form_08022019]		08 February 2019
Letter from sponsor [Covering Letter from Sponsor]	1.0	08 February 2019
Other [Study 2 Debriefing Sheet]	1.0	16 November 2018
Other [Study 2 Receipt]	1.0	30 November 2018
Other [Study 2 Consent to Contact Form]	1	06 February 2019
Other [Study 2 Demographics Information Form]	1.0	08 March 2019
Other [Response to REC provisional study opinion]	1	15 March 2019
Participant consent form [Study 2 Consent Form Amended]	1.4	18 March 2019
Participant information sheet (PIS) [Participant Information Sheet Amended]	1.4	18 March 2019
Referee's report or other scientific critique report [Internal Review Report]	1	13 July 2018
Research protocol or project proposal [Protocol]	2	09 January 2018
Summary CV for Chief Investigator (CI) [Sophie Allan_CI_CV]	1	07 November 2018
Summary CV for student [Student CV]	1	07 November 2018
Summary CV for supervisor (student research) [Supervisor CV]	1	29 November 2018
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Exclusions to Sponsor Insurance]	1	07 May 2018

Statement of compliance

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

After ethical review

<u>Reporting requirements</u>

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

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

19/LO/0398 **Please quote this number on all correspondence**

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

Yours sincerely
PP:

C. Frost

Dr Manish Saxena
Chair

Email:nrescommittee.london-brent@nhs.net

Appendix D. Consent to contact form

CONSENT TO CONTACT FORM

Title of Project: Pathways to Care in At Risk Mental States and First Episode Psychosis

Name of Researcher: Sophie Allan

Please
initial box

1. I confirm that I give consent for the researcher, Sophie Allan, to contact me about this study ☐

______________________	______________________	______________________
Name	Date	Signature
______________________	______________________	______________________
Name of person taking consent	Date	Signature

Appendix E. Participant Information Sheet

Pathways to care in At Risk Mental States and First Episode Psychosis

Participant Information Sheet

I would like to invite you to take part in a research study. It's completely up to you whether you decide to take part. Before you decide it's important you understand what the research is about, why the research is being done, and what taking part would involve. I will go through the information in this sheet with you to help you decide and to answer any questions you might have, for example if anything isn't clear or you would like more information. Take your time to decide whether or not to take part. Feel free to discuss the study with friends or family if you wish.

About the research

The research is looking at places people go to get help when they are first experiencing psychotic symptoms (e.g. hearing voices, seeing things others can't see, or having unusual ideas). We know that it's important for people with psychosis to get help from an Early Intervention in Psychosis Service as early as possible, but sometimes it takes people a long time before they get the right help. We want to understand more about why this happens.

A group of people who have experienced psychosis have been involved in helping design the study (the Lived Experience Advisory Panel). For instance they have helped write this information sheet, decide what questions should be asked in the interview, and will help with the data analysis.

What is the purpose of the study?

The study is taking place as part of the researcher's Doctorate in Clinical Psychology at the University of East Anglia.

Why have I been invited?

You have been invited to take part in the study because you are being seen by the Cameo Early Intervention in Psychosis service.

Do I have to take part?

It is up to you to decide. We will describe the study and go through this information sheet, which we will give to you. We will then ask you to sign a consent form to show you agreed to take part. You are free to withdraw at any time, without giving a reason. Taking part in the study will not affect the care you receive.

What will happen to me if I take part?

If you decide to take part, you will take part in an interview with the researcher. The interview will last about an hour. The interview will be recorded on a Dictaphone and transcribed into text on a Word document, but any information that identifies you will be removed.

Will I be paid?

As a thank you for taking part you will be paid a £15 voucher at the end of the interview to cover your time and travel expenses.

What will I have to do?

If you take part you will be interviewed by the researcher. You will be asked questions about your experience of getting help for your difficulties and how you came to be seen by Cameo. There aren't any right or wrong answers to these questions: we are just interested in your experience and opinions. If you don't want to answer a question that's absolutely fine.

What are the possible disadvantages and risks of taking part?

Some people find that talking about their experiences can be upsetting. If this happens it is fine to stop the interview. At the end of the interview we will give you details of how you can get support afterwards if you feel upset after taking part.

What are the possible benefits of taking part?

We cannot promise the study will help you personally but the information we get will help to increase the understanding of how people with early psychosis can get the right treatment as early as possible.

What if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researcher, Sophie Allan, who will do her best to answer your questions: s.allan@uea.ac.uk, 07939 597 731. If you would rather not do this you can contact her supervisor: s.odoula@uea.ac.uk. If you remain unhappy and wish to complain formally you can do this through CPFT PALS: pals@cpft.nhs.uk, 0800 376 0775, or to Professor Niall Broomfield, n.broomfield@uea.ac.uk, 01603 591 217.

Will my taking part in the study be kept confidential?

Yes. All information which is collected about you during the course of the research will be kept strictly confidential, and any information about you which leaves the trust will have your name and address removed so that you cannot be recognised.

The University of East Anglia (UEA) is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UEA will keep identifiable information about you for 10 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

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

Any data collected will be handled in accordance with the General Data Protection Regulation (GDPR). Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) will collect information from you for this research study in accordance with our instructions.

CPFT will keep your name, NHS number and contact details confidential and will not pass this information to the University of East Anglia (UEA). CPFT will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from UEA and regulatory organisations may look at your medical and research records to check the accuracy of the research study. UEA will only receive information without any identifying information. The people who analyse the information will not be able to identify you and will not be able to find out your name, NHS number or contact details.

CPFT will keep identifiable information about you from this study for 10 years after the study has finished.

The researcher will audio record the interviews. As soon as the interview is finished the researcher will upload the audio file onto an NHS computer and delete the audio file. This means that in the unlikely event the recording is stolen 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: a list of names and participant ID numbers will be held on a password protected NHS computer accessed only by the researcher. Transcripts of the interviews will only be accessed by members of the research team. If you wish, this will include members of the Lived Experience Advisory Panel.

Short examples (quotations) of what you have said in the interviews will be used as examples in the final thesis, journal articles or at conference presentations. These will be chosen so that they do not contain any information that might identify you.

We will inform your clinical care team including your care coordinator to make them aware that you are taking part in the study. This is in case you feel upset after taking part and want to discuss it with them. We will not share any information about what you say in the interview. The only exception to this is if you disclose that you are at risk of harming yourself or others during the interview, or there is a risk of harm to patients or a third party. In this situation we will need to inform your care team about this.

What will happen if I don't carry on with the study?
You can withdraw from the study at any time. If you decide to withdraw from the study all the recordings of the interview will be destroyed. However, once the data analysis has been completed you will not be able to withdraw.

What will happen to the results of the research study?
The results of the study will be submitted to the University of East Anglia and published in an academic journal. You are welcome to have a copy of the results if you wish. You will not be identified in any report or publication.

Who is organising or sponsoring the research?
The research is being organised by the University of East Anglia and Cambridgeshire and Peterborough NHS Foundation Trust.

Further information and contact details:
If you would like further information about the research you can contact the researcher, Sophie Allan, on s.allan@uea.ac.uk or 07398 597 731. If you would like advice about whether or not to participate you can contact the person you usually see at Cameo or talk to family or friends.

Appendix F. Consent form

CONSENT FORM

Title of Project: Pathways to Care in At Risk Mental States and First Episode Psychosis

Name of Researcher: Sophie Allan

Please initial box

1. I confirm that I have read the information sheet dated 18.03.2019 (version 1.4) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I agree to the interview being audio recorded. ☐

4. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from the NHS Trust and the Sponsor organisation, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

5. I give consent for the researcher to inform the health professionals at Cameo who are involved in my care that I am taking part in this study. ☐

6. I am happy for members of the Lived Experience Advisory Group to have access to the anonymised transcript of my interview so that they can help with the analysis of the information (optional). ☐

7. I agree to take part in the above study. ☐

.

Would you like to receive a copy of the results of the study? (please circle) YES NO

If yes, please add your email address or telephone number here: ___________________________________

Name of Participant	Date	Signature
Name of person taking consent	Date	Signature

Appendix G. Debriefing sheet

NHS
Cambridgeshire and Peterborough
NHS Foundation Trust

cameo
Early Intervention Services

NHS
Cambridgeshire and Peterborough
NHS Foundation Trust

DEBRIEFING SHEET

Title of Project: Pathways to Care in At Risk Mental States and First Episode Psychosis

Name of Researcher: Sophie Allan

Thank you for taking part in the above study.

Some people find that talking about their experiences can be difficult and sometimes distressing. If this is the case for you, you can contact:

1. The person you usually see at Cameo (e.g. care coordinator, psychiatrist or psychologist) by texting or phoning them
2. The Cameo office on 01223 341500 option 4 (South team) or 01733 353250 during office hours (Monday-Friday, 9am-5pm)
3. The Samaritans telephone line: 116 123 (open 24 hours a day)

If, out of office hours, you feel that you are in a mental health crisis or at risk of harming yourself you can contact the First Response Service on 111 option 2.

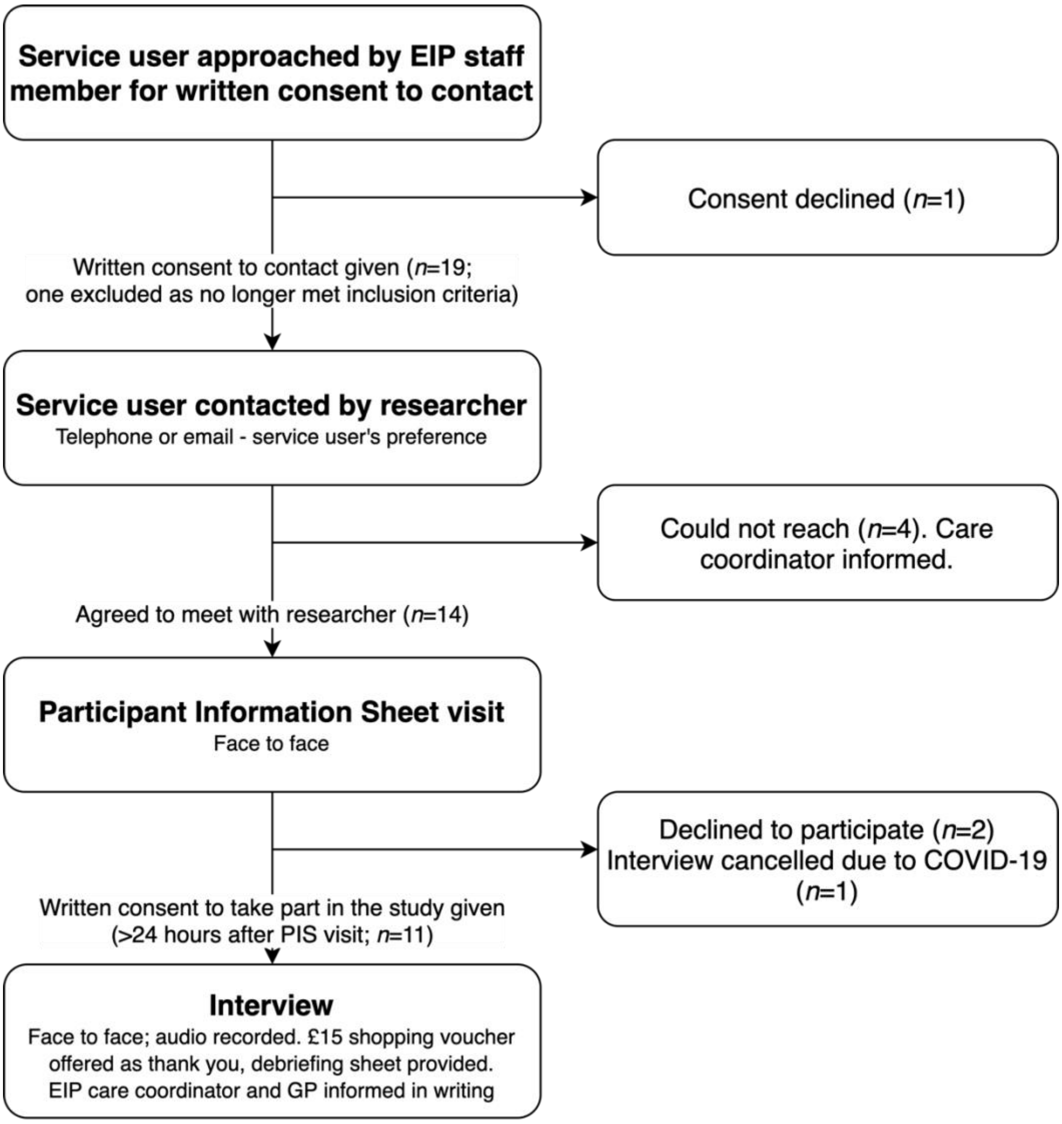
Kind regards,

Sophie

Sophie Allan

Trainee Clinical Psychologist, University of East Anglia

Appendix H. Study procedure diagram



Appendix I. Interview schedule

NHS Cambridgeshire and Peterborough NHS Foundation Trust

cameo Early Intervention Services

NHS Cambridgeshire and Peterborough NHS Foundation Trust

Pathways to care in At Risk Mental States and First Episode Psychosis

Study 2 Interview Schedule

Before audio recording starts:

Thank you for meeting with me again. As we've discussed, the purpose of this interview is to find out a bit more about your experience of getting help for psychotic symptoms like hearing voices. How are you feeling today? *[Check that it is appropriate for interview to continue. Give option to reschedule interview at this point].*

Are you happy for us both to work together to discuss how you came to be seen at Cameo? *[If yes, start audio recording. If no, ask the participant if they would like to withdraw from the study or reschedule the interview]*

Start audio recording

1. Can you tell me a bit about what was going on for you when you first became unwell? When did you realise that things weren't right?

2. I'm going to ask you a bit about the places you might have gone to get seek when you were first feeling unwell with psychosis. Some people find it helpful to draw it out on a map, like this *[show map drawing].* Can we do that together?

3. When you first realised that things weren't right, did you feel able to talk to anyone about this?

If yes:
Where did you go to get help? *[Write down organisation/person sought help for in box 1 on map. e.g. "GP"]*
What was it 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?

4. What happened next? *[Write down organisation/person sought help for in box 2 on map. e.g. "GP"]*
What was it like?
What was good about the help you received?
What got in the way?
Did it make things better or worse?

Repeat question 4 until all pathways to care discussed.

5. Looking back over the places or people you sought help from, how do you feel about the treatment that you had? Overall, was the help useful?

6. What would you have liked to see improve?

7. What would you want to be different?

8. That's the last question I have. Is there anything else you'd like to mention that we haven't talked about already?

Thank you very much for taking part.

Stop audio recording

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

How are you feeling after talking about all of this?
[If participant states they are feeling, or appears to be, distressed, talk through what might have upset them. Conduct risk assessment if necessary. For all participants: give out and go through the debriefing sheet whether or not the participant discloses they are feeling distressed].

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

Appendix J. Confirmation of Capacity and Capability from Cambridgeshire and Peterborough NHS Foundation Trust

Cambridgeshire and Peterborough NHS
NHS Foundation Trust

Understanding mental health, understanding people
Research and Development Department

Joint Research Office
Box 277
Addenbrooke's Hospital
Hills Road
Cambridge
CB2 0QQ

Direct Dial: 01223 256407 ext 256407
E-mail: mary-beth.sherwood@cpft.nhs.uk
www.cpft.nhs.uk

R&D ref: M00921

Ms. Sophie Allan
University of East Anglia
Norwich Research Park
Norwich
NR4 7TJ

16 April 2019

Dear Ms. Sophie Allan

IRAS ID: 248344
Pathways to care in at-risk mental states and first episode psychosis
REC Ref: 19/LO/0398

Thank you for sending details of the above named study.

The R&D department has received the HRA Approval letter and reviewed the study documents. The project has been allocated the internal R&D reference number of **M00921**. Please quote this in all future correspondence regarding this study.

Capacity and capability to conduct this study at Cambridgeshire & Peterborough NHS Foundation Trust is confirmed.

We would like to take this opportunity to remind you of your responsibilities under the terms of the Research Governance Framework for Researchers, Chief Investigators, Principal Investigators and Research Sponsors and to also of the requirement to notify R&D of any amendments or changes made to this study.

You will be aware that the Trust is subject to national reporting requirements for first patient recruitment within 70 days. Further details on this can be found on the NIHR website:
http://www.nihr.ac.uk/policy-and-standards/faster-easier-clinical-research.htm
If you have any questions or concerns about this, please contact me.

I wish you every success with this study.

Yours sincerely

Stephen Kelleher
Senior R&D Manager

Carbon Copy: Dr Michelle Painter, Dr Sheri Oduola

HQ Elizabeth House, Fulbourn Hospital, Cambridge CB21 5EF
Version 1 July 2015
T 01223 726789 F 01480 398501 www.cpft.nhs.uk

In partnership with the University of Cambridge