Understanding the Pathways to Care for Individuals with or at Risk of Psychotic Disorders

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Table of Contents

Thesis Portfolio Abstract

Background: Delays in treatment for people experiencing early signs of psychosis are associated with poorer outcomes. However, it is not uncommon for individuals with an At-Risk Mental State (ARMS) and First Episode Psychosis (FEP) to experience lengthy delays to care and few people presenting with FEP access early intervention in psychosis (EIP) services during the prodromal stage. Pathways to Care (PtC) provides information about how individuals access services. This thesis aimed to explore PtC for individuals with ARMS and FEP, factors associated with accessing EIP at an earlier stage or psychosis, and interventions designed to reduce delays.

Methods: A systematic review synthesised the available evidence on public health interventions designed to reduce delays to treatment for people with ARMS and FEP. An empirical study was conducted exploring PtC during ARMS compared to FEP, and sociodemographic characteristics associated with accessing EIP. Data were collected from a research database of de-identified clinical records.

Results: Nineteen studies met the inclusion criteria for the systematic review. All studies consisted of FEP populations, with no papers investigating ARMS populations. Studies originated from various countries. Findings about the effectiveness of interventions at reducing duration of untreated psychosis (DUP) were mixed and interventions appeared to differentially impact groups. The most effective interventions appeared to be those of a longer duration and targeting multiple populations. PtC information was limited. In the empirical study, 158 individuals presenting with ARMS (n=67) and FEP (n=91) were included. There was strong evidence that ARMS patients accessing EIP were significantly younger and were less likely to be from ethnic minority backgrounds compared to FEP. ARMS patients had fewer PtC contacts, were less likely to be referred via acute services, less likely to have involuntary hospital admissions, and had reduced family involvement in their help-seeking.

Conclusions: Findings regarding the effectiveness of interventions to reduce delays to treatment were inconclusive. The empirical paper highlighted sociodemographic and PtC characteristics associated with accessing EIP during ARMS compared with FEP. Further research is required to replicate these findings and investigate the effectiveness of targeted interventions to encourage and facilitate access to EIP at an earlier stage of psychosis to improve outcomes.

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Chapter One

Introduction

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Chapter One

Introduction

The purpose of this chapter is to introduce the concepts explored within the thesis including first episode psychosis (FEP), At-Risk Mental State (ARMS), models of help-seeking, and pathways to care (PtC). The aims of the thesis will be outlined, and an overview of the chapters presented.

Psychosis

People experiencing psychosis may experience altered perceptions and sense of reality, and changes in their thinking, feeling, and behaviour (National Institute of Health and Care Excellence (NICE)., 2014). Common experiences include hallucinations, delusions, apathy, and social withdrawal (NICE., 2014). In recent years, the continuum model of psychosis has gained increasing attention. This model suggests psychosis lies on a continuum from mild, "subclinical" psychosis-like experiences which may even be perceived as comforting and helpful, to more intense, frequent, and distressing experiences requiring support from mental health services (British Psychological Society (BPS)., 2017; DeRosse & Karlsgodt, 2015). The continuum model arose from research demonstrating that psychosis-like experiences are relatively common in the general population (Johns & Van Os, 2001). For example, a recent review highlighted a lifetime prevalence of psychotic-like experiences of 17% in children, 8% in adolescents and 5-7% in adults (Staines et al., 2022). In addition, prevalence rates of different types of psychotic-like experiences appear to differ, with hallucinations being more common than delusions (McGrath et al., 2015).

The continuum model of psychosis contrasts with traditional, medical models of psychosis which conceptualises psychotic-like experiences as symptoms of a diagnosable mental illness (BPS., 2017) in which individuals are either “healthy” or “mentally ill” (Bentall, 2003). It has been argued that the difference between individuals with “subclinical” psychotic-like experiences and those with “clinically significant symptoms” lies in the severity and frequency of experiences (Van Os et al., 2008), and how individuals appraise and respond to such experiences (Johns et al., 2014) which may result in increased distress, functional impairment, and need for support (BPS., 2017; Van Os et al., 2009).

Early intervention in psychosis (EIP) services are designed to identify and provide appropriate interventions as early as possible during an individual’s first episode of psychosis to reduce duration of untreated psychosis (DUP) and improve outcomes (Singh, 2010). DUP is defined as the period between the onset of psychotic symptoms and the initiation of appropriate treatment (Norman & Malla, 2001). Longer DUP is associated with poorer outcomes for individuals with FEP across multiple domains including clinical, functional, and personal recovery (Harris et al., 2005; Marshall et al., 2005; Penttilä et al., 2014). It is therefore essential to provide rapid access to evidence-based interventions to individuals experiencing FEP such as antipsychotic medication, cognitive behavioural therapy for psychosis, or family interventions (NICE, 2014).

At-Risk Mental State (ARMS)

At-Risk Mental State (ARMS) has been conceptualised as an early and potentially prodromal phase of psychosis characterised by psychotic symptoms of lesser severity and duration than psychosis accompanied by a drop in functioning (Fusar-Poli et al., 2013). Yung and colleagues (2005) defined ARMS as “a state that confers high, but not inevitable risk of development of psychotic disorder in the near future” (p.965). It has been proposed that providing interventions during these early stages of illness may reduce DUP or prevent transition to psychosis altogether (Fusar-Poli et al., 2013; Rietdijk et al., 2010).

The concept of ARMS has not been without its controversies. It has been widely debated as to whether ARMS is truly a prodromal phase of psychosis (van Os & Guloksuz, 2017). In a recent meta-analysis, de Pablo and colleagues (2021) found that 25% of individuals presenting with ARMS transitioned to psychosis within three years, a figure which further increased to 35% within 10 years. A study by Fusar-Poli and colleagues (2017) found that ARMS predicted psychotic disorders with modest accuracy and were not predictive of developing non-psychotic disorders. However, Ajnakina and colleagues (2017) found as few as 4.1% of FEP individuals seen by an EIP service presented during the ARMS stage.

There is growing evidence to suggest that individuals presenting with ARMS may experience poor functional outcomes such as impairments in cognition, social and occupational functioning, comorbidities, and poorer quality of life regardless of whether they transition to psychosis (Beck et al., 2019; Brandizzi et al., 2015; Cotter et al., 2014; Fusar-Poli et al., 2015). Prolonged duration of untreated illness (DUI) in ARMS, defined as the period between the onset of any psychiatric symptom and the initiation of appropriate treatment (Norman & Malla, 2001), is associated with unfavorable outcomes. For example, longer DUI has been found to be associated with increased transition to psychosis rates (Nelson et al., 2016) and worse functional outcomes (Carrión et al., 2016; Fusar-Poli et al., 2009; Zhang et al., 2019). There is therefore evidence in favour of early detection and intervention for this group. In the UK, EIP teams provide interventions to individuals experiencing ARMS with the aim of reducing the risk of transition to psychosis and alleviating distress (NICE., 2014).

Models of Help-Seeking

Given the importance of reducing delays to appropriate treatment for both ARMS and FEP in improving outcomes, it is important to consider the role of help-seeking. Several models and theories of help-seeking and behaviour change have been proposed and utilised in health literature. Firstly, the theory of planned behaviour (Ajzen, 1991) suggests that attitudes, subjective norms, and perceived behavioural control, influences an individual's intention to act and their subsequent behaviour (Ajzen, 2002). For example, an individual's own attitudes and knowledge, and their beliefs about the attitudes of others about mental health and help-seeking influence an individual's help-seeking behaviours, both in terms of intention to act and perseverance (Ajzen, 2002). In addition, help-seeking is influenced by internal factors (such as motivation) and external factors (such as access to services) (Ajzen, 2002). The health belief model (Rosenstock, 1974) suggests that the beliefs held by an individual about the threat of illness and the potential benefits and barriers to behaviour change, influences whether an individual will seek-help for health-related difficulties (Gulliver et al., 2012).

Research into young people's help-seeking for mental health problems has resulted in the development of Rickwood and colleagues' (2005) model of help-seeking and Biddell and colleagues' (2007) model of non-help-seeking. In the first, Rickwood and colleagues (2005) propose that help-seeking involves firstly developing an awareness of the mental health problem requiring help. The individual must then be able and willing to express their distress to others in order to obtain help (Rickwood et al., 2005). This may be particularly important in the area of psychosis given that psychotic experiences are associated with high degrees of stigma (Burke et al., 2016) which may result from limited public awareness and understanding of such experiences (Riches et al., 2019). In addition, poor awareness of, or insight into illness in individuals experiencing psychosis is common and may impede help-seeking (Amador & David, 2004). The second model, the cycle of avoidance model, proposed by Biddle and colleagues (2007) argues that how individuals make sense of their mental distress and the need for help, and societal views of distress and help-seeking, influence whether an individual will seek-help for their mental health concerns. This model again highlights the role of awareness and insight and stigma in help-seeking which is particularly relevant for individuals experiencing psychosis (Amador & David, 2004; Burke et al., 2016).

Pathways to Care

Pathways to Care (PtC) is also an important concept within the mental health, help-seeking literature. Rogler and Cortes (1993) define PtC 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 to these efforts" (p.555). PtC can be measured in terms of duration (the amount of time between onset, initially seeking help, and receiving appropriate intervention), and in terms of number of contacts the individual has with services during this time (von Reventlow et al., 2014). PtC includes both the individual and their family member's help-seeking behaviours, and the accessibility and response of services (Singh & Grange, 2006).

Thesis Overview

This thesis aims to contribute to the evidence base regarding delays to treatment for individuals with FEP and ARMS. It is hoped that the findings will help inform the development of interventions to reduce treatment delays and improve PtC. Chapter Two presents a systematic review of the effectiveness of public health interventions, initiatives, and campaigns designed to reduce treatment delays. Specifically, the review examines whether such interventions are effective in 1) reducing DUP in individuals with FEP, 2) reducing DUI in individuals with ARMS and 3) reducing and improving PtC in individuals with ARMS or FEP. Chapter Three presents a bridging chapter which summarises the findings of the review, introduces the rationale for the empirical paper and discusses conceptual links between the studies. Chapter Four presents the empirical study which compares the PtC and sociodemographic characteristics for ARMS and FEP and explores whether any of these characteristics are predictive of accessing treatment at an earlier stage of illness within a UK EIP service. Finally, Chapter Five presents an overview of the findings across both the systematic review and empirical study. Strengths and limitations are discussed, and clinical, research, and theoretical implications are outlined.

Chapter Two

Systematic Review

The Effectiveness of Public Health Interventions, Initiatives, and Campaigns Designed to Improve Pathways to Care for Individuals with or at Risk of Psychotic Disorders

Prepared for submission to ‘Schizophrenia Research’[1]

Word Count: 5143 (excluding references, in-text citations, tables, and figures in line with author guidelines)

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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 text.

The Effectiveness of Public Health Interventions, Initiatives, and Campaigns Designed to Improve Pathways to Care for Individuals with or at Risk of Psychotic Disorders: A Systematic Review

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Abstract

Purpose: Lengthy duration of untreated psychosis (DUP) and duration of untreated illness (DUI) in people with At-Risk Mental States (ARMS) and first episode psychosis (FEP) is associated with poorer outcomes. However, individuals with FEP often experience negative pathways to care involving contacts with police, crisis services and requiring compulsory admissions, and evidence suggests that individuals with both FEP and ARMS often experience lengthy delays to treatment. Early detection interventions, such as public health interventions, may be one way to reduce delays. This systematic review aimed to synthesise the available evidence on such interventions.

Methods: Searches of four databases were conducted. Studies were included if they compared an intervention designed to improve timely access to treatment for individuals with FEP or ARMS to a control group. Interventions may be targeted at potential patients, their families, the general public, or non-healthcare professionals. Outcomes of interest were DUP or DUI, and/or characteristics of pathways to care.

Results: Nineteen studies met the inclusion criteria. All consisted of FEP populations, none of ARMS populations. There were mixed findings about the effectiveness of interventions at reducing DUP and interventions appeared to differentially impact groups. Pathways to care information was limited and mixed.

Conclusion: Findings on the effectiveness of interventions designed to improve timely access to treatment were inconclusive. More research is warranted to better understand where delays occur and factors which may influence this for both FEP and ARMS populations which may help to develop targeted interventions to address delays.

Keywords: At Risk Mental States, Duration of Untreated Psychosis, First Episode Psychosis, Help Seeking Behaviour, Pathways to Care.

1. Introduction

Accessing treatment at the earliest opportunity improves outcomes for individuals with first episode psychosis (FEP) (Singh, 2010). Longer duration of untreated psychosis (DUP) is associated with poorer clinical and functional outcomes, e.g. more severe symptoms, poorer overall functioning, quality of life and decreased chances of full remission (Harris et al., 2005; Marshall et al., 2005; Penttilä et al., 2014) as well as increased economic costs (Chong et al., 2016). Despite this, people with FEP often experience substantial delays and multiple help-seeking contacts before starting treatment (Anderson et al., 2010; Barnes et al., 2000; Norman et al., 2004). Delays in initiating help-seeking, and the accessibility and response of services appear to contribute to these complex “pathways to care” (PtC): the time between onset, help-seeking, and receiving appropriate treatment (Rogler & Cortes, 1993).

Treatment could occur at an even earlier stage, when individuals are at high risk of developing psychosis, termed “at-risk mental state” (ARMS) (Fusar-Poli et al., 2013). Some researchers have defined ARMS as an early and potentially prodromal phase of psychosis characterised by a drop in functioning and psychotic symptoms of lesser severity and duration than psychosis (Yung & McGorry, 1996; Fusar-Poli et al., 2013). Intervening during this period could potentially reduce DUP or prevent transition to FEP (Fusar-Poli et al., 2013; Rietdijk et al., 2010). However, the concept of ARMS has been widely debated, with some challenging the notion that ARMS is truly a prodromal stage of psychosis given the majority of individuals with ARMS do not develop psychosis (Yung et al., 2021).

Regardless of transition to psychosis, research indicates that ARMS individuals experience poorer outcomes (Beck et al., 2019; Fusar-Poli et al., 2015; Yung et al., 2021). For instance, longer duration of untreated illness (DUI): the time between symptom onset and treatment for ARMS, has been associated with poorer global and social functional outcomes (Carrión et al., 2016; Fusar-Poli et al., 2009; Zhang et al., 2019). These findings highlight the importance of early identification and intervention for this group (Cotter et al., 2014). Compared to FEP, research into PtC and delays in treatment is much more limited in ARMS (Allan et al., 2021), however there is some evidence to suggest that individuals meeting ARMS criteria also experience lengthy delays to treatment (Chung et al., 2010; von Reventlow et al., 2014).

Early detection interventions and initiatives aimed at increasing public awareness of early signs of psychosis and treatment, promoting help-seeking behaviour, and improving recognition of psychosis amongst professionals from whom people may seek help, may be one way to address treatment delays in FEP (Norman et al., 2004). Research has also highlighted a case for public awareness and education campaigns to increase knowledge of early signs and how to access care as a strategy for reducing DUI in ARMS (Chung et al., 2010; Stowkowy et al., 2013; von Reventlow et al., 2014). In 2011, Lloyd-Evans and colleagues (2011) conducted a systematic review evaluating the effectiveness of early detection initiatives at reducing DUP. The review included 11 studies and found that education campaigns aimed at general practitioners and establishing early intervention services, both aimed at reducing service delays, were insufficient to reduce DUP overall. The findings were mixed for campaigns targeting the general public: some studies reported a reduction in DUP, others no change (Lloyd-Evans et al., 2011). The authors hypothesised the mixed findings may have been explained by differences in campaign content, intensity, and duration; and concluded that the current evidence base was limited and further research was required (Lloyd-Evans et al., 2011). To our knowledge, no systematic review has been conducted exploring the effectiveness of such interventions and initiatives at reducing DUI in ARMS or improving PtC for individuals with FEP.

The present systematic review aimed to provide an updated synthesis of the evidence regarding the effectiveness of interventions, initiatives, and campaigns at reducing DUP. Given the previous finding that initiatives and interventions aimed at service delays alone did not reduce overall DUP (Lloyd-Evans et al., 2011), we explored interventions targeting potential patients, their families, friends, or carers, communities, the general public or non-healthcare professionals. In addition, we sought to explore whether such interventions and initiatives are effective in reducing DUI and improving PtC for individuals with FEP or ARMS. This is important due to extensive evidence that individuals with FEP continue to experience long treatment delays (Anderson et al., 2010; Barnes et al., 2000; Norman et al., 2004). Further, the growing evidence-base indicating that individuals with ARMS also experience delays in treatment (Chung et al., 2010; von Reventlow et al., 2014) which may lead to unfavourable outcomes (Carrión et al., 2016; Fusar-Poli et al., 2009; Nelson et al., 2016; Zhang et al., 2019) warrants further investigation.

2. Methods

The systematic review protocol was developed according to Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) (Moher et al., 2009) and was registered with the International Prospective Register of Systematic Reviews (PROSPERO, https://www.crd.york.ac.uk/prospero, registration number CRD42022310218).

2.1 Inclusion/Exclusion Criteria

Studies were included if they:

- Compared interventions, initiatives, and/or campaigns designed to improve timely access to treatment for individuals with psychotic disorders or those with ARMS, to standard service provision.

- Were published in English since 1985. This publication year cut-off was used consistent with previous systematic reviews investigating PtC in ARMS and FEP (Allan et al., 2021; Anderson et al., 2010).
- Included individuals diagnosed with a psychotic disorder or ARMS, with a control-group.
- Included interventions where the target population was patients, family, friends, or carers, communities, the general public or non-health professionals.
- Reported outcomes on DUP or DUI and/or characteristics of PtC such as number of contacts, duration of PtC, contact type or referral source.

Studies in which interventions were targeted solely at healthcare professionals were excluded.

2.2 Search Strategy

The EMBASE, PsychINFO, CINAHL, and MEDLINE databases were searched, with additional hand searches based on reference lists and citations of papers meeting the inclusion criteria. We contacted authors who reported findings at conferences or in supplements to determine if peer reviewed papers had been published. Search terms used were: (campaign* or initiative* or program* or educat* or health promot* or community information or health communicat* or health advert or health messag* or public health) and (schizo* or psychotic or psychos*) and (pathway* or duration of untreated). Search terms were identified from other systematic reviews in the field (Allan et al., 2021; Lloyd-Evans et al., 2011) and finalised in discussion with SA and SO. Searches were carried out on 3rd March 2022.

2.3 Screening and Quality Assessment

Abstracts and full texts from the database searches were screened by RM. Ten percent of abstracts screened for eligibility were re-checked by RM (n=764) and no discrepancies were found. Twenty percent of full text articles screened for eligibility were checked independently by HC and SA (n=12), with two discrepancies resolved following discussion with SO. A further four full text articles were discussed in consensus meetings with SO. Extracted data of included studies was independently checked by SA with 86.76% agreement.

Methodological quality of studies was measured using the Mixed Methods Appraisal Tool (MMAT) (Hong et al., 2018). MMAT is well-established and commonly used for studies adopting quantitative, qualitative, mixed, or randomised control trial methodologies. MMAT contains two generic questions measuring quality, followed by five further questions depending on the study method. A score is obtained by calculating a percentage of criteria questions met; higher percentages indicate better quality studies (Gronholm et al., 2017). Included studies were initially assessed by RM, with twenty percent (n=4) independently assessed by SA, with 78.6% agreement. Discrepancies were discussed and resolved with SO.

2.4 Data Extraction and Narrative Synthesis

Data were extracted from included studies (n=19), with twenty percent (n=4) independently extracted by SA. Data extracted included: study characteristics (study aims, design, country, control-group, intervention target population, description of intervention, duration of intervention), sample characteristics (*n*, gender, age, ethnicity, diagnosis), DUP or DUI (definition of DUP or DUI, measurement, average length) and PtC (definition of PtC, measurement, average number of PtC, average length of PtC, type of PtC contacts, referral source). A narrative synthesis was conducted which explored common patterns, themes and relationships between the data in accordance with the guidance by Popay and colleagues (2006).

3. Results

Figure 1 shows the study selection process. Database searches returned 10396 papers (7633 without duplicates). Following abstract screening, 57 full text papers were screened for eligibility, 18 of which met the inclusion criteria. One additional paper was retrieved through hand searching the reference lists of included papers (McGorry et al., 1996). Overall, ten interventions were evaluated in the 19 included papers. Seven studies evaluated the Treatment and Intervention in Psychosis (TIPS) programme (Ferrara et al., 2019; Hegelstad et al., 2014; Joa et al., 2007; Joa et al., 2008; Johannessen et al., 2001; Larsen et al., 2001; Melle et al., 2004), three examined the Prevention and Early Intervention in Psychosis Programme (PEPP) (Cassidy et al., 2008; Malla et al., 2014; Malla et al., 2005), and two assessed the Early Psychosis Prevention and Intervention Centre (EPPIC) (Krstev et al., 2004; McGorry et al., 1996). The remaining studies evaluated the Early Assessment Service for Young People with Psychosis (EASY) (Chan et al., 2018), Early Psychosis Intervention Programme (EPIP) (Chong et al., 2005), LaCLAve (López et al., 2022), Mindmap (Srihari et al., 2022), early intervention in psychosis (Tidlig Opsporing af Psykose, TOP) (Hastrup et al., 2018), an Early Detection Programme in Camden and Islington Early Intervention Service (CIEIS) (Lloyd-Evans et al., 2015) and YouthSpace (Connor et al., 2016).

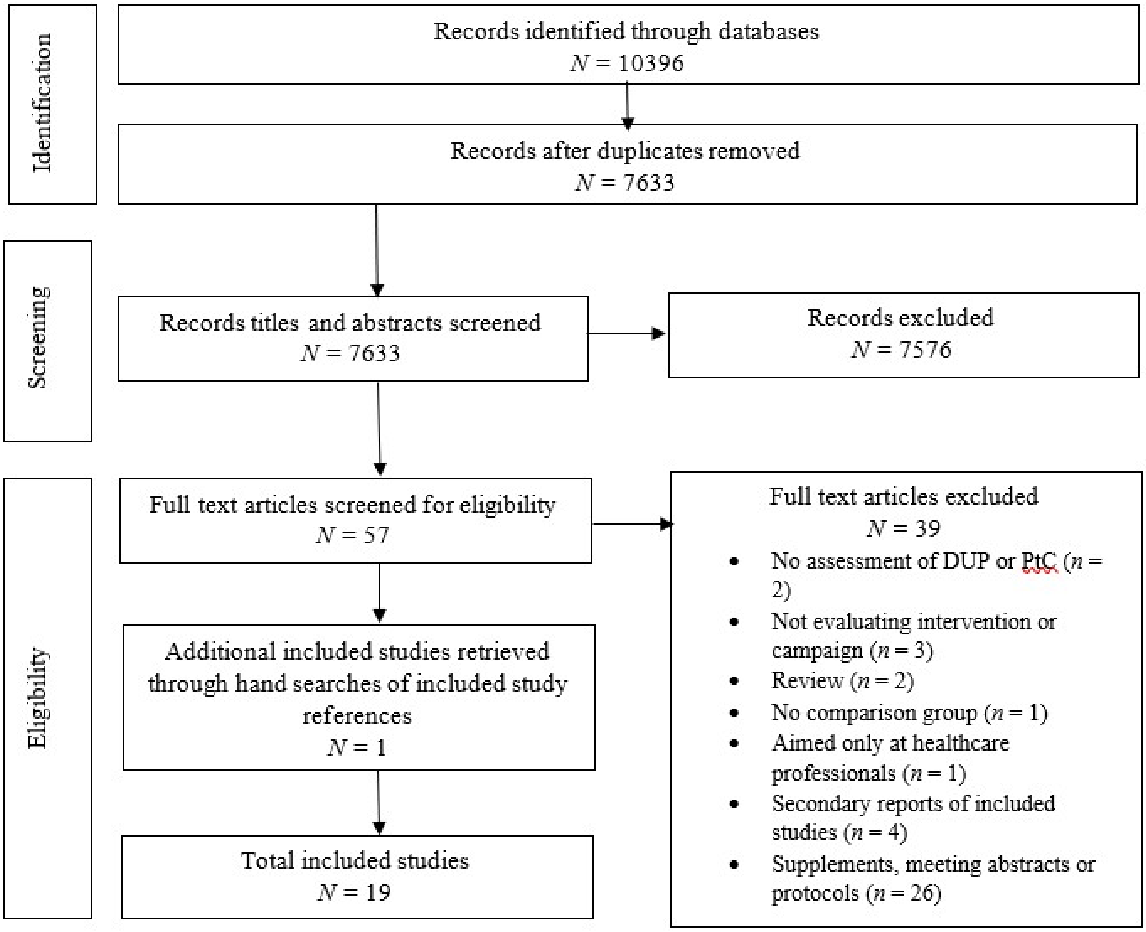

Figure 1. PRISMA flow diagram of the selection process.

3.1 Study Characteristics

Table 1 summarises study characteristics. All studies were quantitative and consisted of FEP populations: none examined ARMS populations. All studies had non-randomised designs with 13 using a historical control, five using a parallel, comparable control site and one using both historical and parallel controls. Sample sizes ranged from 98 (Krstev et al., 2004) to 4299 (Hastrup et al., 2018) with a mean of 460. Mean age of participants ranged from 19.82 (Chan et al., 2018) to 38 (Chong et al., 2005); three studies did not report the average age of participants. Mean percentage of male participants was 63.4% with a range of 38.6% (Chan et al., 2018) to

79% (Cassidy et al., 2008); two studies did not report participant gender. Study locations varied, with seven from Norway (*n*=1 programme; TIPS) (Ferrara et al., 2019; Hegelstad et al., 2014; Joa et al., 2007; Joa et al., 2008; Johannessen et al., 2001; Larsen et al., 2001; Melle et al., 2004), three from Canada (*n*=1 programme; PEPP) (Cassidy et al., 2008; Malla et al., 2014; Malla et al., 2005), two from the United States (*n*=2 programmes; LaCLAve (López et al., 2022); Mindmap (Srihari et al., 2022)), the United Kingdom (*n*=2 programmes, CIEIS (Lloyd-Evans et al., 2015); YouSpace (Connor et al., 2016)), and Australia (*n*=1 programme; EPPIC) (Krstev et al., 2004; McGorry et al., 1996) and one each from Denmark (TOP) (Hastrup et al., 2018), Hong Kong (EASY) (Chan et al., 2018) and Singapore (EPIP) (Chong et al., 2005). Of the 19 included studies, only five reported ethnicities (Chong et al., 2005; Connor et al., 2016; Lloyd-Evans et al., 2015; López et al., 2022; Srihari et al., 2022).

3.2 Intervention Programmes

Details of intervention programmes are given in Table 1. Intervention durations varied between studies, ranging from six-months (Malla et al., 2014) to 120 months (Hegelstad et al., 2014) with a mean duration of 34.4 months. Fifteen studies (*n*=8 intervention programmes; EPIP; EPPIC; LaCLAve; Mindmap; PEPP; TIPS; TOP; YouthSpace) were aimed at multiple targets including the general public and non-healthcare professionals such as schools, universities, youth workers, and community organisations (Cassidy et al., 2008; Chong et al., 2005; Connor et al., 2016; Ferrara et al., 2019; Hastrup et al., 2018; Hegelstad et al., 2014; Joa et al., 2007; Joa et al., 2008; Johannessen et al., 2001; Krstev et al., 2004; Larsen et al., 2001; López et al., 2022; Malla et al., 2005; Melle et al., 2004; Srihari et al., 2022). Two studies' (*n*=2 programmes, EASY; EPPIC) target population was the general public (Chan et al., 2018;

McGorry et al., 1996) and two studies' (*n*=2 programmes, CIEIS; PEPP) targeted non-healthcare professionals only (Lloyd-Evans et al., 2015; Malla et al., 2014).

Intervention content varied across programmes and often involved multiple components. Sixteen studies (*n*=8 programmes, CIEIS; EASY; EPPIC; Mindmap; PEPP; TIPS; TOP; YouthSpace) reported changes in service configuration such as the establishment of early intervention in psychosis services, easy access to early detection teams and/or open referral policies (Cassidy et al., 2008; Chan et al., 2018; Connor et al., 2016; Ferrara et al., 2019; Hastrup et al., 2018; Hegelstad et al., 2014; Joa et al., 2007; Joa et al., 2008; Johannessen et al., 2001; Krstev et al., 2004; Larsen et al., 2001; Lloyd-Evans et al., 2015; Malla et al., 2005; McGorry et al., 1996; Melle et al., 2004; Srihari et al., 2022). Thirteen studies (*n*=7 programmes; EPIP; LaCLAve; Mindmap; PEPP; TIPS; TOP; YouthSpace) reported advertisements and information about psychosis, treatment, and available services delivered to the general public via mass media such as newspapers, local television and radio (Cassidy et al., 2008; Chong et al., 2005; Connor et al., 2016; Ferrara et al., 2019; Hastrup et al., 2018; Hegelstad et al., 2014; Joa et al., 2007; Joa et al., 2008; Johannessen et al., 2001; López et al., 2022; Malla et al., 2005; Melle et al., 2004; Srihari et al., 2022). Two studies (*n*=2 programmes; Mindmap; TIPS) used mass social media to deliver information to the general public (Hegelstad et al., 2014; Srihari et al., 2022). Nine papers (*n*=6 programmes; EPIP; LaCLAve; Mindmap; PEPP; TIPS; YouthSpace) reported information was delivered to the general public using visual and written resources such as posters, pamphlets, and brochures (Cassidy et al., 2008; Chong et al., 2005; Connor et al., 2016; Hegelstad et al., 2014; Joa et al., 2008; Johannessen et al., 2001; López et al., 2022; Malla et al., 2005; Srihari et al., 2022). Six studies (*n*=5 programmes; EASY; LaCLAve; Mindmap; PEPP; TIPS) hoped to increase awareness of psychosis by attending and organising community events

(Cassidy et al., 2008; Chan et al., 2018; Johannessen et al., 2001; López et al., 2022; Malla et al., 2005; Srihari et al., 2022).

Studies also targeted non-healthcare professionals likely to encounter young people including employment, educational and community organisations. Sixteen studies (*n*=9 programmes; CIEIS; EPIP; EPPIC; LaCLAve; Mindmap; PEPP; TIPS; TOP; YouthSpace) reported education about psychosis, treatment and access to services was delivered to professionals via talks, training and workshops (Cassidy et al., 2008; Chong et al., 2005; Connor et al., 2016; Ferrara et al., 2019; Hastrup et al., 2018; Hegelstad et al., 2014; Joa et al., 2007; Joa et al., 2008; Johannessen et al., 2001; Krstev et al., 2004; Lloyd-Evans et al., 2015; López et al., 2022; Malla et al., 2014; Malla et al., 2005; Melle et al., 2004; Srihari et al., 2022). Four studies (*n*=4 programmes; CIEIS; EPIP; Mindmap; PEPP) provided telephone consultation or professional outreach (Chong et al., 2005; Lloyd-Evans et al., 2015; Malla et al., 2005; Srihari et al., 2022) and three studies (*n*=3 programmes; CIEIS; EPPIC; PEPP) provided visual and written information to professionals such as newsletters (Krstev et al., 2004; Lloyd-Evans et al., 2015; Malla et al., 2005).

Table 1. Included study characteristics.

Study, Intervention Name and Location	Duration of Intervention	Target Population	Features of Intervention	*N*	Mean age (SD)	% Male	Intervention Ethnicity
Cassidy et al. (2008) **PEPP** **Canada**	2 years.	General public. Potential patients. Non-healthcare professionals. Family physicians.	Information about psychosis and treatment in posters, pamphlets, and radio. 60–90-minute training and education sessions. Open referral policy.	Intervention: 99 Post-Intervention: 98 Control: 88	Intervention: 25.6 (8) Post Intervention: 24.4 (7.1) Control: 25.1 (7.2)	Intervention: 79 Post Intervention: 75 Control: 78	Not reported.
Chan et al. (2018) **EASY** **Hong Kong**	Not stated.	General public.	Established early intervention services. Information campaigns including educational talks and exhibits. Accessible referral system.	Youth Control: 34 Youth Intervention: 126 Adult Control: 88 Adult Intervention: 353	Youth Control: 21.15 (2.05) Youth Intervention: 19.82 (2.72) Adult Control: 35.72 (7.18) Adult Intervention: 36.55 (8.74)	Youth Control: 58.82 Youth Intervention: 49.21 Adult Control: 38.64 Adult Intervention: 44.19	Not reported
Chong et al. (2005) **EPIP** **Singapore**	2 years.	General public. Primary healthcare workers.	Information about psychosis and treatment via public forums, newspaper, radio, postcards, TV docudrama, radio, website, books, and art exhibitions. Newsletters, talks, forums, workshops, and telephone consultations.	Intervention: 287 Control: 107	Intervention: 28.3 (7) Control: 38 (12.4)	Intervention: 55 Control: 57	71.7% Chinese 20.6% Malay 5.6% Indian 2.1% Other
Connor et al. (2016) **YouthSpace**	23 months.	Local community. Families. Young people. Emergency services. Youth community groups.	Direct youth mental health pathways and website. Information about psychosis and treatment in posters, leaflets, postcards, newspapers, magazines, and websites. Telephone information line. Bespoke training for target populations.	Intervention: 77 Control: 74	Intervention: 22.5 Control: 21.6	Intervention: 68 Control: 62	48% White British 4% White – Other 3% Asian Bangladeshi 3% Asian Indian 4% Asian-Other 6% Asian Pakistani 1% Asian British Pakistani 5% Black African

		Employment agencies. Education agencies.					5% Black Caribbean 8% Mixed White and Black Caribbean 3% Mixed – Other 1% Mixed White Asian 9% Missing
Ferrara et al. (2019) **TIPS** **Norway**	4 years.	General population. Schools. General practitioners.	Low threshold early detection teams. Information about psychosis and treatment in newspapers. Outreach to schools and general practitioners.	Intervention: 141 Control: 140	Intervention: 26.2 (7.6) Control: 31.1 (10.5)	Intervention: 61.7 Control: 56.4	Not reported
Hastrup et al. (2018) **TOP** **Denmark**	4 years.	General public. Professionals.	Mobile, early detection teams. Open referral policy. Information about psychosis and treatment in newspapers, cinemas, TV, social media, public transport, and videos. Education sessions to target population.	4299 Intervention: 613 Control: 3686	22.95 (4.9)	56.6 Intervention: 57.6 Control: 55	Not reported
Hegelstad et al. (2014) **TIPS** **Norway**	11.5 years (18 month pause 2001-2002).	General population. Schools. Healthcare professionals.	Early detection teams. Open referral policy. Information about psychosis and treatment in postcards, brochures, radio, TV, and cinema. Education programmes to target population. TIPS 1: brochures to all households. TIPS 3 and TIPS 4: social media and online newspaper adverts. TIPS 4: information on substance induced psychosis.	Historical control: 44 Intervention (TIPS1): 146 Intervention removed (TIPS2): 115 Intervention (TIPS3): 95 Intervention (TIPS4): 202	Historical control: 28.4 (8.3) Intervention (TIPS1): 25 (7.8) Intervention removed (TIPS2): 26.7 (11.6) Intervention (TIPS3): 28.2 (10.8) Intervention (TIPS4): 27.2 (11.3)	Historical control: 63.6 Intervention (TIPS1): 59.6 Intervention removed (TIPS2): 60.9 Intervention (TIPS3): 56.8 Intervention (TIPS4): 55.4	Not reported
Joa et al. (2007) **TIPS** **Norway**	4 years.	General population. Health professionals. Schools.	Early detection teams. Information about psychosis and treatment in newspapers. Educational programmes to target population.	Early Campaign: 79 Late Campaign: 59 No Intervention: 75	Not reported.	Not reported.	Not reported
Joa et al. (2008) **TIPS**	4 years.	General public. Schools. Healthcare professionals.	Mobile detection teams. Information about psychosis and treatment in brochures to households, newspapers, posters, cinema, TV, radio, website, postcards, and other promotional materials.	Intervention: 108 Control: 75	Intervention: 24.4 (7.5) Control: 26.4 (10.8)	Intervention: 61 Control: 63	Not reported

Norway			Educational programmes to target populations.				
Johannessen et al. (2001) **TIPS** **Norway**	2 years.	General population. Health professionals. Schools.	Mobile detection teams. Information about psychosis and treatment in radio, TV, newspaper, cinemas, brochures to households, postcards, and other promotional materials. Public meetings and free lectures. School outreach. Educational programmes to target populations.	Intervention: 60 Control: 43	Not reported	Not reported	Not reported
Krstev et al. (2004) **EPPIC** **Australia**	12 months.	Young people. Parents. General practitioners. Teachers. Youth workers.	Mobile detection teams. Awareness activities in schools. Education delivered to target population. Information about psychosis and treatment in workshops, newsletters, and videos.	98 Intervention: 40 Control: 58	22.2 (3.4) Intervention: 22.1 (3.4) Control: 22.3 (3.4)	69.4 Intervention: 70.7 Control: 67.5	Not reported
Larsen et al. (2001) **TIPS** **Norway**	2 years.	General population. Health professionals. Schools.	Early detection teams. Education campaigns.	Intervention: 66 Control: 43	Not reported	Intervention: 59 Control: 65	Not reported
Lloyd-Evans et al. (2015) **CIEIS**	12 months.	Non-health community organisations.	Half-day workshops about psychosis and treatment. One-hour top-up sessions after 6-9 months. Educational materials. Link worker offering monthly meetings. Open referral policy.	Intervention: 110 Control: 70	Intervention: 24.3 (6.5) Control: 24.4 (5.9)	Intervention: 67 Control: 71	37% White British 17% White Other 26% Black Ethnic Groups 13% Asian Ethnic Groups 4% Mixed and Other Ethnic Groups 3% Missing
López et al. (2022) **LaCLAve** **United States**	24 months.	General public. Community organisations. Health and mental health professionals.	Information about psychosis and treatment in bilingual brochures, posters, radio, TV, websites, buses, and billboards. Community events. 60–90-minute workshops.	123	25 (8.87)	72	All participants identified as Latinx
Malla et al. (2005) **PEPP** **Canada**	26 months.	General public. Education professionals. Family physicians.	Information about psychosis and treatment in posters, pamphlets, calendars, TV and university cinemas. Community fundraising events. Clinicians at monthly school counselling meetings. Education delivered to target populations.	Intervention: 100 Control: 88	Intervention: 25.9 (8.3) Control: 25 (7.3)	Intervention: 78 Control: 78.4	Not reported

			Open referral policy.				
Malla et al. (2014) **PEPP-Montreal** **Canada**	6 months.	Primary health. Education. Hospitals. Mental health services.	60-90-minute educational sessions. Films about psychosis and intervention. Booster session after 6 months.	Intervention: 159 Control: 136	Intervention: 21.9 (4) Control: 21.95 (4.03)	Intervention: 69.4 Control: 68.4	Not reported
McGorry et al. (1996) **EPPIC** **Australia**	12 months.	General public.	Mobile early detection teams and treatment programme. Networking and community education about psychosis and treatment.	Intervention: 51 Control: 51	Intervention: 22.4 (3.9) Control: 22 (3.7)	Intervention: 65 Control: 65	Not reported
Melle et al. (2004) **TIPS** **Norway**	4 years.	General population. Schools. Social workers. General practitioners.	Low threshold early detection teams. Targeted information about psychosis and treatment in newspapers, radio, and cinema.	Intervention: 141 Control: 140	Intervention: 26.2 (7.6) Control: 31.1 (10.5)	Intervention: 62 Control: 56	Not reported
Srihari et al. (2022) **Mindmap** **United States**	4 years.	Potential patients. Peers. Family. Community and clinical agencies. College and high schools. Judicial systems. Local government.	Information about psychosis in newspapers, transit, cinema, postcards, billboards, and social media channels. Community events. Professional outreach.	Intervention site (including historical): 171 Control site: 75	Intervention site (including historical): 22.5 (3.8) Control: 21.8 (2.8)	Intervention site (including historical): 70.2 Control: 72	33.9% White 44.4% Black 15.8% Interracial 5.8% Other

Abbreviations: DUP = Duration of Untreated Psychosis, FEP = First Episode Psychosis

3.3 Data Sources and Measures

Information regarding DUP and PtC definitions and measures are given in Table 2. Eighteen studies measured DUP, of these 16 defined DUP and 15 reported how it was measured. Of the studies which defined DUP, this was given as the time between the onset of psychotic symptoms and start of treatment. Definitions of start of treatment varied (see Table 2).

DUP measurement tools also varied, with seven using a non-specified interview with participants and significant others (Chong et al., 2005; Connor et al., 2016; Ferrara et al., 2019; Hegelstad et al., 2014; Joa et al., 2008; López et al., 2022; Melle et al., 2004) and nine using medical records (Cassidy et al., 2008; Chan et al., 2018; Chong et al., 2005; Connor et al., 2016; Ferrara et al., 2019; Hegelstad et al., 2014; López et al., 2022; Malla et al., 2014; Malla et al., 2005). Of those studies using non-validated and non-specific measures of DUP, four assessed interrater reliability and reported this to be good (Hegelstad et al., 2014; Joa et al., 2008; López et al., 2022; Melle et al., 2004). Eight studies used established and validated measures. The most commonly used (*n*=4 studies) measure was the Interview for Retrospective Assessment of Onset of Schizophrenia (Häfner et al., 1992) or the adapted version, the Circumstances of Onset and Relapse Schedule (CORS) (Cassidy et al., 2008; Chan et al., 2018; Malla et al., 2014; Malla et al., 2005). Full measurement details are given in Table 2.

Ten studies reported information relating to PtC, only five defined PtC (Connor et al., 2016; Hastrup et al., 2018; Lloyd-Evans et al., 2015; Malla et al., 2014; Srihari et al., 2022) and eight reported how it was measured (Cassidy et al., 2008; Chong et al., 2005; Connor et al., 2016; Hastrup et al., 2018; Lloyd-Evans et al., 2015; Malla et al., 2014; Malla et al., 2005; Srihari et al., 2022). Definitions of PtC varied between studies (Table 2), three studies divided pathways into help-seeking delays and service delays (Connor et al., 2016; Malla et al., 2014;

Srihari et al., 2022). Two studies did not make this distinction, instead reporting the total delay from help-seeking to start of treatment (Hastrup et al., 2018; Lloyd-Evans et al., 2015). Tools used to measure PtC also varied between studies (Table 2). Data were mostly extracted from medical records (*n*=5) (Cassidy et al., 2008; Chong et al., 2005; Connor et al., 2016; Malla et al., 2014; Malla et al., 2005). Four studies used established measures of PtC, the most commonly used (*n*=3) was CORS (Cassidy et al., 2008; Malla et al., 2014; Malla et al., 2005). None of the studies using non-validated measures reported on the inter-rater reliability of their measures.

3.4 Impact of Intervention Programmes on DUP

See Table 2 for results regarding the impact of intervention programmes on DUP and PtC. DUP data were reported in all but one study (Hastrup et al., 2018). Across studies, the median DUP ranged from 28 (Joa et al., 2007) to 227.5 (Cassidy et al., 2008) days in intervention groups, and from 30 (McGorry et al., 1996) to 430 (Srihari et al., 2022) days, in control groups. Significant reductions in mean or median DUP were reported by nine studies (*n*=3 programmes; EPIP; TIPS; YouthSpace) targeting multiple populations (Chong et al., 2005; Connor et al., 2016; Ferrara et al., 2019; Hegelstad et al., 2014; Joa et al., 2007; Joa et al., 2008; Johannessen et al., 2001; Larsen et al., 2001; Melle et al., 2004). Whereas five studies (*n*=4 programmes; EPPIC; LaCLAve; Mindmap; PEPP) reported no significant difference in mean or median DUP as a result of the intervention programme (Cassidy et al., 2008; Krstev et al., 2004; López et al., 2022; Malla et al., 2005; Srihari et al., 2022). Of the two studies targeting the general public only, one found a significant decrease in the median DUP for the adult population but not the youth population (EASY) (Chan et al., 2018) and one study found a significant increase in the median DUP following the intervention programme (EPPIC) (McGorry et al., 1996), however this returned to pre-intervention levels over time (Cassidy et al., 2008). No studies targeting only non-healthcare professionals found a significant difference in mean or median DUP (CIEIS, (Lloyd-Evans et al., 2015); PEPP, (Malla et al., 2014)).

When duration of intervention was explored, none of the studies with an intervention duration of one-year or less found a significant reduction in mean or median DUP (*n*=3 programmes; CIEIS, (Lloyd-Evans et al., 2015); EPPIC, (Krstev et al., 2004; McGorry et al., 1996); PEPP, (Malla et al., 2014), in fact, McGorry and colleagues (1996) found a significant increase in median DUP. Four studies (*n*=3 programmes; EPIP; TIPS; YouthSpace) with an intervention duration between 13- and 26-months found a significant reduction in mean or median DUP (Chong et al., 2005; Connor et al., 2016; Johannessen et al., 2001; Larsen et al., 2001) whereas three studies (*n*=2 programmes; LaCLAve; PEPP) with the same intervention duration did not find a significant difference in DUP (Cassidy et al., 2008; López et al., 2022; Malla et al., 2005). Five studies had an intervention duration of more than four years, of which four (*n*=1 programme; TIPS, (Ferrara et al., 2019; Hegelstad et al., 2014; Joa et al., 2007; Joa et al., 2008; Melle et al., 2004) found a significant reduction in median DUP and one (Mindmap, (Srihari et al., 2022)) found no significant reduction in total mean DUP.

Several studies conducted additional analysis on DUP to determine if the intervention programmes had a differential impact on DUP based on various factors. Two studies found that there were significantly more cases with longer DUP (over two (Hegelstad et al., 2014) or three (Krstev et al., 2004) years) in the intervention group compared to control, suggesting the programmes may have brought individuals into treatment who may previously not have been seen. Cassidy and colleagues (2008) observed a trend for cases with DUP of less than one-year moving towards lower values, i.e., DUP of less than two months, however this was only statistically significant for individuals with schizophrenia spectrum psychosis (*p*=.02) and did not appear to reduce delays in individuals with longer DUP (over one-year). Two studies divided DUP into quartiles (Ferrara et al., 2019; Srihari et al., 2022) with one study finding a significant reduction in DUP in the 50th and 75th percentile (p=.0008 and p=.009 respectively) but not in the 25th percentile (p=.18) (Ferrara et al., 2019). In contrast, Srihari and colleagues (2022), found significant reductions in DUP per campaign year in the first and second quartile (p=.01 and p<.0001) but not in the third quartile. In their adult population, Chan and colleagues (2018) found a significant reduction in DUP for adults with gradual onset psychosis of more than four weeks (p=.003) but not for individuals with acute (<1 week) or sub-acute (1-4 weeks) onset. In addition, they found individuals with no family history of psychiatric illness had significantly shorter DUP than prior to the intervention (p=.01) (Chan et al., 2018). Two studies found a differential impact on DUP based on sex, with Larsen and colleagues (2001) finding the median DUP of men was significantly reduced (p=.0001) but not the median DUP of women (p=.33). Similarly, Ferrara and colleagues (2019) observed significant reductions of DUP for men, but only in the 75th percentile (p=.03); no significant reduction in DUP was observed for women. Ferrara and colleagues (2019) also found a significant reduction in DUP for single individuals in the 75th percentile (p=.02) but not for individuals in relationships; higher financial adequacy was associated with longer DUP in the 25th percentile (p=.04) and increasing episodes of police arrests was associated with increased reduction in DUP in the 25th percentile (p=.047). The impact of the intervention was not found to be significantly associated with having a diagnosis of narrow schizophrenia spectrum disorder, Premorbid Adjustment Scale (PAS) scores (Cannon-Spoor et al., 1982), Global Assessment of Functioning (GAF) scores (American Psychiatric Association, 1987) or number of family contacts (Ferrara et al., 2019).

Table 2. Duration of Untreated Psychosis and Pathways to Care Information

			Median (range) DUP					**Mean (SD) PtC Delay**		
Study and Intervention Name †	**DUP Definition**	**Measure of DUP**	**Intervention**	**Control**	**Statistical test/ Sig. *p***	**PtC Definition**	**Measure of PtC**	**Intervention**	**Control**	**Sig. *p***
Chan et al. (2018) **EASY**	Time between onset of psychosis (one or more positive symptoms) and receipt of antipsychotic treatment.	Interview for the Retrospective Assessment and Onset of Schizophrenia (participant and significant other). Review of medical records.	Youth: 90 days Adult: 93 days	Youth: 120 days Adult: 180 days	Non-parametric: Youth: .63 Adult: .01	Not defined.	Not measured.	Not reported.	Not reported.	Not reported.
Chong et al. (2005) **EPIP**	Time between the onset of psychotic symptoms and when a definitive diagnosis and treatment were established.	Interview (participant and significant other). Review of medical records.	4 (0-240) months	12 (0.1-336 months)	Non-parametric: .002	Not defined.	Interview (participant and significant other). Review of medical records.	Not reported.	Not reported.	Not reported.
McGorry et al. (1996) **EPPIC**	Not defined.	Royal Park Multidiagnostic Instrument for Psychosis (RPMIP)	52 days	30 days	Non-parametric: Significant. P value not reported.	Not defined.	Not measured.	Not reported.	Not reported.	Not reported.
Krstev et al. (2004) **EPPIC**	Time between the onset of psychosis and commencement of treatment.	Royal Park Multidiagnostic Instrument for Psychosis (RPMIP)	59 days	207.5 days	Log transformed t-test: .0557	Not defined.	Not measured.	Not reported.	Not reported.	Not reported.
López et al. (2022) **LaCLAve**	DUP-Any: Time between onset of first episode psychosis (positive	Interview (participant and significant other). Review of medical records.	Not reported.	Not reported.	Log-transformed data ANOVA:	Not defined.	Not measured.	Not reported.	Not reported.	Not reported.

	symptoms) and any treatment. DUP-Med: Time between onset of first episode psychosis (positive symptoms) and medication.				Main effect of campaign (onset to any treatment): .13 Main effect of campaign (onset to medication): .43					
Srihari et al. (2022) **Mindmap**	Time between the onset of psychosis and enrollment in first episode schizophrenia service.	The Structured Interview for Psychosis-Risk Syndromes (SIPS) (input from all available stakeholders).	149 (2-1189) days	Historical Control: 311.5 (8-1060) days Comparable Site Control: 430 (13-1416) days	Log-transformed ANOVA: Non-significant main effect of site or campaign (no p value reported). Site by campaign interaction .39	Demand: Time between onset of psychosis to first antipsychotic medication. Supply: Time between first antipsychotic medication and enrollment in a first episode schizophrenia service.	Pathways to care instrument modified for the study.	Demand 145.3 (234) days Supply 138.7 (242.2) days	Demand Historical Control: 173.5 (177.2) days Comparable Site Control: 186.4 (236.7) days Supply Historical Control: 153 (218.7) days Comparable Site Control: 180.8 (175.5) days	Non-significant main effect of site or campaign (no p value reported). Demand Site by campaign interaction .60 Supply Site by campaign interaction .23
Malla et al. (2005) **PEPP**	The time between onset of psychotic symptoms contiguous with the presenting episode, plus any previous episodes of psychotic symptoms, to the time of adequate treatment with antipsychotic medication (1month unless	Circumstances of onset and relapse schedule (CORS) (participant and significant other). Review of medical records.	24.3 weeks	21.9 weeks	Non-parametric: Non-significant. P value not reported.	Not defined.	Circumstances of onset and relapse schedule (CORS) (participant and significant other). Review of medical records.	Not reported.	Not reported.	Not reported.

	remission of positive symptoms is earlier).									
Cassidy et al. (2008) **PEPP**	The time between onset of psychotic symptoms and adequate treatment with antipsychotic medication (1month unless remission of positive symptoms is earlier).	Circumstances of Onset and Relapse Schedule (CORS) (participant and significant other). Review of medical records.	Intervention: 32.5 weeks Post Intervention: 24.5 weeks	22.8 weeks	Non-parametric: Non-significant. P value not reported.	Not defined.	Circumstances of onset and relapse schedule (CORS) (participant and significant other). Review of medical records.	Not reported.	Not reported.	Not reported.
Malla et al. (2014) **PEPP-Montreal**	The time between onset of current psychotic episode and adequate treatment with antipsychotic medication (30days unless remission of positive symptoms is earlier).	Circumstances of onset and relapse schedule (CORS) (participant and significant other). Review of medical records.	109 days	124 days	Non-parametric: Non-significant. P value not reported.	Help-seeking: Time between onset of current episode of psychosis and first mental health contact for the presenting psychotic symptoms. Referral: Time between the mental health first contact and final referral resulting in assessment at PEPP.	Circumstances of onset and relapse schedule (CORS). Review of medical records.	Help-Seeking: 183.81 (373.93) days Referral: 90.8 (240.88) days	Help-Seeking: 146.8 (265.46) days Referral: 93.04 (250.90) days	Help-Seeking: .431 Referral: .928

Lloyd-Evans et al. (2015) **CIEIS**	Time between first psychotic symptoms to first contact with early intervention service.	Nottingham Onset Schedule (participant, significant other, and other healthcare professionals)	116.5 days	133.5 days	Non-parametric test: .875	Number of steps in the referral pathway and type of referral from first contact point and date of appropriate referral to early intervention service.	Computerised assessment package	Not reported.	Not reported.	Not reported.
Connor et al. (2016) **YouthSpace**	The time between onset of psychosis (positive symptoms) and the start of adequate treatment (at least 1month or until a significant reduction in symptoms).	Regularly collected from all clients entering the service via interviews and review of electronic records.	39 days	79.5 days	Linear transformed regression: .0039 (Relative reduction 0.75, 95% CI 0.348-0.893)	Help-seeking delay: Time between onset of psychosis and first help-seeking contact. Mental health service delay: Time between first contact with secondary mental health services after onset of psychosis and onset of criteria treatment.	Interviews. Review of electronic care records.	Help-seeking delay: 41.49 (105.93) days Mental health service delay: 42.32 (86.74) days	Help-seeking delay: 116.97 (229.02) days Mental health service delay; 124.19 (216.45) days	Not reported.
Johannessen et al. (2001) **TIPS**	Not defined.	Not defined.	5 weeks	26 weeks	Non-parametric: <.0005	Not defined.	Not measured.	Not reported.	Not reported.	Not reported.

Larsen et al. (2001) **TIPS**	Time from onset of psychosis (positive symptoms) to initiation of adequate treatment.	Not defined.	4.5 weeks	26 weeks	Non-parametric: .0005	Not defined.	Not measured.	Not reported.	Not reported.	Not reported.
Melle et al. (2004) **TIPS**	Time from onset of psychosis (first appearance of positive symptoms) to start of adequate treatment (antipsychotic medication or psychiatric hospitalisation).	Interview (participant and significant other).	5 (0-1196) weeks	16 (0-996) weeks	Non-parametric: .003	Not defined.	Not measured.	Not reported.	Not reported.	Not reported.
Joa et al. (2007) **TIPS**	The time from onset of psychosis (first appearance of positive psychotic symptoms) to the start of adequate treatment with antipsychotic medication and/or psychotherapy.	Not defined.	Early Campaign: 4 weeks Late Campaign: 7 weeks	14 weeks	Non-parametric: .017 (Early campaign and no campaign) No other significant differences reported.	Not defined.	Not measured.	Not reported.	Not reported.	Not reported.
Joa et al. (2008) **TIPS**	The time from onset of psychosis (first appearance of positive psychotic symptoms) to the start of adequate treatment (antipsychotic medication, hospitalisation or psychotherapy).	Interviews (participant and significant other).	5 weeks	15 weeks	Non-parametric: <.005	Not defined.	Not measured.	Not reported.	Not reported.	Not reported.

Hegelstad et al. (2014) **TIPS**	The time from onset of psychosis to the start of adequate treatment.	Interview (participant and significant other). Review of medical records.	Intervention (TIPS1; 1997-1998): 6 (0-416) weeks Intervention (TIPS1; 1999-2000): 8 (0-364) weeks Intervention (TIPS3): 14 (0-520) Intervention (TIPS 4; 2007-2008): 25 (0-1530) Intervention (TIPS 4; 2009-2010): 8 (0-1300)	Historical Control: 26 (0-936) weeks Intervention Removed (TIPS2): 15(0-2080)	Non-parametric: TIPS1 to TIPS2: <.014 Historical control to TIPS1 1997-1998): .001 TIPS 3 to TIPS4 (2007-2008): .093 No other comparisons reported.	Not defined.	Not measured.	Not reported.	Not reported.	Not reported.
Ferrara et al. (2019) **TIPS**	Time from psychosis onset (first appearance of positive symptoms) to start of adequate treatment (medication, psychiatric hospitalisation or structured psychotherapy).	Interview (participant and significant others). Review of medical records.	5 weeks (0-1196)	16 weeks (0-966)	Quartile regression: .0008	Not defined.	Not measured.	Not reported.	Not reported.	Not reported.

Hastrup et al. (2018) **TOP**	Not defined.	Not measured.	Not reported	Not reported	Not reported	Contacts with mental health services and GP in the two years prior to first diagnosis of schizophrenia.	Extracted from national databases. No formal tool reported.	Not reported.	Not reported.	Not reported.

Abbreviations: DUP = Duration of Untreated Psychosis, PtC = Pathways to Care, GP = General Practitioner.
† Studies ordered by intervention programme name for ease of comparison.

3.5 Impact of Intervention Programmes on PtC

Only one paper (Lloyd-Evans et al., 2015) reported the mean number of PtC between first help-seeking contact and referral to EIP and found a significant increase following the intervention programme (p=.002). The authors argued that this may have been due to improved recording of PtC information during the study. Three studies (n=3 programmes) reported mean duration of PtC, these were defined and measured differently across studies. Srihari and colleagues (2022) found no significant main effect or interaction of site or intervention programme on demand delays (days between onset of psychosis and first antipsychotic medication) or supply delays (days between first antipsychotic medication and referral to EIP). However, the authors observed a significant reduction in demand delay days per intervention year in the 75th percentile (p=.006) and supply delay days in the 50th (p=.008) and 75th percentile (p=.03). Malla and colleagues (2014) found no significant difference in mean help-seeking delays (days between onset of psychosis and first mental health contact) or mean referral delays (days between first mental health contact and referral to EIP) between intervention and control groups. Connor and colleagues (2016) reported the mean delay in help-seeking and mental health services, however, did not compare these statistically.

Three studies (n=3 programmes) compared key pathway contacts, two of which found significant differences between intervention and control group contacts. One study found a significantly higher proportion of new referrals reached EIP without the involvement of other mental health services, however the authors argue that most referrals came through GPs who were not the target of the intervention (Lloyd-Evans et al., 2015). One study found the intervention group had significantly fewer mental health contacts and consultations with GPs, but significantly more GP telephone contacts than the control group (Hastrup et al., 2018). One paper found no significant differences in contacts between the intervention and control group (Malla et al., 2014).

Five studies compared referral sources, three of which found significant differences between the intervention and control groups (Chong et al., 2005; Hastrup et al., 2018; Joa et al., 2007). Chong and colleagues (2005) found a significant increase in self and family referrals and a significant reduction in police involvement. Hastrup and colleagues (2018) found no difference between GP or hospital referrals, however individuals in the intervention group were more likely to be referred through other, unspecified, sources. Joa and colleagues (2007) found a significant increase in internal referrals such as hospital emergency and outpatient, and a significant reduction in GP referrals following the end of the intervention programme. Two studies found no significant differences in referral sources between the intervention and control group (Cassidy et al., 2008; Malla et al., 2005).

3.6 Quality Appraisal

The quality assessment ratings are given in Table 3. The methodological quality of studies varied, ranging from 42.86% (Johannessen et al., 2001) to 100% (Connor et al., 2016; Hastrup et al. 2018; Hegelstad et al., 2014; Joa et al., 2008; Krstev et al., 2004; Melle et al., 2004; Srihari et al., 2022). Overall, studies generally used appropriate measurements, it was agreed during consensus meetings that measures would be scored as appropriate if DUP and PtC were appropriately defined and how data were collected was consistent with this definition. Only one study (Lloyd-Evans et al., 2015) reported that the intervention was not administered as intended. In addition, most papers considered potential confounders in their design and analysis procedures. Data was considered complete if it reached 60%, consistent with quality assessment guidelines (Thomas, 2003) and a previous review (Lloyd-Evans et al., 2011). Limitations were generally due to a lack of comparison of the sample to the population or failure to compare participants to non-participants, making it difficult to assess if the participants were representative of the target population.

Table 3. Quality Appraisal

		Quality assessment of included studies																		
Domain	**Quality criteria**	Cassidy et al. (2008)	Chan et al. (2018)	Chong et al. (2005)	Connor et al. (2016)	Ferrara et al. (2019)	Hastrup et al. (2018)	Hegelstad et al. (2014)	Joa et al. (2007)	Joa et al. (2008)	Johannessen et al. (2001)	Krstev et al. (2004)	Larsen et al. (2001)	Lloyd-Evans et al. (2015)	López et al. (2022)	Malla et al. (2005)	Malla et al. (2014)	McGorry et al. (1996)	Melle et al. (2004)	Srihari et al. (2022)
Screening Questions	Are there clear research questions?	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
	Do the collected data allow to address the research questions?	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Quantitative Non-Randomised Studies	Are the participants representative of the target population?	-	-	?	+	?	+	+	?	+	?	+	+	+	-	?	?	+	+	+
	Are measurements appropriate regarding both the outcome and intervention (or exposure)?	+	+	+	+	+	+	+	?	+	?	+	?	+	+	+	+	+	+	+
	Are there complete outcome data?	+	?	?	+	?	+	+	?	+	?	+	+	+	+	+	+	?	+	+
	Are the confounders accounted for in the design and analysis?	+	+	+	+	+	+	+	+	+	?	+	+	+	?	+	+	+	+	+
	During the study period, is the intervention administered (or exposure occurred) as intended?	+	+	+	+	+	+	+	+	+	+	+	+	-	+	+	+	+	+	+
Total percentage		85.71	71.43	71.43	100	71.43	100	100	57.14	100	42.86	100	85.71	85.71	71.42	85.71	85.71	85.71	100	100

+yes, - no, ? can't tell

4. Discussion

4.1 Main Findings

This systematic review aimed to explore the effectiveness of interventions, initiatives, and campaigns at reducing DUP or DUI, and improving PtC, for individuals with FEP or ARMS. The review found no studies investigating the impact of such initiatives aimed towards an ARMS population and 19 studies aimed towards a FEP population. There were mixed findings about the effectiveness of interventions at reducing DUP and few studies reported on the impact of these interventions on PtC. Of the studies that reported PtC information there was heterogeneity in definition and measurement. Interventions targeting multiple populations (general public and non-healthcare professionals) and those lasting more than 12-months, appeared to be more likely to result in a reduction in DUP, however this was not a universal finding. There were differences in how interventions impacted the DUP for different groups.

4.2 Interpretation of Findings

The fact that no papers were identified investigating interventions to reduce delays for individuals with ARMS highlights that PtC continues to be a more neglected area in ARMS than FEP (Allan et al., 2021). This is despite research findings that prolonged DUI is associated with poorer outcomes in ARMS (Carrión et al., 2016; Fusar-Poli et al., 2009; Zhang et al., 2019). In addition, research has suggested that public awareness and education campaigns may be one way to address delays for people with ARMS (Chung et al., 2010; Stowkowy et al., 2013; von Reventlow et al., 2014). One possible reason for this is the difficulty defining and measuring the onset of illness in ARMS (Allan et al., 2021; Jorgensen et al., 2000).

The included FEP studies originate from a variety of countries with different healthcare contexts and processes and therefore collective findings should be interpreted with caution. In addition, population and intervention characteristics differed across studies. These differences may help to explain some of the variation in findings across intervention programmes. Mixed findings regarding the effectiveness of interventions on DUP were consistent with the earlier review by Lloyd-Evans and colleagues (2011). The authors found that multi-focus campaigns with greater intensity appeared to be more successful in reducing DUP. Similarly, this current review suggested that interventions targeting multiple populations were more successful than those targeting professionals only. However, it should be noted that results were still mixed for multi-focus interventions and only two interventions targeted non-healthcare professionals only (Lloyd-Evans et al., 2015; Malla et al., 2014). Further, interventions that were longer in duration appeared to be more likely to find a significant reduction in DUP (Chong et al., 2005; Connor et al., 2016; Ferrara et al., 2019; Hegelstad et al., 2014; Joa et al., 2007; Joa et al., 2008; Johannessen et al., 2001; Larsen et al., 2001; Melle et al., 2004; Srihari et al., 2022).

Some studies observed more individuals with DUP over two-years following the intervention programme (Hegelstad et al., 2014; Krstev et al., 2004; Malla et al., 2005). It may be that intervention programmes, at least initially, identify cases with long DUP who may not otherwise have been detected, and therefore any effect of intervention campaign on DUP may have been masked. Given that a long DUP is associated with poor outcomes, identifying more patients with longer DUP who may otherwise have gone undetected may in itself be an important and valuable outcome (Lloyd-Evans et al., 2011).

Several studies found that the intervention programmes differentially impacted the DUP of different groups. For example, greater reductions in DUP were seen in adult participants with gradual onset psychosis (Chan et al., 2018), no family history of psychiatric illness (Chan et al., 2018), men (Ferrara et al., 2019; Larsen et al., 2001) single individuals (Ferrara et al., 2019), and more episodes of police arrest (Ferrara et al., 2019). The impact on DUP also appeared to differ across the distribution of DUP (Ferrara et al., 2019; Srihari et al., 2022). Of note, none of the studies investigated whether the intervention programme differentially impacted DUP based on ethnicity, employment status, or urban or rural living. Research suggests that unemployment, ethnic minority status, and rural living are all associated with longer and more negative PtC which may contribute to longer DUP (Boonstra et al., 2012; Kvig et al., 2017; Morgan et al., 2005; Nishii et al., 2010; Singh & Grange, 2006). The differential impact of interventions warrants further investigation to determine what works best and for whom.

Studies investigating the impact of intervention programmes on PtC were limited. Direct comparison between studies is difficult given the variability in definitions of PtC and lack of a consistent, validated measurement tool. This is surprising given that a validated measure of PtC in FEP has been recommended for many years (Singh & Grange, 2006) and standardised measures completed with several relevant informants is best practice (Schiffman et al., 2015). There is need for the development of such a tool for both FEP (Singh & Grange, 2006) and ARMS (Allan et al., 2021). Of the studies that reported data on PtC, findings were heterogenous about the effectiveness of intervention programmes in altering PtC (Cassidy et al., 2008; Chong et al., 2005; Hastrup et al., 2018; Joa et al., 2007; Lloyd-Evans et al., 2015; Malla et al., 2014; Malla et al., 2005; Srihari et al., 2022). Lloyd-Evans and colleagues (2011) recommended in their systematic review that even if intervention programmes do not reduce DUP, they may alter PtC which may result in reduced economic costs and increased patient satisfaction. It is therefore an important consideration for future research.

Effective public health interventions rely on behaviour change, it is therefore important that interventions are theory driven and draw on models of behaviour (West et al., 2011), as recommended by the UK Medical Research Council (Michie et al., 2005). This is necessary to understand the nature and mechanisms of behaviour change and implement an appropriate intervention based on this understanding (West et al., 2011). Few of the included studies (*n*=5) explicitly reported using any theoretical framework to inform the development of their intervention programmes (Connor et al., 2016; Krstev et al., 2004; López et al., 2022; Malla et al., 2014; Srihari et al., 2022). Future research should report what and how theoretical models have been used which may support the adaptation and implementation of interventions in different contexts.

4.3 Limitations

It is possible that some literature may have been missed in the searches either due to availability in databases or being contained in grey literature. Whilst a broad approach was taken to the literature search terms around psychosis, papers may have been missed which used only ARMS or ultra-high-risk terminology. It may have been beneficial to include additional search terms such as "at-risk mental state" and "ultra-high risk".. Interventions were categorised similarly to the previous systematic review by Lloyd-Evans and colleagues (2011) by dividing them into those targeting multiple populations, the general public only, or non-healthcare professionals only. This may have resulted in missing differences in specific components of the interventions which may account for some of the variability in results. Due to the lack of cut-offs for quality ratings in the MMAT, it is difficult to objectively qualify the quality of included studies.

Results of this review should be interpreted with caution for several reasons. Firstly, none of the studies were randomised controlled trials (RCTs). This would have reduced potential confounders, strengthened reliability and validity, and improved confidence in attributing observed differences in outcomes to the intervention strategy. The studies originated from several different countries with different healthcare contexts and processes. Many of the papers did not use validated measures of PtC. Some studies reported small sample sizes which may have limited the power to detect differences between groups (Cassidy et al., 2008; Chan et al., 2018; Krstev et al., 2004; Srihari et al., 2022).

4.4 Research and Clinical Implications

The findings in this review present a mixed picture and the intervention programmes do not appear to have a uniform effect. It would be useful for future research to investigate PtC to better understand where delays may occur in help-seeking and factors which may influence these delays. For example, current research suggests that certain social and demographic factors are associated with longer and more negative PtC, such as unemployment (Morgan et al., 2005; Nishii et al., 2010), ethnic minority status (Morgan et al., 2005; Singh & Grange, 2006) and rural living (Boonstra et al., 2012; Kvig et al., 2017). Understanding sources of delay and associated factors will help to inform the development of targeted interventions to address these. Additionally, a meaningful benefit of public health interventions at improving PtC and reducing DUP and/or DUI would be improvement of patient clinical and functional outcomes. Future research would therefore benefit from investigating whether such changes lead to an improvement in longer-term outcomes.

Understanding PtC will be particularly important in the ARMS population in which research is lacking. A recent systematic review highlighted only ten studies which explored PtC for individuals with ARMS (Allan et al., 2021). To the authors' knowledge only four studies have compared PtC for ARMS and FEP, all of which found similarities between PtC for both populations (Allan, 2020; Ferrara et al., 2021; Fridgen et al., 2013; Platz et al., 2006). There are, however, likely to be some differences in factors associated with individuals who present during earlier stages of illness (ARMS) and those who present with FEP. Further research is warranted to investigate these differences, which could inform specific interventions targeted towards individuals with ARMS. Furthermore, understanding and reducing delays in ARMS may help to improve the outcomes for individuals with ARMS who do not transition to FEP or help to reduce DUP for individuals who do transition as individuals will already be in contact with specialist services (Cotter et al., 2014; Lloyd-Evans et al., 2011). Given that ARMS is characterised by psychotic symptoms of lesser severity and duration, or non-specific symptoms of psychosis such as depression and anxiety (Yung & McGorry, 1996), it may be helpful for interventions aimed at individuals with ARMS to increase public and non-health professionals' awareness of early signs of psychosis and available specialist EIP services (Allan et al., 2021). This may result in more rapid help-seeking and referral and reduce treatment delays.

Qualitative approaches may provide a detailed understanding of the PtC and sources of delay for individuals with both FEP and ARMS. These types of studies may also help to understand individual experiences of interventions. For example Lloyd-Evans and colleagues (2015) found that following their intervention programme, staff continued to have uncertainties about where to refer young people who may be experiencing FEP and concerns around stigma or damaging their working relationships. This may help to understand why the intervention was ineffective at reducing delays and could inform intervention development and adaptations.

The review highlights some promising findings about the effectiveness of interventions at reducing DUP, particularly those aimed at multiple populations and lasting more than 12-months. Interventions also appear to differentially impact the DUP of different groups. It is important that local services are aware of potential barriers and delays in care for their local population in order to develop strategies to address these (Cocchi et al., 2013; Lloyd-Evans et al., 2011; Srihari et al., 2014). These would benefit from being devised alongside experts by experience (Bradley, 2015). Mental health services are well positioned to deliver such interventions as they are situated within their local communities and have the opportunity to target specific groups to raise awareness of psychosis and potentially reduce delays to treatment and improve long-term outcomes (Singh, 2010).

Despite this, EIP services in the UK are impacted by underfunding and lack of resources (Rethink Mental Illness, 2014). This has resulted in delays in treatment, reduced access to care, and variation in the care services are able to provide (Gilburt, 2018). For instance, services are often having to focus on acute intervention rather than prevention (Gates & Killacky, 2020). This highlights the need for commissioning groups and policy makers to prioritise preventative care, to make funding and resources available to services to deliver such interventions. Public health interventions are often expensive (Chong et al., 2004), however reducing treatment delays has the potential to improve outcomes (Singh, 2010) and offset costs by providing savings in other areas associated with such delays (Cocchi et al., 2011; Chong et al., 2004).

4.5 Conclusion

The findings from this review suggest that intervention programmes may differentially impact the DUP of different groups and their effect on PtC for FEP individuals is lacking. The lack of studies evaluating interventions to reduce DUI or improve PtC for ARMS also highlight the urgent need for investigating delays and influencing factors within this population to help develop appropriate interventions to address these and potentially improve outcomes.

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Statement of Declaration

The authors have no competing interests to declare that are relevant to the content of this article. Data sharing is not applicable to this article as no new data were created or analysed.

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Chapter Three

Bridging Chapter

Word Count: 575

Chapter Three

Bridging Chapter

The systematic review presented in Chapter Two examined the available literature regarding the effectiveness of interventions, initiatives, and campaigns at reducing DUP in FEP and DUI in ARMS. In addition, the review explored whether such interventions were effective at improving PtC for these groups. The review highlighted a lack of research investigating interventions to reduce delays aimed at an ARMS population, with searches returning no studies in this area. All of the included studies (*n*=19) were aimed at a FEP population. The majority of these studies (*n*=18) investigated the impact of such interventions on DUP, with limited exploration of the impact on PtC. Interventions targeting multiple populations and with a duration of more than 12-months, showed the most promise in reducing DUP, however this was not a universal finding. There was some evidence for differences in how interventions impacted DUP for different groups of people for example based on gender (Ferrara et al., 2019; Larsen et al., 2001), family history of psychiatric disorder (Chan et al., 2018) and marital status (Ferrara et al., 2019), individuals with more episodes of police arrests (Ferrara et al., 2019), and individuals with gradual onset of psychosis (Chan et al., 2018). The impact on DUP also appeared to differ across the distribution of DUP (Ferrara et al., 2019; Srihari et al., 2022).

Given these findings, it seems important that further research explores PtC and aims to identify potential sources of delay and individual factors which may influence this in order to develop targeted interventions. This seems to be particularly important in the area of ARMS, where evidence is lacking. Furthermore, research comparing PtC for individuals with ARMS and FEP is pertinent to provide insights into factors associated with individuals who present during earlier stages of illness (ARMS) and those who present with psychosis (FEP).

Despite this, there is currently very little research comparing PtC for ARMS and FEP. Three papers interviewed individuals with ARMS and FEP, two in Switzerland and one in the United States, about their help-seeking behaviour (Ferrara et al., 2021; Fridgen et al., 2013; Platz et al., 2006). The studies found no significant differences between ARMS and FEP on duration (Ferrara et al., 2021; Fridgen et al., 2013; Platz et al., 2006) or number (Fridgen et al., 2013; Platz et al., 2006) of PtC. Of note, Switzerland and the United States have different healthcare systems to the UK and therefore findings may not be generalisable to a UK, National Health Service (NHS) context. A further, qualitative study was conducted in a UK, NHS setting (Allan, 2020). The study highlighted common themes of experiences of PtC for individuals with ARMS and FEP, including negative and prolonged PtC for both groups (Allan, 2020). To the authors' knowledge, there is no further research currently in this area and no quantitative studies, conducted in the UK, comparing PtC for individuals with ARMS and FEP.

Therefore, Chapter 4 presents an empirical paper which sought to address gaps in the current literature. The paper compares PtC and sociodemographic characteristics of individuals with ARMS and FEP. In addition, it examines whether any of these characteristics are independently predictive of whether individuals seek help during ARMS compared to during FEP. The paper has the potential to provide insights into factors associated with people accessing care at an earlier stage of illness. In addition, the results may inform the development of interventions aimed at reducing treatment delays and ultimately improve recovery outcomes.

Chapter Four

Empirical Paper

A Comparison of Pathways to Care in At-Risk Mental States and First Episode Psychosis: A Mental Health Electronic Clinical Records Analysis in the East of England, UK.

Prepared for submission to ‘Social Psychiatry and Psychiatric Epidemiology’[2]

Word Count: 4910 (excluding references, tables, and figures)

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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 text.

A Comparison of Pathways to Care in At-Risk Mental States and First Episode Psychosis: A Mental Health Electronic Clinical Records Analysis in the East of England, UK.

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Abstract

Purpose: Delays in treatment for individuals experiencing early signs of psychosis are associated with poorer outcomes. Few people presenting with first episode psychosis (FEP) access early intervention in psychosis (EIP) services during the prodromal stage. In this study, we compared pathways to care (PtC) in people with At-Risk Mental States (ARMS) and FEP and explored the sociodemographic variables associated with accessing EIP during ARMS or FEP.

Methods: Sociodemographic and PtC data were collected from the Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) Research Database. All individuals referred and accepted to CPFT EIP services as either ARMS or FEP between 1st April 2018 and 31st October 2019 (N=158) were included.

Results: There was strong evidence that ARMS patients accessing EIP were younger and were less likely to be of White non-British and Any Other ethnic groups than FEP patients. In terms of PtC, ARMS patients had fewer numbers of contacts, were less likely to be referred via the acute services, less likely to be involuntarily admitted and had reduced family involvement in their help-seeking. No differences were identified between ARMS and FEP in terms of living circumstances, deprivation, urbanicity, employment status, duration of PtC, or police involvement in PtC.

Conclusion: Findings highlight sociodemographic and PtC characteristics associated with accessing EIP during ARMS compared with FEP. Further research is required to replicate these findings and investigate the effectiveness of interventions to encourage and facilitate access to EIP at an earlier stage to improve outcomes.

Keywords: At Risk Mental States, First Episode Psychosis, Early Intervention, Pathways to Care, Sociodemographic Determinants

Introduction

The earlier people receive appropriate treatment for first episode psychosis (FEP) the better their outcomes [1]. Longer duration of untreated psychosis (DUP) is associated with lower overall functioning, more severe symptoms, lower quality of life, and reduced likelihood of full remission [2-4]. Additionally, longer DUP is associated with increases in both direct and indirect economic costs [5] and ultimately results in prolonged distress for the individual and their families [6].

Interventions could occur at an even earlier stage of illness, when individuals are at high risk of developing psychosis, referred to as "At-Risk Mental State" (ARMS)[7]. Some research has defined ARMS as a prodromal stage of psychosis consisting of psychotic symptoms of lesser severity and duration than FEP and accompanied by a drop in functioning [7]. It has been suggested that receiving interventions during the ARMS period may alter outcome trajectories by reducing duration of untreated illness (DUI): the time between symptom onset and treatment for ARMS and/or DUP, therefore improving outcomes, or preventing transition to psychosis altogether [7, 8]. Whether ARMS is truly a prodromal stage of psychosis has been widely debated [9] with evidence suggesting that only a small percentage of individuals with ARMS transition to psychosis [10]. However, research findings highlight that individuals with ARMS experience poorer functional outcomes, comorbidities, and poorer quality of life, regardless of transition to psychosis [11-14] therefore early identification and intervention for this group are warranted.

Additionally, evidence suggests only a small proportion of individuals presenting with FEP have been identified by prodromal services [15]. Given how few people presenting with FEP reach prodromal services [15], it is important to investigate pathways to care (PtC): the time between help-seeking initiation, and receiving appropriate intervention [16], for individuals who present during earlier stages of illness (ARMS) and those who do not (FEP). It is crucial that PtC for individuals with ARMS and FEP are as direct, timely, and straightforward as possible owing to the importance of achieving better recovery outcomes through a shorter DUP [1, 3, 6]. Despite this, PtC for people with psychosis are often complex and involve multiple contacts with different services [17] and lengthy delays [6].

In FEP, several social and demographic factors have been found to be associated with longer and more negative PtC. Negative PtC have been defined as contacts with police and emergency services, crisis teams, and compulsory inpatient admissions [18-20]. Living alone [21], lack of family involvement [22], unemployment [22, 23], being a first-generation immigrant [24], or from an ethnic minority background [22], living in a rural area [24, 25], or areas with higher-than-average social deprivation [26], and being male [27, 28] have all been associated with longer and more negative PtC.

Literature regarding PtC for ARMS is scarcer than FEP. A recent systematic review [29] found that only a small percentage of ARMS patients had PtC via emergency services or compulsory admissions, with first help-seeking contacts more commonly made through a GP or mental health professional. The review found some evidence that family involvement may support help-seeking in ARMS [29].

There is also limited research comparing PtC for ARMS and FEP. This is important as it would further understanding of factors associated with individuals who present during earlier stages of illness (ARMS) and those who present with FEP. To date there are four studies directly comparing the groups. Two were conducted in Switzerland and found no significant differences between ARMS and FEP on duration or number of PtC [30, 31]. One study was conducted in the

United States and found no differences in duration of PtC or sociodemographic characteristics between ARMS and FEP[20]. It is worth noting that the healthcare systems in these countries differ to the United Kingdom (UK) National Health Service (NHS) and therefore PtC also likely differ. The final study, was a qualitative study carried out in a UK, NHS setting which identified common themes between experiences of PtC for both groups including negative experiences of PtC and significant treatment delays [32]. To our knowledge there have been no quantitative studies conducted in the UK, comparing PtC for individuals with ARMS and FEP.

This study aimed to compare PtC in ARMS and FEP in UK Early Intervention in Psychosis (EIP) services and explore factors which may be associated with accessing treatment at an earlier stage of illness. Research questions were: 1) Are there differences in the PtC characteristics between individuals with ARMS and FEP? 2) Do individuals with ARMS and FEP differ by sociodemographic characteristics? 3) Are any of the sociodemographic and PtC factors predictive of whether someone seeks help during ARMS compared with FEP, independent of confounders?

Methods

Design

A cross-sectional design was employed.

Study Setting and Participants

The study was conducted within the area of Cambridgeshire and Peterborough. According to the 2021 census [33], in both Cambridgeshire and Peterborough the largest proportion of people are aged between 35-49 years (Cambridgeshire: 19.8%, Peterborough: 21.5%), are female (Cambridgeshire and Peterborough: 50.6%), identify as White British or

White Non-British (Cambridgeshire: 88.6%, Peterborough: 75.4%) and are in Employment (Cambridgeshire: 58.2%, Peterborough: 58.9%).

Data were collected within Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) EIP services, providing assessment and intervention to people presenting with ARMS (as assessed by the Comprehensive Assessment of At-Risk Mental States)[34] or FEP. CPFT serves a population of approximately 950,000 across Cambridgeshire and Peterborough including both rural and urban areas [35], and affluent and deprived areas [36]. Referrals to CPFT EIP services are accepted from any source.

Procedure

Data were collected from all individuals accepted onto the EIP caseload as either ARMS or FEP between 1st April 2018 and 31st October 2019, using the CPFT Research Database (CPFTRD)[37]. This period was selected to include the most recent cohort of EIP users prior to the COVID-19 pandemic. It was anticipated that access and use of services would have been adversely impacted by the pandemic [38], however this was not the focus of the present study.

Data were collected from the CPFTRD [37], using Clinical Records Anonymisation and Text Extraction (CRATE)[39]. CPFTRD is a database of de-identified clinical records used for research purposes and contains information from approximately 260,000 people receiving care from CPFT [40]. The research database contains structured data fields (including demographic variables and dates) and unstructured free-text fields (including clinical information from clinical documents, assessments, and progress notes). The database contains information pertaining to care received from secondary mental health, psychiatric liaison, and psychiatric inpatient services within CPFT and sources of referral.

Case Identification, Inclusion/Exclusion Criteria

Initial searches of the database were conducted to identify individuals referred and accepted onto the EIP caseload between 1st April 2018 and 31st October 2019. Each individual record was then screened to determine if the individual met the eligibility criteria. We included individuals if they were:

- presenting with and clinically assessed as ARMS or FEP
- accepted to a CPFT EIP caseload during the study period
- residing in the Cambridgeshire and Peterborough catchment areas during the study period
- aged 14- to 35-years

We excluded individuals who were deemed by clinicians not to be presenting with psychosis and were not accepted to a CPFT EIP service.

Following the introduction of the NHS Access and Wait Time Standards for EIP [41] CPFT EIPs extended the age acceptability criterion for FEP from 14-35 years to 14-65 years [42] but not for ARMS. Therefore, we restricted our analyses to those aged 14-35 years in both ARMS and FEP groups.

Data Collection and Instruments

Sociodemographic Characteristics

Sociodemographic data were collected using an adapted version of the Medical Research Council Sociodemographic Schedule (MRC-SDS)[43]. This measure has been widely used in previous studies to collect sociodemographic characteristics [44-47]. Sociodemographic information collected included age at EIP assessment, gender, ethnicity, living circumstances and employment status.

Ethnicity was classified according to the 18 categories used by the UK Office of National Statistics (ONS)[48] within the CPFTRD. Due to the small number of patients belonging to minority ethnic groups and for data analysis purposes, we collapsed ethnicity into four categories: White British; White non-British (white Irish, white Gypsy, white Other); Any Other Ethnic Groups (black African, black Caribbean, other black, any mixed ethnic group, Indian, Pakistani, Bangladeshi, Chinese, other Asian, any other ethnic group); Not Stated. This is consistent with previous studies [46, 49].

Living circumstances were coded as binary: living alone or living with others (i.e., with family and friends, in supported or sheltered accommodation, and within student accommodation).

Employment status was categorised as Employed; Unemployed; Student. The ONS statistical bulletin [50] categorised individuals as either employed or unemployed, it highlighted higher rates of unemployment in younger people and suggested this may be linked to staying in education for longer. The EIP accepts individuals from the age of 14, and therefore will see several younger people who may be in full-time education. As a result, the additional category of "student" was included consistent with previous studies [49, 51].

Additional socio-environmental information pertaining to ARMS and FEP patients' rural/urban and area-level deprivation status was collected. In CPFTRD, patients' residential addresses e.g., postcodes are replaced with administrative geographical level of Lower Super Output Area (LSOA) information.

Rural-urban status was determined using the ONS Rural-Urban Classifications linked to LSOA [52]. The ONS Rural-Urban Classification assigns areas to one of four urban categories (major conurbation; minor conurbation; city and town; city or town in sparse settings) or six rural categories (town or fringe; town or fringe in sparse settings; village; village in sparse settings; hamlets and isolated dwellings; hamlets and isolated dwellings in a sparse setting)[52]. These categories were collapsed into two: urban and rural, in line with ONS guidelines [52].

Area-level deprivation is linked to de-identified clinical records in CPFTRD using the index of multiple deprivation (IMD) score, which is a measure of relative deprivation for small areas of England, ranking areas from one (most deprived) to 32,844 (least deprived)[53]. These ranks were collapsed into quintiles from one (most deprived) to five (least deprived).

Pathways to Care

PtC data were extracted from CPFTRD for each individual using an adapted version of the Personal and Psychiatric History Schedule [54] consistent with previous research investigating PtC [45, 46, 55].

Duration of PtC was measured from the date of referral into CPFT services (leading to EIP referral), to the date of EIP assessment.

Number of PtC was defined as the number of referrals accepted to CPFT services during this time.

Mode of contact was classified as the source of referral to EIP and categorised as Primary Services (e.g., GP and primary mental health services); Secondary Services (e.g., community mental health teams); Acute Services (e.g., accident and emergency, crisis, and inpatient services); Informal (e.g., self, family, or non-mental health organisations such as educators or charities).

Additional PtC data were collected pertaining to whether an individual had been detained under the Mental Health Act (MHA); a legal framework allowing for involuntary hospital admission for mental health problems [56], or whether family and friends, or police or criminal justice services, had been involved in an individual's PtC during the period between first CPFT contact and EIP assessment. Involvement of family or friends was classified as family or friends initiating or supporting help-seeking and included initiating referrals or contact with services for advice or supporting patients to appointments. Police or criminal justice involvement was classified as contact with police or criminal justice system for reasons relating to presenting difficulties resulting in EIP assessment. For example, being detained under Section 136 of the MHA [56], arrests or criminal proceedings, or telephone calls to the police with concerns about the individual's behaviour.

Reliability

Steps were taken to ensure the reliability of data collection procedures from the de-identified clinical records. Each variable was operationalised and a document was produced indicating where information could be found in CPFTRD. This was used by RM for data collection and SO for data checking. Data on around fifteen percent (n=21) of the sample were checked by SO who was blind to the original extraction. A kappa score of 0.81(p<0.001), and 90.5% agreement was achieved for ARMS or FEP information. A kappa score of 0.65(p<0.001), and 71.4% agreement was achieved for number of PtC.

Ethical Approval

The CPFTRD was approved by an NHS Research Ethics Committee (reference:17/EE/0442) for secondary analysis. This study was also granted ethical approval by the London-Chelsea Research Ethics Committee (reference:19/LO/0398). Local approval was obtained from the CPFTRD Oversight Committee (reference:M00921). See Appendices C-D for approval documentation. Under UK law, participant consent was not required for this study [37].

Statistical Analysis

Data were analysed using PSPP [57]. An alpha level of *p*=0.05 was used for all analyses. Descriptive statistics including frequencies and percentages for categorical variables, mean and standard deviation, or median and ranges for continuous variables were used to describe the sample.

Continuous data were checked for normality. Independent t-tests were used for normally distributed data and Mann-Whitney U tests were used where data were not normally distributed for continuous variables. We performed chi-square or Fisher's exact for categorical variables to determine if there were significant differences between participants with ARMS and FEP, based on sociodemographic and PtC variables. Variables demonstrating statistically significant differences between individuals with ARMS and FEP were first tested individually with univariate binary logistic regression (Model 1) followed by controlling for *a-priori* confounders (age, gender, and ethnicity) in Model 2. These provided estimates of crude and adjusted odds ratios of associations between PtC and sociodemographic characteristics among ARMS and FEP patients.

Results

Sample Selection

A flow diagram of case identification is given in Figure 1. Initial searches of the CPFTRD returned 289 patients referred to EIP between 1st April 2018 and 31st October 2019. Of these, 208 patients aged 14-65 years were accepted to the service as either ARMS or FEP, of whom 158 were aged between 14-35 years. Sociodemographic and PtC characteristics of the 208 accepted patients are shown in Appendix E. Data and results presented here are on the 158 patients aged 14-35 years accessing EIP as ARMS or FEP.

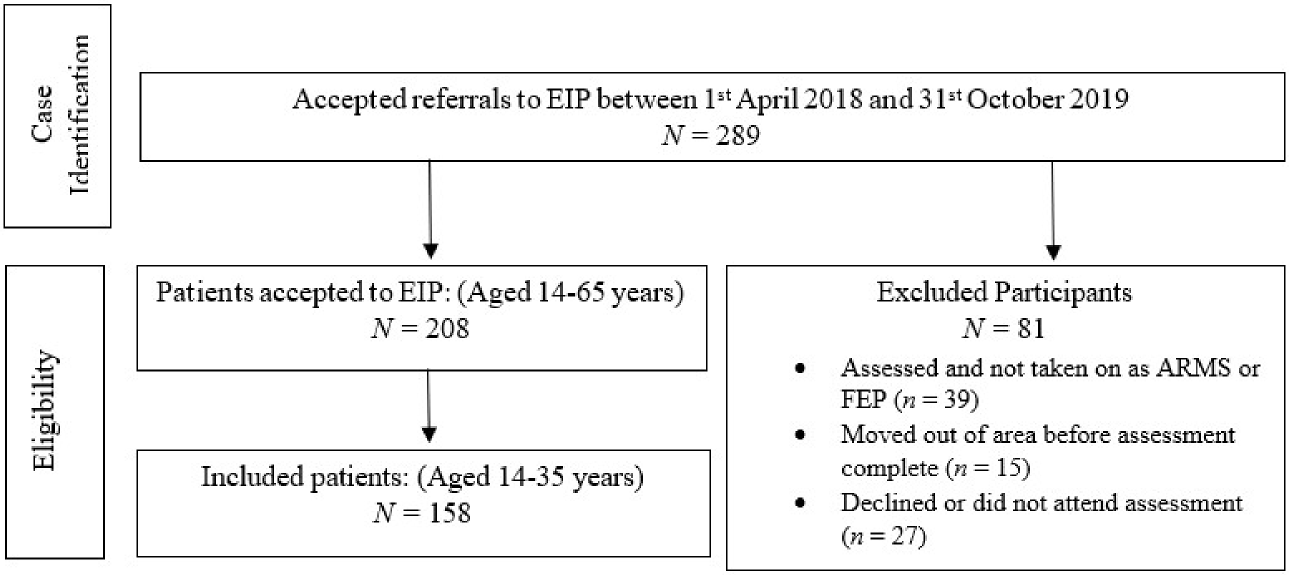

*Figure 1.*Flow diagram of the inclusion process.

Sample Characteristics

Sample sociodemographic and PtC descriptive statistics are shown in Table 1. The mean age of was 23.95 (SD=5.4) and there were more men (61.4%) than women (38.6%). Most patients were White British (62%), from urban areas (73.4%), and living with others (88.6%). There was a similar proportion of patients in terms of employment status: employed (36.7%), unemployed (32.3%) and students (31%). The mean IMD score for the sample was 17650.03 (SD=9942.6), falling within the 3rd IMD quintile. The largest proportion of patients were within the least deprived quintile (28.5%). More patients were accepted by EIP as FEP (57.6%) compared to ARMS (42.4%).

The median duration of PtC was 12 days (range=0-312) and the median number of PtC contacts was 2 (range=1-28). During their PtC, there were fewer patients detained under the MHA (17.7%) and less police or criminal justice involvement (21.5%). Family/friend involvement in help-seeking was common (65.2%). Mode of contact with EIP varied, with most patients being referred by acute services (38.6%) followed by primary services (29.7%).

Table 1.

Sample characteristics

	N = 158 (%)
Diagnosis	
ARMS	67 (42.4)
FEP	91 (57.6)
Mean age (sd) years	23.95 (5.4)
Gender	
Men	97 (61.4)
Women	61 (38.6)
Ethnicity	
White British	98 (62.0)
White Non-British	19 (12.0)
Any Other Ethnic Group	34 (21.5)
Not Stated	7 (4.4)
Living Circumstances	
Alone	11 (7.0)
With Others	140 (88.6)
Missing	7 (4.4)

Mean IMD Scores (sd)	17650.03 (9942.6)
IMD Quintiles	
1 (Most Deprived)	24 (15.2)
2	29 (18.4)
3	32 (20.3)
4	25 (15.8)
5 (Least Deprived)	45 (28.5)
Missing	3 (1.9)
Urbanicity	
Rural	39 (24.7)
Urban	116 (73.4)
Missing	3 (1.9)
Employment Status	
Employed	58 (36.7)
Student	49 (31.0)
Unemployed	51 (32.3)
Median Duration of PtC (range) days	12 (0-312)
Median Number of PtC (range)	2 (1-28)
Mode of Contact	
Primary Services	47 (29.7)
Secondary Services	29 (18.4)
Acute Services	61 (38.6)
Informal	21 (13.3)
Detained under MHA	
Yes	28 (17.7)
No	130 (82.3)
Family/Friend Involvement	
Yes	103 (65.2)
No	55 (34.8)
Police Involvement	
Yes	34 (21.5)
No	124 (78.5)

Abbreviations: SD = Standard Deviation, PtC = Pathways to Care, MHA = Mental Health Act, IMD = Index of Multiple Deprivation

Differences in ARMS and FEP by sociodemographic and PtC characteristics

Descriptive comparisons of PtC and sociodemographic variables between ARMS and FEP patients are summarised in Table 2. The number of PtC contacts were fewer for ARMS patients (median=1, range=1-9) compared to FEP patients (median=3, range=1-28)(Mann-Whitney *U*:1905.5, $p<0.001$). Chi-square test revealed ARMS patients were more likely to contact EIP via primary care services compared with FEP patients (ARMS:43.3% vs. FEP:19.8%, $p<0.001$) and less likely to be referred via acute services (ARMS:17.9% vs. FEP: 53.8%, $p<0.001$). Compared with ARMS patients, FEP patients were more likely to be admitted involuntarily (ARMS:3.0% vs. FEP:28.6%, $p<0.001$) and had increased family/friend involvement (ARMS:49.3% vs. FEP:76.9%, $p<0.001$). No significant differences were found in police and/or criminal justice involvement or duration of PtC between ARMS and FEP patients.

In terms of sociodemographic characteristics, ARMS patients were significantly younger (Mean=22.26(SD=5.03) years) than FEP patients (Mean=25.19(SD=5.32) years), $p=0.001$. Patients of White Non-British (ARMS:4.5% vs. FEP:17.6%, $p=0.001$) and Any Other Ethnic (ARMS:11.9% vs. FEP:28.6%, $p=0.001$) groups were less likely to access EIP during ARMS. No differences were observed between ARMS and FEP patients by gender, living circumstances, IMD scores, rural/urban, or employment status.

Table 2.

Differences in ARMS and FEP by sociodemographic and pathways to care characteristics

	ARMS *n*=67(%)	**FEP *n*=91(%)**	**X^2/ t-/ Mann Whitney tests, (df), *p***
Mean age (sd) years	22.26 (5.03)	25.19 (5.32)	*t* = -3.50, *p* = 0.001**
Gender			
Men	36 (53.7)	61 (67.0)	2.88 (1), *p* = 0.09
Women	31 (46.3)	30 (33.0)	
Ethnicity			
White British	53 (79.1)	45 (49.5)	15.94 (3), *p* = 0.001**
White Non-British	3 (4.5)	16 (17.6)	
Any Other Ethnic Group	8 (11.9)	26 (28.6)	
Not Stated	3 (4.5)	4 (4.4)	
Living Circumstances†			
Alone	5 (7.9)	6 (6.8)	0.07 (1), *p* = 0.794
With Others	58 (92.1)	82 (93.2)	
Mean IMD Scores (sd)	18378.42 (9324.5)	17113.75 (10392.4)	*t* = 0.79, *p* = 0.431
IMD Quintiles†			
1 (Most Deprived)	7 (10.4)	17 (19.3)	3.74 (4), *p* = 0.442
2	16 (23.9)	13 (14.8)	
3	13 (19.4)	19 (21.6)	
4	11 (16.4)	14 (15.9)	
5 (Least Deprived)	20 (29.9)	25 (28.4)	
Urbanicity†			
Rural	20 (29.9)	19 (21.6)	1.38 (1), *p* = 0.24
Urban	47 (70.1)	69 (78.4)	
Employment Status			
Employed	25 (37.3)	33 (36.3)	0.05 (2), *p* = 0.977
Student	21 (31.3)	28 (30.8)	
Unemployed	21 (31.3)	30 (33.0)	
Median Duration of PtC (range) days	14 (0-182)	12 (0-312)	*U*: 2940, *p* = 0.702
Median Number of PtC (range)	1 (1-9)	3 (1-28)	*U*: 1905.5, *p* < 0.001**

Mode of Contact			
Primary Services	29 (43.3)	18 (19.8)	23.41 (3), $p < 0.001$**
Secondary Services	13 (19.4)	16 (17.6)	
Acute Services	12 (17.9)	49 (53.8)	
Informal	13 (19.4)	8 (8.8)	
Detained under MHA			
Yes	2 (3.0)	26 (28.6)	17.33 (1), $p < 0.001$**
No	65 (97.0)	65 (71.4)	
Family/Friend Involvement			
Yes	33 (49.3)	70 (76.9)	13.02 (1), $p < 0.001$**
No	34 (50.7)	21 (23.1)	
Police Involvement			
Yes	11 (16.4)	23 (25.3)	1.79 (1), $p = 0.181$
No	56 (83.6)	68 (74.7)	

Abbreviations: SD = Standard Deviation, PtC = Pathways to Care, MHA = Mental Health Act, IMD = Index of Multiple Deprivation
† Incongruent n is due to missing data
*$p \leq .05$
**$p \leq .001$

Association Between PtC and Sociodemographic Variables in ARMS and FEP

In the unadjusted binary logistic regression model, there was strong evidence of an association between age, ethnicity, number of PtC, mode of contact, being detained under the MHA, and having family/friend involvement in PtC and accessing EIP during ARMS compared to FEP (Model 1, Table 3). After adjusting for *a-priori* confounding variables (age, gender, and ethnicity) there remained strong evidence of an association between PtC and sociodemographic variables and accessing EIP during ARMS compared to FEP (Model 2, Table 3). Compared with FEP patients, ARMS patients were younger (adjusted OR=0.89, CI=0.82-0.95), less likely to be White Non-British (adjusted OR=0.17, CI=0.04-0.66) and Any Other Ethnicity (adjusted OR=0.18, CI=0.07-0.48). There was strong evidence ARMS patients were less likely to access EIP via acute services (adjusted OR=0.17, CI=0.06-0.45) and less likely to be detained under the MHA (adjusted OR=0.10, CI=0.02-0.45). We found strong evidence ARMS patients were less likely to have family/friend involvement (adjusted OR=0.33, CI=0.15-0.72) in their access to EIP. There was weak evidence ARMS patients were less likely to be male (adjusted OR=0.50, CI=0.24-1.05), and less likely to access EIP via secondary services (adjusted OR=0.37, CI=0.13-1.07).

Table 3.

Binary logistic regression analysis of factors associated with accessing EIP as ARMS compared to FEP

	Model 1 **Unadjusted OR**	**95% CI**	**Model 2** **Adjusted OR**	**95% CI**
Mean age (sd) years	0.89	0.84 to 0.96**	0.89	0.82 to 0.95**
Gender				
Female	1.00		1.00	
Male	0.57	0.30 to 1.09	0.50	0.24 to 1.05
Ethnicity				
White British	1.00		1.00	
White Non-British	0.16	0.04 to 0.58*	0.17	0.04 to 0.66*
Any Other Ethnic Group	0.26	0.11 to 0.63*	0.18	0.07 to 0.48**
Not Stated	0.64	0.14 to 3.00	0.91	0.16 to 5.07
Number of PtC	0.67	0.55 to 0.82**	0.72	0.59 to 0.87**
Mode of Contact				
Primary Services	1.00		1.00	
Secondary Services	0.50	0.20 to 1.29	0.37	0.13 to 1.07
Acute Services	0.15	0.06 to 0.36**	0.17	0.06 to 0.45**
Informal	1.01	0.35 to 2.91	1.13	0.33 to 3.86
Detained under MHA				

No	1.00		1.00	
Yes	0.08	0.02 to 0.34**	0.10	0.02 to 0.45*
Family/Friend Involvement				
No	1.00		1.00	
Yes	0.29	0.15 to 0.58**	0.33	0.15 to 0.72*

Abbreviations: OR = Odds Ratio, CI = Confidence Interval, SD = Standard Deviation, PtC = Pathways to Care, MHA = Mental Health Act.
Model 1 – Unadjusted.
Model 2 – Adjusted for age, gender, ethnicity.
*$p \leq .05$
**$p \leq .001$

Discussion

Main Findings

This study compared PtC and sociodemographic characteristics for individuals with ARMS and FEP accessing EIP services in Cambridgeshire and Peterborough, UK. It explored whether any of these characteristics were predictive of accessing EIP during ARMS compared to FEP. There was strong evidence ARMS patients were younger, less likely to have a minority ethnic background, have fewer PtC contacts, and less likely to access EIP via acute services, compared to FEP patients. In addition, ARMS patients were less likely to be involuntarily admitted or have family and/or friend involvement during their PtC. There was weak evidence to suggest ARMS patients were less likely to be men. We found no differences between ARMS and FEP in terms of living circumstances, deprivation, urbanicity, employment status, duration of PtC, or police involvement.

Interpretation of Findings

Pathways to Care

The definition of PtC used for this study was the time between the individual's first referral into CPFT services and EIP assessment, based on data available in the CPFTRD. Apart from the referral source into CPFT (such as primary care or self-referrals), it was not possible to collect data on length of help-seeking and contacts outside of secondary mental health services. This is an important consideration when interpreting the study findings.

Consistent with previous research, no significant differences were found in duration of PtC between ARMS and FEP patients [20, 30, 31]. The median duration of PtC within CPFT was short for both groups (14 and 12 days for ARMS and FEP patients respectively) and significantly shorter than reported in previous research [20, 30, 31]. Similarly, in their UK, qualitative study, Allan and colleagues [32] found the average duration of PtC was two-years for both ARMS and FEP patients. The contrasting results reflect differences in PtC definition and suggest PtC prior to accessing secondary mental health services may be longer than within such services. The relatively short delays observed once referred to secondary mental health services may be accounted for by the introduction of the Access and Waiting Time Standards in 2016 which highlighted the need for, and duty of secondary services to rapidly refer those suspected of experiencing FEP to EIP services [58].

ARMS patients were more likely to have fewer PtC contacts than FEP patients. This contrasts with previous research which found no difference in the number of PtC contacts between ARMS and FEP [30, 31]. These contrasting findings likely reflect differences in PtC definitions, with previous research including help-seeking contacts outside of secondary mental health services [30-32]. Our finding that ARMS patients were more likely than FEP patients to access EIP via primary care services than acute services, or to a lesser extent, secondary services, chimes with previous research. For example, contact with emergency services and inpatient admissions are common in FEP [17] and poor awareness or insight into illness may impede help-seeking [59] resulting in more contacts within secondary and acute mental health services.

In keeping with previous research, ARMS patients were less likely to be detained under the MHA during their PtC than FEP patients [32, 60, 61]. No differences were found between ARMS and FEP in terms of police or criminal justice involvement in their PtC which is consistent with previous findings [20]. This is surprising given that systematic reviews have identified that police and emergency service contact accounts for a small proportion of PtC in ARMS [29] and are relatively frequent in FEP [17].

Although family and/or friend involvement during PtC were common for both groups, our data showed ARMS patients were less likely than FEP patients to have family and/or friend involvement [20, 30]. A possible explanation could be limited insight, FEP patients more often rely on others to seek-help on their behalf [20, 32]. Additionally, early, non-specific symptoms experienced by individuals with ARMS [7, 34] may be less easily detected by others than positive psychotic symptoms [29, 62]. Furthermore, similar to previous findings [20, 30], ARMS patients are more likely to be younger than FEP patients. Earlier signs may be more likely to be interpreted as “normal” adolescent behaviour [63] resulting in less concern raised within families and less involvement in PtC.

Sociodemographic Factors

To our knowledge this is the first UK study to investigate the role of sociodemographic factors on whether someone accesses EIP during ARMS or FEP. One previous study from the United States directly compared sociodemographic characteristics between ARMS and FEP and found no differences in gender, ethnicity, accommodation or household income [20]. In contrast, our study found that being younger and White British were strongly associated with accessing EIP during ARMS compared to FEP. This is unsurprising, given that being from an ethnic minority background has been associated with prolonged PtC within the FEP literature [22]. Evidence suggests that treatment delays are significantly longer for first generation immigrants [24] and patients of Black ethnicity are more likely to have longer PtC [19]. To date within the ARMS literature, the effect of ethnicity on PtC has been neglected [29].

The findings of this study are limited by the small number of patients belonging to minority groups. Research suggests that how individuals access EIP services varies between ethnic minority groups, for example individuals from Black ethnic backgrounds are more likely to be treated within acute care settings and experience more coercive PtC, whereas individuals from South Asian backgrounds are more likely to access EIP via primary care [64]. Further research is warranted with patients from diverse backgrounds, this will provide a more nuanced understanding of the influence of ethnicity on help-seeking for ARMS and help develop culturally appropriate strategies and interventions to facilitate timely access to care [19].

Our findings indicated a weaker association between gender and accessing EIP during ARMS, with women more likely to access EIP during ARMS compared to men. A larger sample size may have found stronger evidence for this association. Although Fridgen and colleagues [30] did not find a significant difference between ARMS and FEP patients in terms of gender, they did find differences in the help-seeking patterns of men and women. For example, women seemed more likely to seek help from mental health professionals than men [30]. Evidence suggests that women may have more positive attitudes towards seeking psychological help [65], whereas men described difficulties in talking about symptoms and believed help-seeking was perceived as weakness by their peers [66]. These beliefs may mean men do not seek support during earlier stages of illness, resulting in the need for more crisis interventions such as involuntary admissions. An important limitation of this study is that gender is recorded in a binary way within the CPFTRD, and therefore gender-diversity is not accounted for in the findings. Future research is warranted to investigate whether this would impact on accessing EIP services at an earlier stage given there is evidence to suggest gender-diverse individuals may face barriers to accessing mental health services [67].

Evidence within FEP research suggests living alone [21] being unemployed [22, 23], socioeconomic deprivation [68] and rural living [24, 25] are associated with longer PtC. The results of this study suggest these factors are not significantly associated with accessing EIP during ARMS compared to FEP.

Strengths and Limitations

To our knowledge, this study was the first quantitative study conducted in a UK, NHS setting exploring sociodemographic and PtC variables associated with accessing EIP during ARMS compared to FEP. The study included all individuals accepted onto the CPFT EIP caseload between 1st April 2018 and 31st October 2019. CPFT is the only mental healthcare provider for the catchment area, and private sector provision in minimal. Therefore, the sample is representative of ARMS and FEP individuals presenting to services during this time.

Limitations should be considered. Firstly, due to the availability of information on the CPFTRD, duration, and number of PtC information was limited to those which occurred within CPFT and provides an estimate of treatment delays within secondary mental health services. Therefore, a comprehensive PtC: time between onset, help-seeking, and receiving appropriate treatment has not been achieved. This could have been improved through data linkage such as the use of the Clinical Practice Research Datalink (CPRD) [69]. The CPRD collects anonymised patient data from primary care and would have provided insights into duration and number of PtC within these settings. In addition, it was not possible to capture information pertaining to help-seeking contacts within non-healthcare settings such as the education sector. Given the high number of students in the sample (31%) it is possible that individuals may have sought help from educators during their PtC.

The sample size was relatively small which may have hindered the ability to detect relationships between some of the study variables. In addition, the sample was of individuals accepted by the EIP services in Cambridgeshire and Peterborough only. This may have limited the generalisability of results to other areas serving different populations. For example, most patients were from a White British background (62%) and other ethnic groups were collapsed into two broad categories (White Non-British and Any Other Ethnic group). Any variations in access to EIP between subgroups were consequently missed. The study is also limited by the cross-sectional design, and therefore it is not possible to infer causality. Furthermore, the CPFTRD consists of de-identified clinical information recorded by clinicians and administrative staff. The accuracy of this information is dependent on the quality and detail of documentation.

Research and Clinical Implications

This study provides important exploratory findings about sociodemographic and PtC variables associated with accessing EIP during ARMS compared to FEP in the UK. Future research with larger sample sizes across diverse catchment areas is warranted to validate these findings. Additionally, it would be beneficial for future research to investigate differences in PtC between ARMS and FEP individuals prior to entering secondary mental health services, including primary services, non-healthcare professionals, and informal help-seeking contacts with family or friends. This would provide a more complete picture of individual’s PtC and factors associated with accessing help at an earlier stage.

Intervention studies aimed at improving access to treatment would be beneficial. It would be useful for interventions to raise awareness about early signs, the importance of early treatment, and how to access care in groups less likely to access help during ARMS. For example, potential patients and their families, and organisations working with young people, men, or individuals from ethnic minority backgrounds. Current evidence for early detection interventions is mixed, however strategies have often been aimed at broad groups [70]. It may be that more targeted interventions have more promising results. EIP services are situated within their local communities and are therefore well positioned to deliver such interventions with the aim to reduce delays and improve outcomes [1]. In order for such interventions to be feasible, it is vital that commissioning groups and policy makers ensure funding and resources are made available. In the UK, mental health services have experienced underfunding which has impacted on access and provision of care [71]. This has led to more focus on acute, rather than preventative, intervention [72].

PtC depend on the accessibility of local mental health services [30]. It is therefore vital to consider whether clinical services are sensitive and responsive to the needs of the populations they serve. To do this, it would be helpful for services to work alongside their local communities to understand the community needs, preferences, and potential barriers to care and develop strategies to address these [49, 64, 70]. For example, community and religious leaders have been found to be important help-seeking contacts for some individuals from ethnic minority groups [73] and would be invaluable collaborators to help services ensure they are culturally sensitive and accessible.

Although not explored in this study, it is important to consider the possible role of clinician bias in identifying early signs of psychosis in different groups. Evidence suggests that clinicians demonstrate more uncertainty in the recognition of emotional difficulties in patient from ethnic minority backgrounds [74, 75]. Future research may investigate the role of clinician bias in recognising early signs of psychosis. Additionally, staff training may be warranted to ensure understanding of how such experiences may present in ethnic minority populations to ensure recognition and equitable access to care.

Conclusion

Further research is required to replicate these preliminary findings and to investigate the effectiveness of interventions aimed at encouraging and facilitating access to EIP at an earlier stage of illness to improve outcomes.

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Author contributions

All authors contributed to the study conception and design. The data collection was carried out by RM and SO. RM analysed the data and drafted the manuscript with guidance and supervision from SO. All authors commented on previous versions of the manuscript and approved the final manuscript.

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Chapter Five

Discussion and Critical Evaluation

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Chapter Five

Discussion and Critical Evaluation

This thesis aimed to explore the effectiveness of interventions designed to reduce treatment delays for individuals with, or at risk of developing psychosis. In addition, it compared PtC for individuals with ARMS and FEP and explored factors which may be associated with accessing treatment at an earlier stage of illness. This chapter presents an overview of the findings of the systematic review and empirical study, and discusses strengths, limitations, and implications.

Summary of Findings

Systematic Review: The Effectiveness of Public Health Interventions, Initiatives, and Campaigns Designed to Improve Pathways to Care for Individuals with or at Risk of Psychotic Disorders.

Four databases (EMBASE, PsychINFO, CINAHL and MEDLINE) were searched for papers published between January 1985 and March 2022. Searches found nineteen studies, evaluating 10 intervention programmes, which met the inclusion criteria. Studies originated from a wide range of countries with differing healthcare contexts. No papers were found evaluating interventions aimed at reducing treatment delays in an ARMS population. Findings were mixed regarding the effectiveness of interventions, initiatives, or campaigns at reducing DUP in people with FEP and suggested that there may be differences in how interventions impact DUP for different groups of people. Interventions appeared to differentially impact DUP based on gender (Ferrara et al., 2019; Larsen et al., 2001), family history of psychiatric disorder (Chan et al., 2018), marital status (Ferrara et al., 2019), more episodes of police arrest (Ferrara et al., 2019), and gradual onset of psychosis (Ferrara et al., 2019). Impact also appeared to differ across the distribution of DUP (Ferrara et al., 2019; Srihari et al., 2022). However, it should be noted only a small number of papers investigated possible moderating variables on DUP, and for those that did, there was variability in the type of variables investigated. Interventions targeting multiple populations such as the public and non-health professionals and with a duration of more than 12-months appeared to be more likely to result in a significant reduction in DUP, however this was not a consistent finding across studies. There were limited papers investigating the impact of intervention programmes on PtC and there was considerable variability in how PtC were defined and measured across studies.

Empirical Study: A Comparison of Pathways to Care in At-Risk Mental States and First Episode Psychosis: A Mental Health Electronic Clinical Records Analysis in the East of England, UK.

The empirical study investigated whether individuals with ARMS compared to FEP differed by PtC and sociodemographic characteristics. The study also investigated whether any of these factors were predictive of whether someone seeks help during ARMS compared to FEP. Individuals accessing EIP during ARMS were more likely to be younger, and less likely to be men or from a minority ethnic group compared to FEP. ARMS patients were more likely to have fewer PtC contacts than FEP patients. Additionally, ARMS patients were less likely to be detained under the MHA or have involvement from family and/or friends during their PtC. Furthermore, ARMS patients were less likely to access EIP via acute services compared to FEP. No differences were identified between ARMS and FEP patients in relation to living circumstances, deprivation, urbanicity, employment status, duration of PtC, or police or criminal justice involvement in PtC.

Strengths and Limitations

This thesis contributes to the current evidence base regarding PtC and treatment delays for individuals with ARMS and FEP. The findings may help inform the development of interventions to reduce such delays and improve PtC for these populations. The systematic review provided a comprehensive summary of the current evidence of the effectiveness of interventions, initiatives, and campaigns at reducing delays and improving PtC in individuals with FEP and ARMS. The review focused on interventions targeting potential patients, families, friends, carers, communities, the public, and/or non-healthcare professionals. This review further expanded on previous literature by including individuals with ARMS and considering PtC.

To the author’s knowledge, the empirical study was the first quantitative study conducted in the UK comparing PtC in ARMS and FEP. The study provides important exploratory findings about PtC and sociodemographic factors associated with accessing EIP during ARMS compared to FEP. As CPFT is the only mental healthcare provider for the catchment area, and all individuals accepted by the CPFT, EIP service were included, the sample was representative of ARMS and FEP individuals accessing services during the study period.

There are several limitations which are important to consider when interpreting the findings of this thesis. Firstly, for the purposes of comparison, interventions were categorised based on their targeted population in the systematic review. This was consistent with the earlier systematic review by Lloyd-Evans and colleagues (2011). However, this broad categorisation may have meant that specific components of the interventions, which may have accounted for some of the variability in the results, were missed. Few studies investigated the impact of interventions on PtC and for those that did there was great variability in how PtC was defined and measured. This makes direct comparison of PtC between studies difficult. Improving consensus on the definition of PtC and developing a validated measure of PtC for FEP and ARMS would improve consistency between studies. This is something that has previously been highlighted as a priority for PtC research (Singh & Grange, 2006). In addition, studies originated from several different countries with different healthcare contexts and processes. This further complicates direct comparisons between studies as routes to care will differ between countries and settings.

The empirical paper was limited by a relatively small sample size and presented data from individuals entering EIP from one catchment area limiting the generalisability of findings. In addition, due to small numbers of individuals in ethnic minority groups, data were analysed by collapsing these individuals into two broad categories (White Non-British and Any Other Ethnic group). It was therefore not possible to investigate variations in service access between subgroups. Furthermore, the study was limited by the availability and nature of data recorded on the CPFTRD. For instance, apart from referral source, PtC information was only available for contacts made within CPFT and therefore provides an estimate of delay within secondary mental health services rather than across individual's entire PtC. Gender is also recorded in a binary way within the database, and therefore it was not possible to investigate the impact of gender diversity and accessing help during ARMS compared to FEP. It is also worth noting that CPFTRD consists of de-identified clinical information recorded by clinicians and is therefore limited to the accuracy and quality of clinical documentation.

Clinical Implications

The findings of the systematic review were mixed however suggest that interventions targeting multiple populations were more successful in reducing DUP than those targeting non-healthcare professionals only. This is consistent with the findings of an earlier review (Lloyd-

Evans et al., 2011) which also highlighted that interventions aimed at healthcare professionals only were not sufficient to reduce DUP. The empirical study suggests that one reason for this may be that delays within healthcare are already relatively short, this was true for both ARMS and FEP patients. The short delays observed may be explained by the introduction of the access and waiting time standards in 2016 (NICE, 2016). Interventions targeting potential patients, families, the public and non-healthcare professionals appear to be the most promising for reducing delays.

Interventions aimed at reducing delays do not appear to have a uniform effect across groups. In addition, the empirical study found that some groups were more likely to access EIP during ARMS compared to FEP. It is important that local services are aware of potential barriers and delays to care faced by the populations they serve and that services and interventions are sensitive and responsive to their needs to minimise treatment delays (Cocchi et al., 2013; Fridgen et al., 2013; Lloyd-Evans et al., 2011; Mir et al., 2015; Srihari et al., 2014). Interventions aimed at reducing delays to treatment may be more successful if they are targeted at groups more likely to access services at later stages of psychosis.

The empirical study highlighted that individuals from minority ethnic groups were less likely to access EIP during ARMS compared to FEP, suggesting that these groups are accessing care during later stages of psychosis or clinician bias in identifying symptoms in these groups. Previous research has highlighted potential barriers to timely access to mental health services for individuals from ethnic minority backgrounds. Firstly, mental health services in the UK are designed based on Western and largely medical explanatory models of illness (Baumeister et al., 2017; Friskney et al., 2023), however understanding and explanation of psychotic experiences differ according to cultural and spiritual background (McCabe & Priebe, 2004; Naeem et al., 2016). Beliefs about mental health and distress influence how individuals seek-help for their difficulties (Lloyd et al., 1998) and may be associated with increased stigma and shame (Friskney et al., 2023). Furthermore, evidence suggests that when explanatory models between patient and services are conflicting, this can impact help-seeking behaviour (Kleinman et al., 1985; Patel, 1995; Saravanan et al., 2007). Secondly, mistrust of mental health services may lead to delays in help-seeking and result in care being more frequently accessed during times of crisis by ethnic minority groups, particularly individuals from Black ethnic backgrounds (Islam et al., 2015; Nicholas, 2020). This has been described as the “circle of fear” whereby individuals avoid mental health services until times of crisis due to fear and mistrust, often resulting in more coercive and adverse PtC, which in itself may be driven by fear and racist stereotypes within services, further increasing fear and mistrust within the communities (Keating et al., 2002). Finally, research highlights a lack of awareness of where and how to access mental health services (Friskney et al., 2023). Services should work alongside individuals and their local communities such as community and spiritual organisations and leaders to develop a shared understanding of different explanatory models of psychosis and preferences of care in order to ensure services are accessible and acceptable (Friskney et al., 2023; Islam et al., 2015). This collaboration and sharing of information should include raising awareness of early signs of psychosis and available services to improve signposting and early identification (Friskney et al., 2023). These insights could inform interventions to reduce delays to treatment, such as public health campaigns, to raise awareness, normalise experiences and reduce stigma (Friskney et al., 2023). Research suggests that such interventions could be enhanced by using advocates and past service users from diverse backgrounds, which may also help to improve trust (Ahmed, 2019).

A weaker association was found between gender and accessing EIP during ARMS, with men less likely to access care during ARMS. Previous research has highlighted differences in help-seeking between men and women (Fridgen et al., 2013). Evidence suggests that these differences may result from different beliefs and attitudes towards help-seeking for mental health problems (Ferrari et al., 2018; Mackenzie et al., 2006). For example, men report finding it more difficult to discuss mental health symptoms and holding beliefs that help-seeking was perceived as a sign of weakness (Ferrari et al., 2018) whereas women appear to have more positive attitudes towards seeking psychological help (Mackenzie et al., 2006). Two papers within the systematic review found significant reductions in DUP for men but not for women following public health interventions (Ferrara et al., 2019; Larsen et al., 2001). It may be that these interventions were able to improve awareness of early signs and improve attitudes towards help-seeking for psychosis in men, however this warrants further investigation.

Previous evidence demonstrates the importance of accessing appropriate treatment as early as possible for improved recovery outcomes for people with psychosis (Singh, 2010). That is, the earlier people receive treatment the better their overall functioning, quality of life and likelihood of full remission of symptoms (Harris et al., 2005; Marshall et al., 2005; Penttilä et al., 2014). In addition, shorter DUP is associated with reduced direct and indirect economic costs (Chong et al., 2016). The findings of the empirical study further highlight the importance of early access to treatment by demonstrating that individuals accessing EIP during ARMS were more likely to access services via primary care, compared to crisis services such as crisis teams and inpatient admissions, and were less likely to be detained during their PtC. Consequently, ARMS patients may have less negative PtC, defined in previous research as pathways including contact with crisis teams and compulsory admissions (Anderson et al., 2014; Ferrara et al., 2021; Singh

& Grange, 2006). Negative PtC have been associated with reduced satisfaction and engagement with services (Anderson et al., 2010) and therefore providing treatment during ARMS may be the optimum time to intervene. Furthermore, accessing care during ARMS may be less costly than FEP due to reduced use of costly hospital admissions during PtC (Cocchi et al., 2011). Public health interventions are often expensive (Chong et al., 2004) therefore targeting groups who experience longer delays to treatment, such as those less likely to access support during ARMS, may offset these costs by providing savings in other areas associated with delays in treatment (Cocchi et al., 2011; Chong et al., 2004).

Research Implications

The findings of this thesis contribute to the limited evidence base. The findings of the empirical study offer some support for existing research. For instance, no differences were found in duration of PtC between ARMS and FEP (Ferrara et al., 2021; Fridgen et al., 2013; Platz et al., 2006) or police involvement in PtC (Ferrara et al., 2021). Consistent with existing research, individuals with ARMS were less likely to be detained under MHA (Cocchi et al., 2013; Valmaggia et al., 2015) and less likely to have family involvement in their PtC (Ferrara et al., 2021).

In contrast to the existing literature, the empirical study found that there was a significant different in the number of PtC contacts made, with ARMS patients having significantly fewer contacts than FEP patients (Fridgen et al., 2013; Platz et al., 2006). These contrasting findings likely reflect the differences in how PtC were measured in this study compared to previous research, with previous research including help-seeking contacts outside of secondary mental health services (Fridgen et al., 2013; Platz et al., 2006). In addition, studies were carried out in different countries with differing healthcare contexts and processes.

The empirical study provides exploratory findings regarding the association between sociodemographic characteristics and accessing EIP during ARMS compared to FEP. To the author's knowledge only one other paper conducted in the United Stated directly compared these groups (Ferrara et al., 2021). The empirical study also found that men and ethnic minority groups were less likely to access EIP during ARMS compared to FEP. This contrasts with findings from the earlier study which found no significant differences between ARMS and FEP across these characteristics (Ferrara et al., 2021). Further research is warranted to explore sociodemographic characteristics and any associations with accessing care at an earlier stage.

The empirical paper was limited by a relatively small sample size. This meant it was not possible to investigate the influence of ethnicity on help-seeking for ARMS compared to FEP in detail. It was also not possible to investigate the influence of gender-diversity on help-seeking as gender was recorded in a binary fashion on CPFTRD. These are important areas to investigate given that access to EIP varies between ethnic minority groups (Friskney et al., 2023) and gender-diverse individuals may experience barriers to accessing mental health services (McNair & Bush, 2016). Research would benefit from larger sample sizes and studies carried out across diverse catchment areas in order to address these limitations.

Future research may adopt qualitative approaches such as the use of semi-structured interviews with patients, families, and healthcare professionals. Interviews may provide a more detailed understanding of individual PtC and potential sources of delay. Findings from the systematic review about the effectiveness of interventions at reducing DUP were mixed, however highlighted the differential impact of such interventions on different groups. Detailed understanding of sources of delays in different groups will inform the development of targeted interventions to reduce such delays.

The systematic review identified no studies of interventions aimed at reducing delays in the ARMS population. Research investigating PtC in ARMS continues to be limited (Allan et al., 2021) despite evidence that prolonged DUI is associated with poorer outcomes (Carrión et al., 2016; Fusar-Poli et al., 2009; Zhang et al., 2019) and public health campaigns may help to address delays with people with ARMS (Chung et al., 2010; Stowkowy et al., 2013; von Reventlow et al., 2014). Further research in this area is therefore necessary and should be a priority.

The systematic review found limited research regarding the impact of interventions of PtC and for studies which did report PtC information, findings were mixed. Future research should not only investigate the impact of interventions on DUI and DUP, but also on PtC. Improving PtC for example by reducing duration, number of contacts, and/or fewer negative pathways may result in reduced costs, improved patient satisfaction (Lloyd-Evans et al., 2011) and better engagement with treatment (Anderson et al., 2010).

Theoretical Implications

The findings of the empirical study highlighted similarities between individuals accessing EIP during ARMS and FEP. For example, no significant differences were detected between groups in terms of living circumstances, level of deprivation, urbanicity, and employment status. In addition, police involvement in PtC and duration of PtC were similar for both groups. These commonalities broadly fit with the continuum model of psychosis which suggests that psychotic-like experiences exist on a continuum from mild to more severe and debilitating and are relatively common in the general population (BPS., 2017; DeRosse & Karlsgodt, 2015; Johns et al., 2014). This contrast with traditional medical models of psychosis which argues for clear distinguishable diagnostic categories (Bentall, 2003; BPS., 2017).

Findings from the systematic review provided some evidence that interventions, particularly those targeting multiple populations, were effective at reducing DUP. These findings fit with existing models of help-seeking. Firstly, findings suggest that improving awareness of early signs of psychosis and where to access help may improve help-seeking behaviours, this is consistent with Rickwood's (2005) model of help-seeking which highlights the importance of awareness and knowledge of difficulties in prompting individuals to seek-help. Public health interventions may help to alter attitudes and societal norms, thus reduce stigma, improve sense of control, and help-seeking which have been highlighted as core components of health related help-seeking in both the theory of planned behaviour (Ajzen, 1991) and the cycle of avoidance model (Biddle et al., 2007). Furthermore, information pertaining to psychosis may help to normalise the experience, thereby reducing perceived threat and stigma, and enhancing individual's beliefs about the benefits of behaviour change consistent with the health belief model (Rosenstock, 1974). It should be noted that few of the included studies in the systematic review explicitly reported using theoretical frameworks or models of behaviour change to inform the development of their interventions (Connor et al., 2016; Krstev et al., 2004; López et al., 2022; Malla et al., 2014; Srihari et al., 2022). This will be an important consideration for future research in order to understand the mechanisms of behaviour change and implement appropriate interventions based on this (West et al., 2011).

The empirical study also offered some evidence consistent with existing models of help-seeking. Ethnic minority patients and men were less likely to access EIP during ARMS, possible explanations for this can be drawn from previous research. For instance, evidence suggests that men's personal and perceived beliefs and attitudes of others towards help-seeking is more negative than that of women (Ferrari et al., 2018; Mackenzie et al., 2006). This fits with the theory of planned behaviour which highlights the importance of both personal and societal norms in influencing whether or not someone seeks help (Ajzen, 1991). Within ethnic minority groups delays to help-seeking may arise from cultural and spiritual explanations of mental health problems which may result in increased stigma (Friskney et al., 2023; McCabe & Priebe, 2004; Naeem et al., 2016). Again, this is consistent with the role of societal norms and views of distress and help-seeking highlighted in the theory of planned behaviour (Ajzen, 1991) and the cycle of avoidance (Biddle et al., 2007). Furthermore, environmental, and contextual factors likely impact on individual's beliefs and attitudes towards seeking help. For example, research highlights the role of mistrust in help-seeking for ethnic minority groups (Islam et al., 2015; Nicholas, 2020) which may arise from the experience of more coercive and adverse PtC (Keating et al., 2002). This fits with Rosenstock's (1974) health belief model which highlights the role of perceived threat of illness (associated with societal norms and stigma) and threat of accessing help for these difficulties. Finally, the finding that ARMS patients were less likely than FEP patients to have family and/or friend involvement in their PtC, may be a result of limited insight into difficulties and therefore the need for others to seek-help on their behalf (Allan, 2020). Both Rickwood's (2005) model of help-seeking, and Biddle's (2007) cycle of avoidance highlight the importance of awareness of own mental health difficulties (insight) and need for help in influencing help-seeking behaviour.

Conclusions

Taken together, this thesis contributes to the existing evidence base regarding PtC for individuals with ARMS and FEP. Exploratory findings indicate that individuals accessing EIP during ARMS had fewer PtC contacts, were less likely to be detained under the MHA, have family or friend involvement in their PtC and were more likely to access care via primary services compared to acute services. In addition, ARMS patients were younger and less likely to be from minority ethnic groups. Further research is warranted to replicate these findings. Current evidence regarding the effectiveness of intervention programmes at reducing delays to care is mixed. There is some evidence to suggest that interventions differentially impact the DUP of different groups and therefore it may be useful for interventions to be tailored and targeted at groups accessing care at a later stage of psychosis. Further research is needed investigating the impact of such interventions on PtC and evaluating interventions to reduce DUI or improve PtC for an ARMS population. Developing effective interventions to reduce DUP, DUI, and improve PtC for individuals with ARMS and FEP is vital to improve outcomes for these groups.

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Appendices

List of Appendices

Appendix A Schizophrenia Research Author Guidelines

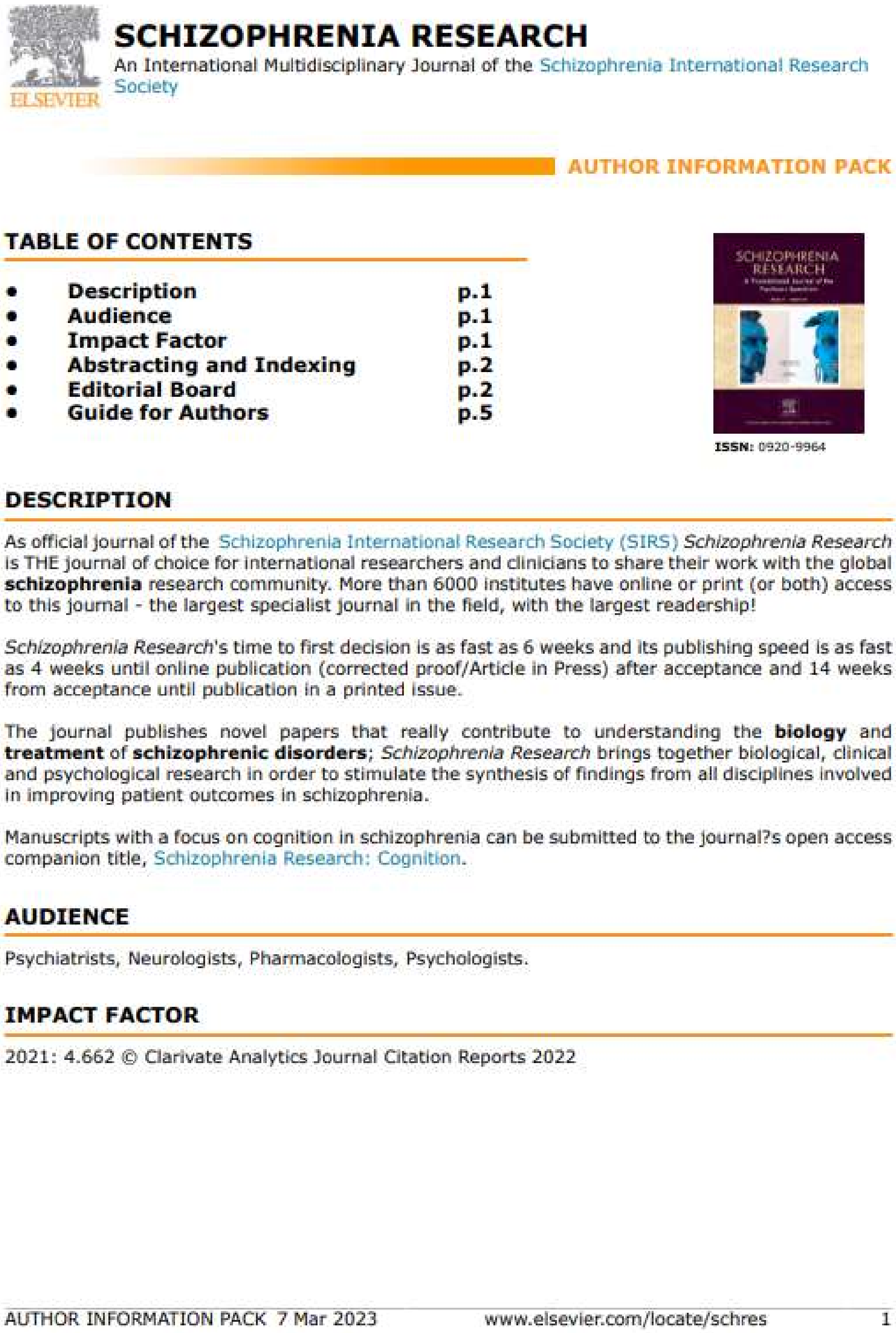
Appendix B Social Psychiatry and Psychiatric Epidemiology Author Guidelines

Appendix C REC Ethical Approval Confirmation

Appendix D REC Substantial Amendment Approval

Appendix E Empirical Paper Supplementary Tables

Appendix A. Schizophrenia Research Author Guidelines



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AUTHOR INFORMATION PACK

TABLE OF CONTENTS

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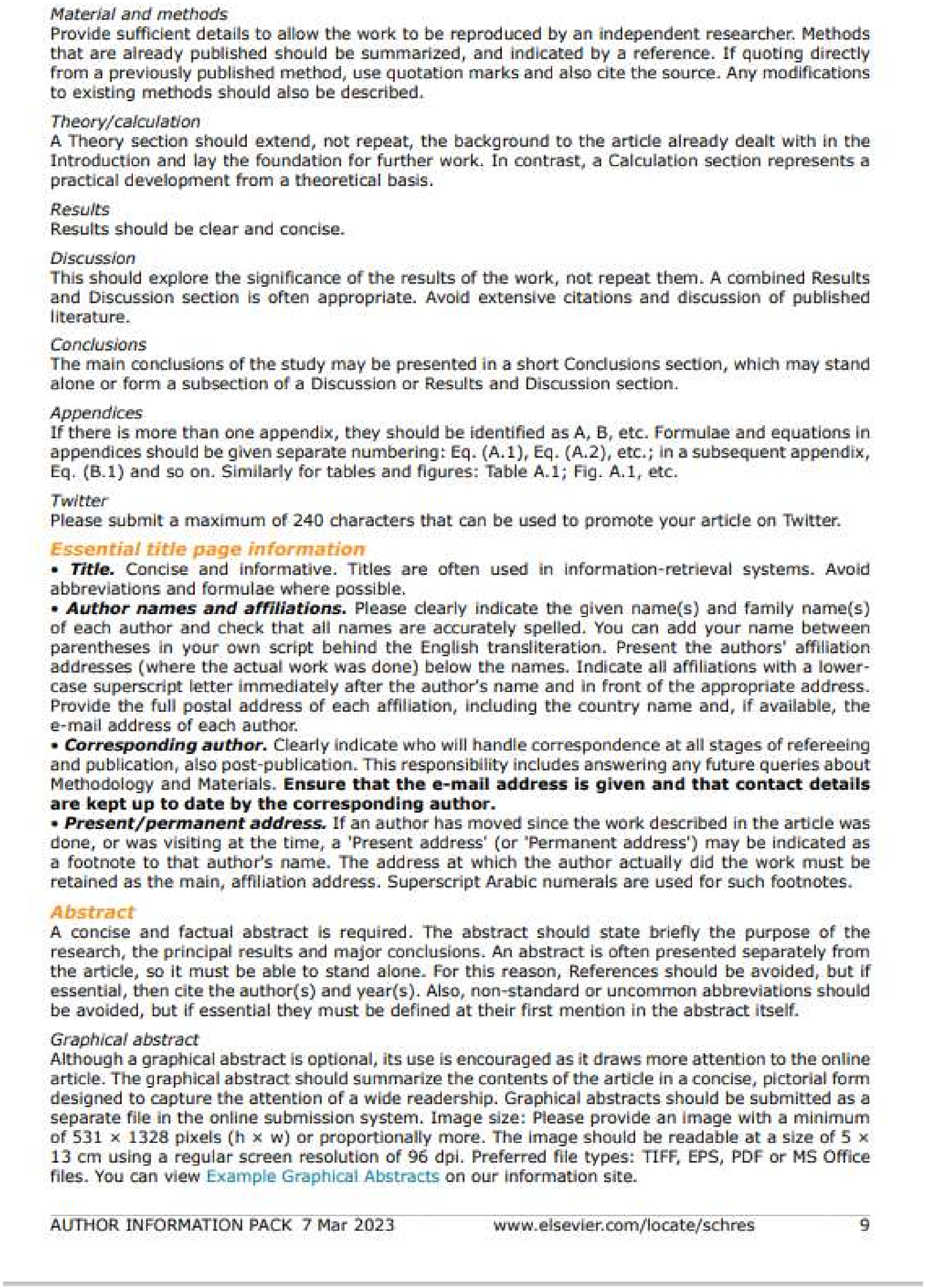

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Please submit math equations as editable text and not as images. Present simple formulae in line with normal text where possible and use the solidus (/) instead of a horizontal line for small fractional terms, e.g., X/Y. In principle, variables are to be presented in italics. Powers of e are often more conveniently denoted by exp. Number consecutively any equations that have to be displayed separately from the text (if referred to explicitly in the text).

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Footnotes should be used sparingly. Number them consecutively throughout the article. Many word processors can build footnotes into the text, and this feature may be used. Otherwise, please indicate the position of footnotes in the text and list the footnotes themselves separately at the end of the article. Do not include footnotes in the Reference list.

Artwork

Electronic artwork

General points

- Make sure you use uniform lettering and sizing of your original artwork.
- Embed the used fonts if the application provides that option.
- Aim to use the following fonts in your illustrations: Arial, Courier, Times New Roman, Symbol, or use fonts that look similar.
- Number the illustrations according to their sequence in the text.
- Use a logical naming convention for your artwork files.
- Provide captions to illustrations separately.
- Size the illustrations close to the desired dimensions of the published version.
- Submit each illustration as a separate file.
- Ensure that color images are accessible to all, including those with impaired color vision.

A detailed guide on electronic artwork is available.

You are urged to visit this site; some excerpts from the detailed information are given here.

Formats

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Regardless of the application used other than Microsoft Office, when your electronic artwork is finalized, please 'Save as' or convert the images to one of the following formats (note the resolution requirements for line drawings, halftones, and line/halftone combinations given below):

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TIFF (or JPEG): Color or grayscale photographs (halftones), keep to a minimum of 300 dpi.

TIFF (or JPEG): Bitmapped (pure black & white pixels) line drawings, keep to a minimum of 1000 dpi.

TIFF (or JPEG): Combinations bitmapped line/half-tone (color or grayscale), keep to a minimum of 500 dpi.

Please do not:

- Supply files that are optimized for screen use (e.g., GIF, BMP, PICT, WPG); these typically have a low number of pixels and limited set of colors;
- Supply files that are too low in resolution;
- Submit graphics that are disproportionately large for the content.

Color artwork

Please make sure that artwork files are in an acceptable format (TIFF (or JPEG), EPS (or PDF), or MS Office files) and with the correct resolution. If, together with your accepted article, you submit usable color figures then Elsevier will ensure, at no additional charge, that these figures will appear in color online (e.g., ScienceDirect and other sites) regardless of whether or not these illustrations are reproduced in color in the printed version. **For color reproduction in print, you will receive information regarding the costs from Elsevier after receipt of your accepted article**. Please indicate your preference for color: in print or online only. Further information on the preparation of electronic artwork.

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Ensure that each illustration has a caption. Supply captions separately, not attached to the figure. A caption should comprise a brief title (**not** on the figure itself) and a description of the illustration. Keep text in the illustrations themselves to a minimum but explain all symbols and abbreviations used.

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Please submit tables as editable text and not as images. Tables can be placed either next to the relevant text in the article, or on separate page(s) at the end. Number tables consecutively in accordance with their appearance in the text and place any table notes below the table body. Be sparing in the use of tables and ensure that the data presented in them do not duplicate results described elsewhere in the article. Please avoid using vertical rules and shading in table cells.

References

Citation in text

Please ensure that every reference cited in the text is also present in the reference list (and vice versa). Any references cited in the abstract must be given in full. Unpublished results and personal communications are not recommended in the reference list, but may be mentioned in the text. If these references are included in the reference list they should follow the standard reference style of the journal and should include a substitution of the publication date with either 'Unpublished results' or 'Personal communication'. Citation of a reference as 'in press' implies that the item has been accepted for publication.

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As a minimum, the full URL should be given and the date when the reference was last accessed. Any further information, if known (DOI, author names, dates, reference to a source publication, etc.), should also be given. Web references can be listed separately (e.g., after the reference list) under a different heading if desired, or can be included in the reference list.

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This journal encourages you to cite underlying or relevant datasets in your manuscript by citing them in your text and including a data reference in your Reference List. Data references should include the following elements: author name(s), dataset title, data repository, version (where available), year, and global persistent identifier. Add [dataset] immediately before the reference so we can properly identify it as a data reference. The [dataset] identifier will not appear in your published article.

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Where a preprint has subsequently become available as a peer-reviewed publication, the formal publication should be used as the reference. If there are preprints that are central to your work or that cover crucial developments in the topic, but are not yet formally published, these may be referenced. Preprints should be clearly marked as such, for example by including the word preprint, or the name of the preprint server, as part of the reference. The preprint DOI should also be provided.

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Please ensure that the words 'this issue' are added to any references in the list (and any citations in the text) to other articles in the same Special Issue.

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Reference style
Text: All citations in the text should refer to:
1. *Single author:* the author's name (without initials, unless there is ambiguity) and the year of publication;
2. *Two authors:* both authors' names and the year of publication;
3. *Three or more authors:* first author's name followed by 'et al.' and the year of publication.
Citations may be made directly (or parenthetically). Groups of references can be listed either first alphabetically, then chronologically, or vice versa.
Examples: 'as demonstrated (Allan, 2000a, 2000b, 1999; Allan and Jones, 1999).... Or, as demonstrated (Jones, 1999; Allan, 2000)... Kramer et al. (2010) have recently shown ...'
List: References should be arranged first alphabetically and then further sorted chronologically if necessary. More than one reference from the same author(s) in the same year must be identified by the letters 'a', 'b', 'c', etc., placed after the year of publication.
Examples:
Reference to a journal publication:
Van der Geer, J., Hanraads, J.A.J., Lupton, R.A., 2010. The art of writing a scientific article. J. Sci. Commun. 163, 51–59. https://doi.org/10.1016/j.Sc.2010.00372.
Reference to a journal publication with an article number:
Van der Geer, J., Hanraads, J.A.J., Lupton, R.A., 2018. The art of writing a scientific article. Heliyon. 19, e00205. https://doi.org/10.1016/j.heliyon.2018.e00205.
Reference to a book:
Strunk Jr., W., White, E.B., 2000. The Elements of Style, fourth ed. Longman, New York.
Reference to a chapter in an edited book:
Mettam, G.R., Adams, L.B., 2009. How to prepare an electronic version of your article, in: Jones, B.S., Smith , R.Z. (Eds.), Introduction to the Electronic Age. E-Publishing Inc., New York, pp. 281–304.
Reference to a website:
Cancer Research UK, 1975. Cancer statistics reports for the UK. http://www.cancerresearchuk.org/aboutcancer/statistics/cancerstatsreport/ (accessed 13 March 2003).
Reference to a dataset:
[dataset] Oguro, M., Imahiro, S., Saito, S., Nakashizuka, T., 2015. Mortality data for Japanese oak wilt disease and surrounding forest compositions. Mendeley Data, v1. https://doi.org/10.17632/xwj98nb39r.1.
Reference to software:
Coon, E., Berndt, M., Jan, A., Svyatsky, D., Atchley, A., Kikinzon, E., Harp, D., Manzini, G., Shelef, E., Lipnikov, K., Garimella, R., Xu, C., Moulton, D., Karra, S., Painter, S., Jafarov, E., & Molins, S., 2020. Advanced Terrestrial Simulator (ATS) v0.88 (Version 0.88). Zenodo. https://doi.org/10.5281/zenodo.3727209.

Journal abbreviations source
Journal names should be abbreviated according to the List of Title Word Abbreviations.

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Supplementary material

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In addition, you can link to relevant data or entities through identifiers within the text of your manuscript, using the following format: Database: xxxx (e.g., TAIR: AT1G01020; CCDC: 734053; PDB: 1XFN).

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Appendix B. Social Psychiatry and Psychiatric Epidemiology Author Guidelines

Accessed from:

Submission guidelines

Contents

Instructions for Authors

Types of Papers

- Papers must be written in English.
- Accepted article types: Research, Review, Brief Report, Editorial, Comment, Correspondence, and Study Protocol.
- Research papers or Reviews should not exceed 4,500 words, not including references, plus 5 tables or figures. An abstract (150 to 250 words) and 4-6 keywords are required (please see also section 'title page').
- Submissions for Study Protocols are welcome which describe the rationale, the design, procedures, and sample characteristics of large epidemiological studies in the context of existing research. Papers should not exceed 4,500 words. An abstract (150 to 250 words) and 4-6 keywords are required.
- Brief Reports should not contain more than 1,500 words plus 1 figure or table. Please submit a short abstract of max. 100 words and 4-6 keywords.
- Editorials and Correspondence articles will be considered for publication; they should not contain more than 1,500 words.
- Comments should not contain more than 10,000 characters and less than 10 references. Please do not include an abstract or keywords.
- Exceptions to the word limits can be made only with the agreement of the Editor-in-Chief.
- Authors are required to state the word count of their paper when submitting the manuscript.

Manuscript Submission

Manuscript Submission

Submission of a manuscript implies: that the work described has not been published before; that it is not under consideration for publication anywhere else; that its publication has been approved by all co-authors, if any, as well as by the responsible authorities – tacitly or explicitly – at the institute where the work has been carried out. The publisher will not be held legally responsible should there be any claims for compensation.

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Online Submission

Please follow the hyperlink "Submit manuscript" and upload all of your manuscript files following the instructions given on the screen.

Source Files

Please ensure you provide all relevant editable source files at every submission and revision. Failing to submit a complete set of editable source files will result in your article not being considered for review. For your manuscript text please always submit in common word processing formats such as .docx or LaTeX.

Title Page

Title Page

Please make sure your title page contains the following information.

TITLE

The title should be concise and informative.

AUTHOR INFORMATION

- The name(s) of the author(s)
- The affiliation(s) of the author(s), i.e. institution, (department), city, (state), country
- A clear indication and an active e-mail address of the corresponding author
- If available, the 16-digit ORCID of the author(s)

If address information is provided with the affiliation(s) it will also be published.

For authors that are (temporarily) unaffiliated we will only capture their city and country of residence, not their e-mail address unless specifically requested.

Abstract

Please provide a structured abstract of 150 to 250 words which should be divided into the following sections:

- Purpose (stating the main purposes and research question)
- Methods
- Results
- Conclusion

For life science journals only (when applicable)

- Trial registration number and date of registration for prospectively registered trials
- Trial registration number and date of registration followed by "retrospectively registered", for retrospectively registered trials

Keywords

Please provide 4 to 6 keywords which can be used for indexing purposes.

Statements and Declarations

The following statements should be included under the heading "Statements and Declarations" for inclusion in the published paper. Please note that submissions that do not include relevant declarations will be returned as incomplete.

- COMPETING INTERESTS: Authors are required to disclose financial or non-financial interests that are directly or indirectly related to the work submitted for publication. Please refer to “Competing Interests and Funding” below for more information on how to complete this section.

Please see the relevant sections in the submission guidelines for further information as well as various examples of wording. Please revise/customize the sample statements according to your own needs.

Text

Text Formatting

Manuscripts should be submitted in Word.

- Use a normal, plain font (e.g., 10-point Times Roman) for text.
- Use italics for emphasis.
- Use the automatic page numbering function to number the pages.
- Do not use field functions.
- Use tab stops or other commands for indents, not the space bar.
- Use the table function, not spreadsheets, to make tables.
- Use the equation editor or MathType for equations.
- Save your file in docx format (Word 2007 or higher) or doc format (older Word versions).

Manuscripts with mathematical content can also be submitted in LaTeX. We recommend using Springer Nature’s LaTeX template.

Headings

Please use no more than three levels of displayed headings.

Abbreviations

Abbreviations should be defined at first mention and used consistently thereafter.

Footnotes

Footnotes can be used to give additional information, which may include the citation of a reference included in the reference list. They should not consist solely of a reference citation, and they should never include the bibliographic details of a reference. They should also not contain any figures or tables.

Footnotes to the text are numbered consecutively; those to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data). Footnotes to the title or the authors of the article are not given reference symbols.

Always use footnotes instead of endnotes.

Acknowledgments

Acknowledgments of people, grants, funds, etc. should be placed in a separate section on the title page. The names of funding organizations should be written in full.

References

Citation

Reference citations in the text should be identified by numbers in square brackets. Some examples:

1. Negotiation research spans many disciplines [3].
2. This result was later contradicted by Becker and Seligman [5].

3. This effect has been widely studied [1-3, 7].

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text.

The entries in the list should be numbered consecutively.

If available, please always include DOIs as full DOI links in your reference list (e.g. "https://doi.org/abc").

- Journal article
  Gamelin FX, Baquet G, Berthoin S, Thevenet D, Nourry C, Nottin S, Bosquet L (2009) Effect of high intensity intermittent training on heart rate variability in prepubescent children. Eur J Appl Physiol 105:731-738. https://doi.org/10.1007/s00421-008-0955-8
  Ideally, the names of all authors should be provided, but the usage of "et al" in long author lists will also be accepted:
  Smith J, Jones M Jr, Houghton L et al (1999) Future of health insurance. N Engl J Med 965:325–329

- Article by DOI
  Slifka MK, Whitton JL (2000) Clinical implications of dysregulated cytokine production. J Mol Med. https://doi.org/10.1007/s001090000086

- Book
  South J, Blass B (2001) The future of modern genomics. Blackwell, London

- Book chapter
  Brown B, Aaron M (2001) The politics of nature. In: Smith J (ed) The rise of modern genomics, 3rd edn. Wiley, New York, pp 230-257

- Online document
  Cartwright J (2007) Big stars have weather too. IOP Publishing PhysicsWeb. http://physicsweb.org/articles/news/11/6/16/1. Accessed 26 June 2007

- Dissertation
  Trent JW (1975) Experimental acute renal failure. Dissertation, University of California

Always use the standard abbreviation of a journal's name according to the ISSN List of Title Word Abbreviations, see ISSN.org LTWA

If you are unsure, please use the full journal title.

Authors preparing their manuscript in LaTeX can use the bibliography style file sn-basic.bst which is included in the Springer Nature Article Template.

Tables

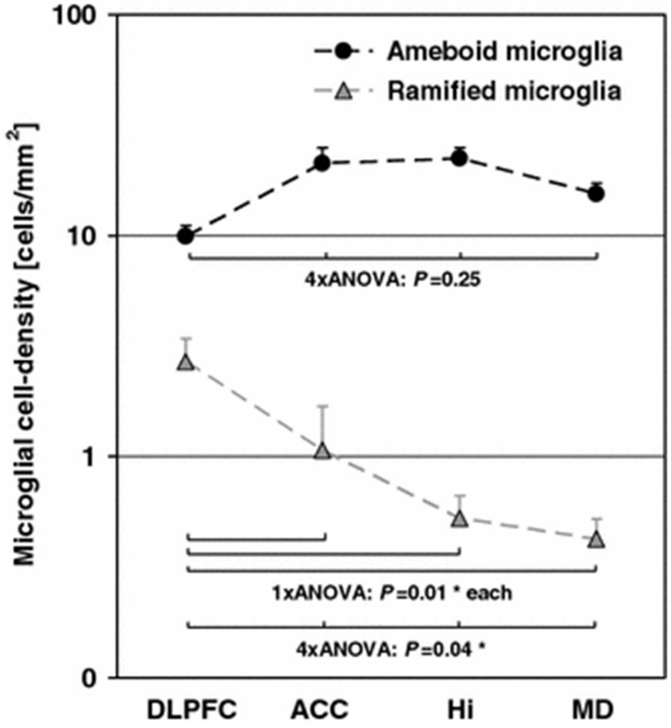
- All tables are to be numbered using Arabic numerals.
- Tables should always be cited in text in consecutive numerical order.
- For each table, please supply a table caption (title) explaining the components of the table.
- Identify any previously published material by giving the original source in the form of a reference at the end of the table caption.
- Footnotes to tables should be indicated by superscript lower-case letters (or asterisks for significance values and other statistical data) and included beneath the table body.

Artwork and Illustrations Guidelines

Electronic Figure Submission

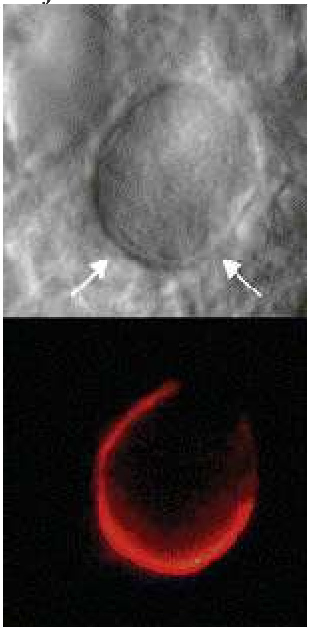
- Supply all figures electronically.
- Indicate what graphics program was used to create the artwork.
- For vector graphics, the preferred format is EPS; for halftones, please use TIFF format. MSOffice files are also acceptable.
- Vector graphics containing fonts must have the fonts embedded in the files.
- Name your figure files with "Fig" and the figure number, e.g., Fig1.eps.

Line Art



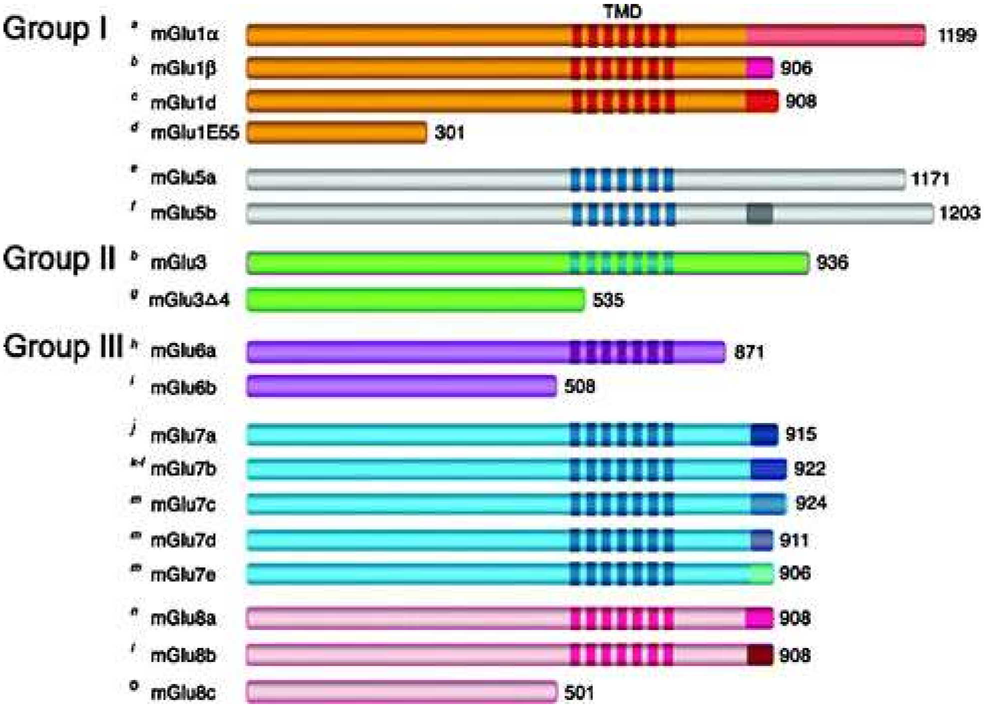
- Definition: Black and white graphic with no shading.
- Do not use faint lines and/or lettering and check that all lines and lettering within the figures are legible at final size.
- All lines should be at least 0.1 mm (0.3 pt) wide.
- Scanned line drawings and line drawings in bitmap format should have a minimum resolution of 1200 dpi.
- Vector graphics containing fonts must have the fonts embedded in the files.

Halftone Art



- Definition: Photographs, drawings, or paintings with fine shading, etc.
- If any magnification is used in the photographs, indicate this by using scale bars within the figures themselves.
- Halftones should have a minimum resolution of 300 dpi.

Combination Art



- Definition: a combination of halftone and line art, e.g., halftones containing line drawing, extensive lettering, color diagrams, etc.
- Combination artwork should have a minimum resolution of 600 dpi.

Color Art

- Color art is free of charge for online publication.
- If black and white will be shown in the print version, make sure that the main information will still be visible. Many colors are not distinguishable from one another when converted to black and white. A simple way to check this is to make a xerographic copy to see if the necessary distinctions between the different colors are still apparent.
- If the figures will be printed in black and white, do not refer to color in the captions.
- Color illustrations should be submitted as RGB (8 bits per channel).

Figure Lettering

- To add lettering, it is best to use Helvetica or Arial (sans serif fonts).
- Keep lettering consistently sized throughout your final-sized artwork, usually about 2–3 mm (8–12 pt).
- Variance of type size within an illustration should be minimal, e.g., do not use 8-pt type on an axis and 20-pt type for the axis label.
- Avoid effects such as shading, outline letters, etc.
- Do not include titles or captions within your illustrations.

Figure Numbering

- All figures are to be numbered using Arabic numerals.
- Figures should always be cited in text in consecutive numerical order.
- Figure parts should be denoted by lowercase letters (a, b, c, etc.).
- If an appendix appears in your article and it contains one or more figures, continue the consecutive numbering of the main text. Do not number the appendix figures,"A1, A2, A3, etc." Figures in online appendices [Supplementary Information (SI)] should, however, be numbered separately.

Figure Captions

- Each figure should have a concise caption describing accurately what the figure depicts. Include the captions in the text file of the manuscript, not in the figure file.
- Figure captions begin with the term Fig. in bold type, followed by the figure number, also in bold type.
- No punctuation is to be included after the number, nor is any punctuation to be placed at the end of the caption.
- Identify all elements found in the figure in the figure caption; and use boxes, circles, etc., as coordinate points in graphs.
- Identify previously published material by giving the original source in the form of a reference citation at the end of the figure caption.

Figure Placement and Size

- Figures should be submitted within the body of the text. Only if the file size of the manuscript causes problems in uploading it, the large figures should be submitted separately from the text.
- When preparing your figures, size figures to fit in the column width.
- For large-sized journals the figures should be 84 mm (for double-column text areas), or 174 mm (for single-column text areas) wide and not higher than 234 mm.
- For small-sized journals, the figures should be 119 mm wide and not higher than 195 mm.

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In order to give people of all abilities and disabilities access to the content of your figures, please make sure that

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- Patterns are used instead of or in addition to colors for conveying information (colorblind users would then be able to distinguish the visual elements)
- Any figure lettering has a contrast ratio of at least 4.5:1

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Submission

- Supply all supplementary material in standard file formats.
- Please include in each file the following information: article title, journal name, author names; affiliation and e-mail address of the corresponding author.
- To accommodate user downloads, please keep in mind that larger-sized files may require very long download times and that some users may experience other problems during downloading.
- High resolution (streamable quality) videos can be submitted up to a maximum of 25GB; low resolution videos should not be larger than 5GB.

Audio, Video, and Animations

- Aspect ratio: 16:9 or 4:3
- Maximum file size: 25 GB for high resolution files; 5 GB for low resolution files
- Minimum video duration: 1 sec
- Supported file formats: avi, wmv, mp4, mov, m2p, mp2, mpg, mpeg, flv, mxf, mts, m4v, 3gp

Text and Presentations

- Submit your material in PDF format; .doc or .ppt files are not suitable for long-term viability.
- A collection of figures may also be combined in a PDF file.

Spreadsheets

- Spreadsheets should be submitted as .csv or .xlsx files (MS Excel).

Specialized Formats

- Specialized format such as .pdb (chemical), .wrl (VRML), .nb (Mathematica notebook), and .tex can also be supplied.

Collecting Multiple Files

- It is possible to collect multiple files in a .zip or .gz file.

Numbering

- If supplying any supplementary material, the text must make specific mention of the material as a citation, similar to that of figures and tables.
- Refer to the supplementary files as “Online Resource”, e.g., "... as shown in the animation (Online Resource 3)", “... additional data are given in Online Resource 4”.
- Name the files consecutively, e.g. “ESM_3.mpg”, “ESM_4.pdf”.

Captions

- For each supplementary material, please supply a concise caption describing the content of the file.

Processing of supplementary files

- Supplementary Information (SI) will be published as received from the author without any conversion, editing, or reformatting.

Accessibility

In order to give people of all abilities and disabilities access to the content of your supplementary files, please make sure that

- The manuscript contains a descriptive caption for each supplementary material
- Video files do not contain anything that flashes more than three times per second (so that users prone to seizures caused by such effects are not put at risk)

Integrity of research and reporting

Ethical standards

Manuscripts submitted for publication must contain a statement to the effect that all human and animal studies have been approved by the appropriate ethics committee and have therefore been performed in accordance with the ethical standards laid down in the 1964 Declaration of Helsinki and its later amendments.
It should also be stated clearly in the text that all persons gave their informed consent prior to their inclusion in the study. Details that might disclose the identity of the subjects under study should be omitted.
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It is easy to find funding to support open access – please see our funding and support pages for more information.
*) Within the first three years of publication. Springer Nature hybrid journal OA impact analysis, 2018.
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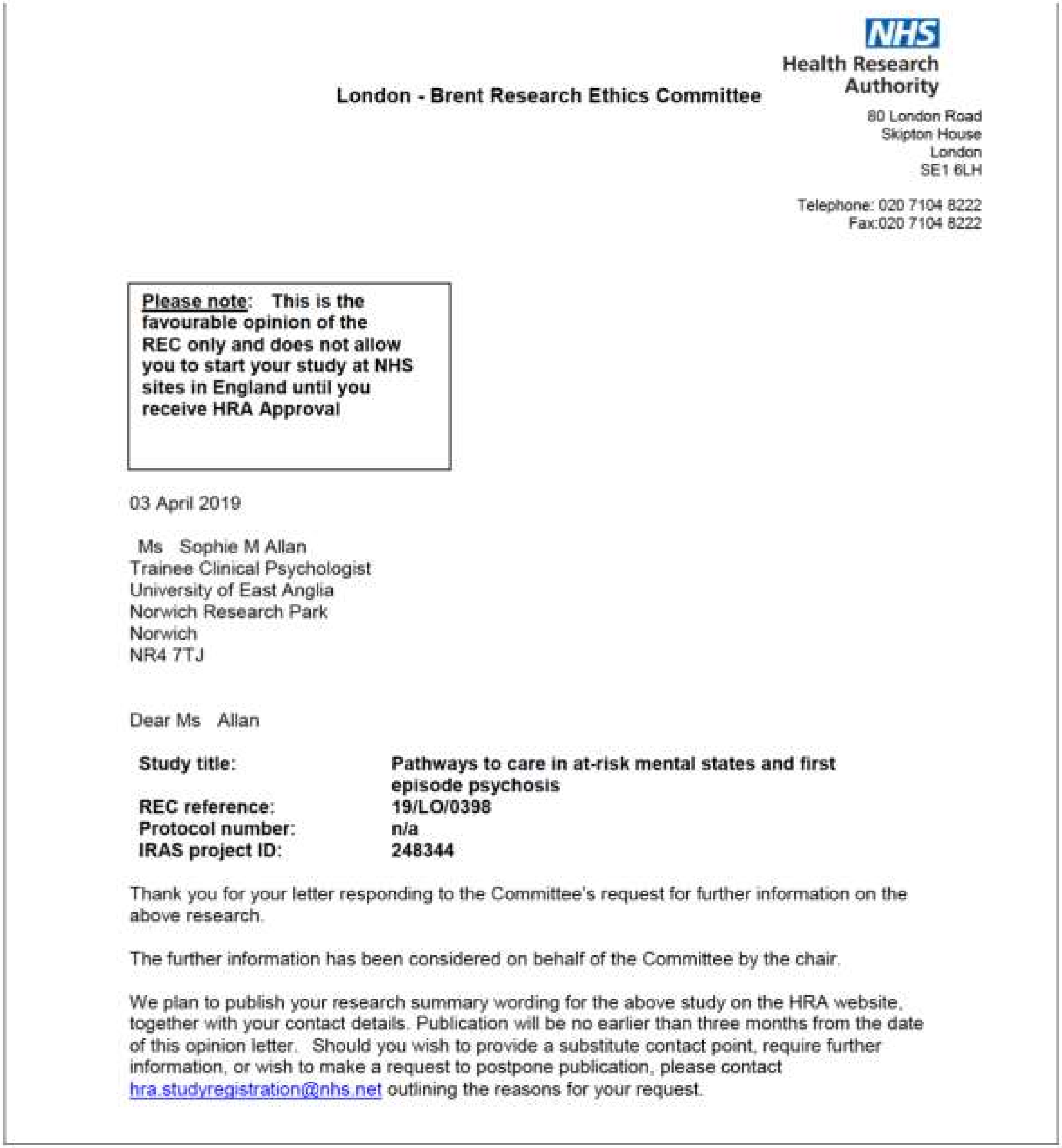
Funding and Support pages

Appendix C REC Ethical Approval Confirmation



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

Reporting requirements

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.

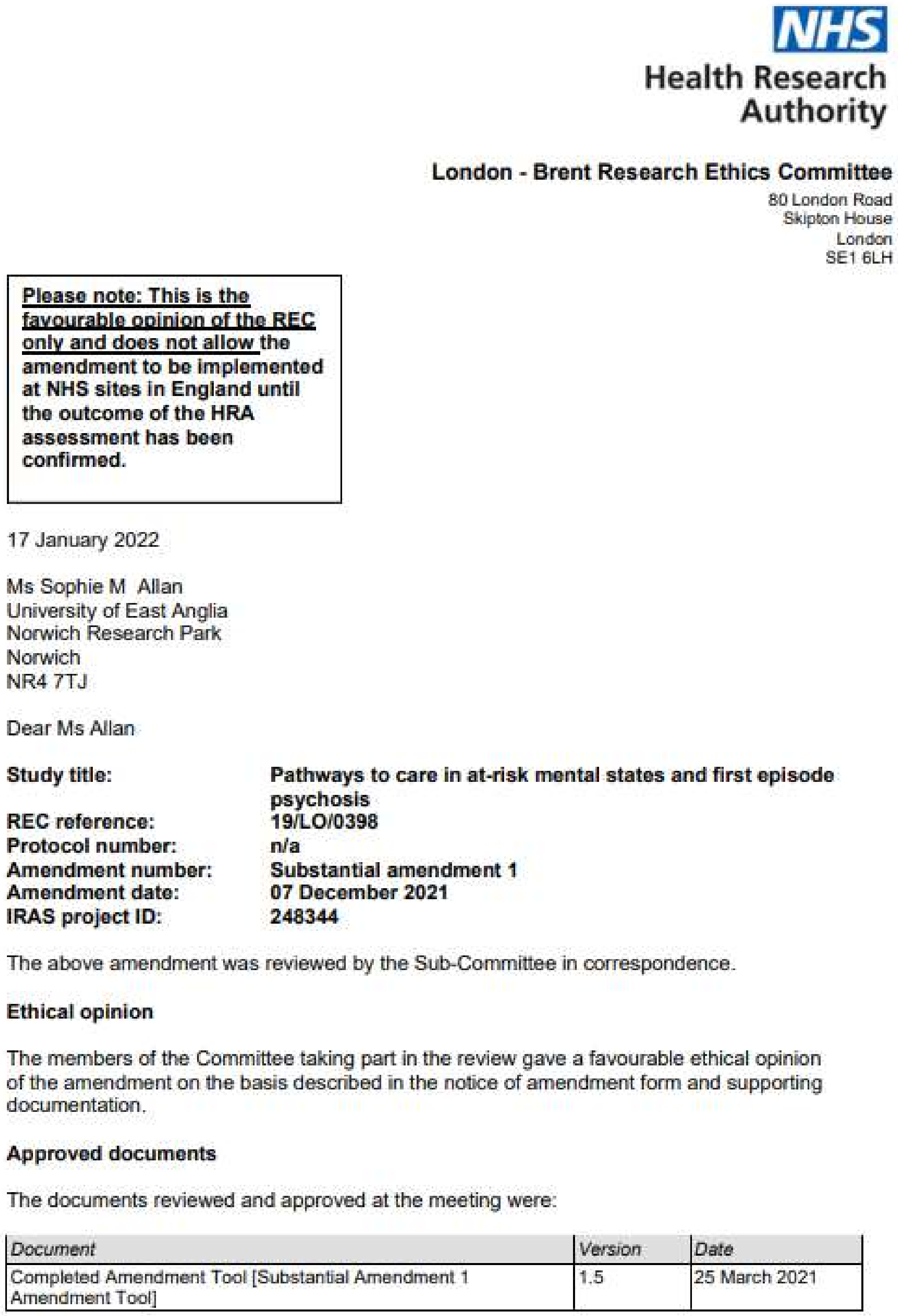
Yours sincerely
PP:

C. Frost

Dr Manish Saxena
Chair

Email:nrescommittee.london-brent@nhs.net

Appendix D REC Substantial Amendment Approval



NHS
Health Research
Authority

London - Brent Research Ethics Committee
80 London Road
Skipton House
London
SE1 6LH

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

17 January 2022

Ms Sophie M Allan
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**
Amendment number:	**Substantial amendment 1**
Amendment date:	**07 December 2021**
IRAS project ID:	**248344**

The above amendment was reviewed by the Sub-Committee in correspondence.

Ethical opinion

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

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Completed Amendment Tool [Substantial Amendment 1 Amendment Tool]	1.5	25 March 2021

Other [Annual Progress Report]	1	08 November 2021
Research protocol or project proposal [Pathways to Care Protocol Accepted Changes]	5	01 November 2021
Research protocol or project proposal [Pathways to Care Protocol tracked changes]	5	01 November 2021
Summary CV for Chief Investigator (CI) [CI Summary CV]		10 December 2021

Membership of the Committee

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

Working with NHS Care Organisations

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

Amendments related to COVID-19

We will update your research summary for the above study on the research summaries section of our website. During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you have not already done so, please register your study on a public registry as soon as possible and provide the HRA with the registration detail, which will be posted alongside other information relating to your project.

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.

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/

IRAS Project ID - 248344: Please quote this number on all correspondence

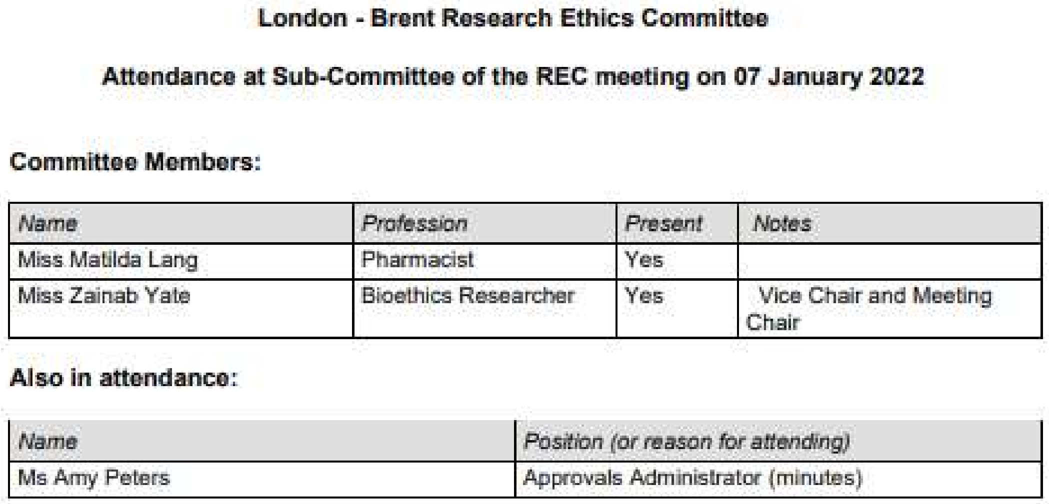
Yours sincerely

pp
Miss Zainab Yate
Vice Chair

E-mail: brent.rec@hra.nhs.uk

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

Copy to: *Ms Sophie M Allan*



London - Brent Research Ethics Committee

Attendance at Sub-Committee of the REC meeting on 07 January 2022

Committee Members:

Name	*Profession*	*Present*	*Notes*
Miss Matilda Lang	Pharmacist	Yes	
Miss Zainab Yate	Bioethics Researcher	Yes	Vice Chair and Meeting Chair

Also in attendance:

Name	*Position (or reason for attending)*
Ms Amy Peters	Approvals Administrator (minutes)

Appendix E Empirical Paper Supplementary Tables

Supplementary Table 1.

Sample characteristics of patients (13-35 years old)

	N = 158 (%)
Diagnosis	
ARMS	67 (42.4)
FEP	91 (57.6)
Mean age (sd) years	23.95 (5.4)
Gender	
Men	97 (61.4)
Women	61 (38.6)
Ethnicity	
White British	98 (62.0)
White – Irish	1 (0.6)
Any other White Background	18 (11.4)
Mixed – White and Black African	2 (1.3)
Mixed – White and Asian	1 (0.6)
Mixed – Any other Mixed Background	4 (2.5)
Asian/Asian British – Indian	2 (1.3)
Asian/Asian British – Pakistani	2 (1.3)
Asian/Asian British – Bangladeshi	1 (0.6)
Asian/Asian British – Any other Asian Background	12 (7.6)

Black/Black British – African	1 (0.6)
Black/Black British – Any other Black Background	1 (0.6)
Other Ethnic Groups – Chinese	2 (1.3)
Other Ethnic Groups – Any other Ethnic Group	6 (3.8)
Not Stated	3 (1.9)
Not Known	4 (2.5)
Living Circumstances	
Alone	11 (7.0)
With Others	140 (88.6)
Missing	7 (4.4)
Mean IMD Scores (sd)	17650.03 (9942.6)
IMD Quintiles	
1 (Most Deprived)	24 (15.2)
2	29 (18.4)
3	32 (20.3)
4	25 (15.8)
5 (Least Deprived)	45 (28.5)
Missing	3 (1.9)
Urbanicity	
Rural	39 (24.7)
Urban	116 (73.4)
Missing	3 (1.9)

Employment Status	
Employed	58 (36.7)
Student	49 (31.0)
Unemployed	51 (32.3)
Median Duration of PtC (range) days	12 (0-312)
Median Number of PtC (range)	2 (1-28)
Mode of Contact	
GP	9 (5.7)
Primary Care Mental Health Service	32 (20.2)
Psychological Wellbeing Service (IAPT)	6 (3.8)
Child and Adolescent Mental Health Service (CAMHS)	6 (3.8)
Child and Adolescent Substance Use Service	1 (0.6)
Community Mental Health Team (CMHT)	7 (4.4)
Perinatal Services	1 (0.6)
Out of Area EIP	14 (8.9)
First Response Service (FRS)	15 (9.5)
Crisis Team	13 (8.2)
Liaison Psychiatry Service	2 (1.3)
Acute Admissions Unit (AAU)	1 (0.6)
Inpatient (Informal)	8 (5.1)
Inpatient (Detained)	22 (13.9)
Self	9 (5.7)
Family	6 (3.8)

College/University Mental Health Worker/	2 (1.3)
Charitable Organisations	4 (2.5)
Detained under MHA	
Yes	28 (17.7)
No	130 (82.3)
Family/Friend Involvement	
Yes	103 (65.2)
No	55 (34.8)
Police Involvement	
Yes	34 (21.5)
No	124 (78.5)

Abbreviations: SD = Standard Deviation, PtC = Pathways to Care, MHA = Mental Health Act, IMD = Index of Multiple Deprivation

Supplementary Table 2.

Characteristics of all patients accepted to EIP (14-65 years old)

	N = 208 (%)
Diagnosis	
ARMS	69 (33.2)
FEP	139 (66.8)
Mean age (sd) years	29.28 (11.2)
Gender	
Men	118 (56.7)
Women	90 (43.3)
Ethnicity	
White British	123 (59.1)
White – Irish	1 (0.5)
Any other White Background	26 (12.5)
Mixed – White and Black African	2 (1.0)
Mixed – White and Asian	2 (1.0)
Mixed – Any other Mixed Background	5 (2.4)
Asian/Asian British – Indian	4 (1.9)
Asian/Asian British – Pakistani	4 (1.9)
Asian/Asian British – Bangladeshi	1 (0.5)
Asian/Asian British – Any other Asian Background	13 (6.3)
Black/Black British – Caribbean	1 (0.5)
Black/Black British – African	1 (0.5)

Black/Black British – Any other Black Background	4 (1.9)
Other Ethnic Groups – Chinese	5 (2.4)
Other Ethnic Groups – Any other Ethnic Group	7 (3.4)
Not Stated	4 (1.9)
Not Known	5 (2.4)
Living Circumstances	
Alone	27 (13.0)
With Others	174 (83.6)
Missing	7 (3.4)
Mean IMD Scores (sd)	18193.39 (9597.2)
IMD Quintiles	
1 (Most Deprived)	32 (15.4)
2	33 (15.9)
3	42 (20.2)
4	39 (18.8)
5 (Least Deprived)	58 (27.9)
Missing	4 (1.9)
Urbanicity	
Rural	52 (25.0)
Urban	152 (73.1)
Missing	4 (1.9)
Employment Status	
Employed	81 (38.9)

Student	50 (24.0)
Unemployed	77 (37.0)
Median Duration of PtC (range) days	13 (0-312)
Median Number of PtC (range)	2 (1-28)
Mode of Contact	
GP	12 (5.8)
Primary Care Mental Health Service	38 (18.3)
Psychological Wellbeing Service (IAPT)	7 (3.4)
Child and Adolescent Mental Health Service	6 (2.9)
(CAMHS)	1 (0.5)
Child and Adolescent Substance Use Service	12 (5.8)
Community Mental Health Team (CMHT)	1 (0.5)
Perinatal Services	15 (7.2)
Out of Area EIP	21 (10.1)
First Response Service (FRS)	15 (7.2)
Crisis Team	5 (2.4)
Liaison Psychiatry Service	3 (1.4)
Acute Admissions Unit (AAU)	15 (7.2)
Inpatient (Informal)	34 (16.3)
Inpatient (Detained)	11 (5.3)
Self	6 (2.9)
Family	2 (1.0)
College/University Mental Health Worker/	4 (1.9)

Charitable Organisations	
Detained under MHA	
Yes	41 (19.7)
No	167 (80.3)
Family/Friend Involvement	
Yes	138 (66.3)
No	70 (33.7)
Police Involvement	
Yes	48 (23.1)
No	160 (76.9)

Abbreviations: SD = Standard Deviation, PtC = Pathways to Care, MHA = Mental Health Act, IMD = Index of Multiple Deprivation