Mixed methods exploration of how people who have experienced psychosis develop a social identity as a ‘person in recovery’

Emilia Deakin

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Abstract

Introduction

Personal Recovery involves the development of new meaning and purpose in one’s life as a person grows beyond the effects of mental illness. A key recovery process is redefining and rebuilding a positive sense of identity. The Social Identity Approach provides a theoretical framework for understanding identity changes in recovery. The overall aim of the thesis was to develop a model of social identity change in recovery from psychosis.

The original thesis aims (Unfold 1) were to assess digital data collection methods to evaluate prospective assessment of identity change and to characterise the processes involved in developing an identity as a ‘person in recovery’ with particular attention to social identity and sense of wellbeing. The Unfold 1 study was closed at the recruitment stage due to the impact of COVID-19 on health research.

The Unfold 2 study was designed in accordance with NIHR guidance for reopening research studies during the pandemic. The aims were to characterise the processes involved in developing an identity as a ‘person in recovery’ for people with experience of psychosis who are in the Rebuilding and Growth recovery stages. The study had three research objectives: 1) to explore the role of social identity change processes in recovery from psychosis; 2) to investigate the relationship between social identity change, wellbeing and recovery; and 3) to develop a theory of social identity change in recovery from psychosis.

Methods

Unfold 1 and 2 were mixed methods studies with convergent designs. They were informed by the philosophy of pragmatism. Unfold 1 was planned as a 19-month prospective longitudinal study and also included a systematic review of experience sampling methods (ESM) used in psychosis. An ESM study was then designed based on the resulting typology of design choices used in ESM studies. Participants used the RADAR-base app installed on their Android smartphone which prompted them to answer questionnaires several times a day about their social contact and level of wellbeing. Social identity was measured using the social identity mapping tool (SIM-tool). Some participants were expected to participate in semi-structured interviews regarding experiences of social identity change over the previous nine months and their experience of using the RADAR-base app.

The Unfold 2 study was a retrospective study, with two distinct interactive phases. First, quantitative data were collected about social groups using the online social identity mapping (OSIM) tool. Second, semi-structured interviews were conducted about experiences of social identity change and recovery.

Quantitative data were analysed using the Wilcoxon signed-rank test to measure group differences and a Spearman's rank correlation coefficient to measure relationships between groups, wellbeing and recovery. Interview transcripts were analysed using Reflexive Thematic Analysis. Qualitative and quantitative results were integrated using a joint display table to develop the Unfold Model of Social Identity Change in Recovery from Psychosis.

Results

In Unfold 1, the systematic review resulted in a typology of design choices used in ESM studies. The typology comprised three superordinate categories of design choice: Study context, ESM approach and ESM implementation. Design decisions found to predict data completeness include type of ESM protocol used, length of time participants are enrolled in the study, and if there is contact with the research team during data collection. The Unfold 1 study was paused due to COVID-19 after 13 participants had been recruited, however no interviews were conducted.

In Unfold 2, qualitative analysis of responses from 36 participants identified three themes: 1) ‘Illness identity is incompatible with positive social identity’, 2) ‘Illness identity becomes less salient’ and 3) ‘Positive social identity’. Quantitative results from 50 participants showed that, as they recovered, the number of social groups increased by 1.20 groups. Increases in the levels of positivity (0.86 out of 5) and social support (0.27 out of 5) were identified. The results also showed that participants were more likely to report higher levels of wellbeing if they had increased their number of social identity groups ($\rho=0.316$, $p=0.023$). Integration of the findings resulted in the Unfold Model, which illustrates processes of social identity change during recovery from psychosis. Key components of the model are that it builds on previous literature by describing the consequences of not maintaining multiple social identity group memberships during a significant life change. It also illustrates the specific processes involved in gaining new social identity groups.

Discussion

This is the first study to used mixed methods to explore the processes involved in developing a social identity as a ‘person in recovery’ from psychosis.

This thesis produced five knowledge contributions. First, the typology of design choices used in ESM studies and predictors of data completeness. Second, identification of experiences of social identity change in recovery relating to illness identity being incompatible with positive social identity, illness identity becoming less salient and positive social identity. Third, identification of total number of social identity groups, group positivity and group supportiveness as measurable aspects of social identity change in recovery from psychosis. Fourth, identification of the relationship between social identity change, wellbeing and recovery. Finally, the Unfold Model of Social Identity Change in Recovery from Psychosis was produced.

The typology fills a knowledge gap related to design decisions for ESM studies recruiting people with psychosis. The classification of design choices provides knowledge and guidance for researchers designing future ESM studies. Identification of design decisions which predict data completeness will enable researchers to make informed design decisions to maximise opportunities for data completeness.

The Unfold Model of Social Identity Change in Psychosis can be used to characterise and further investigate social identity processes involved in recovery in psychosis. The Unfold Model can be used to inform clinical decisions when treating people with psychosis. This may include informing criteria for service entry or assessment processes for group interventions.

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List of abbreviations

ANOVA	Analysis of variance
App	Smartphone application
COVID-19	Coronavirus disease 2019
CRN	Clinical Research Network
DAT	Data abstraction table
DSM-5	Diagnostic and statistical manual of mental Disorders, fifth edition
Ehealth	Electronic health. The use of information communication technologies (ICT) in support of health
ESM	Experience sampling methods
GDPR	General Data Protection Regulation
GPS	Global positioning systems
ICF	Informed Consent Form
ICT	Information and communication technologies
MCA	Mental Capacity Act
MeSH	Medical Subject Headings
MHealth	Mobile health
MMR	Mixed methods research
NIHR	National Institute for Health and Care Research
NHFT	Nottinghamshire Healthcare NHS Foundation Trust
NHS	National Health Service
OSIM	Online Social Identity Mapping tool
OT	Occupational Therapist
PHC	Personalised Healthcare
PHQ-8	Eight-item Patient Health Questionnaire
PI	Personal Informatics
PIS	Participant information sheet

PPI	Patient and public involvement
PROSPERO	International prospective register of systematic reviews
PWB	Psychological wellbeing
RADAR-base	Remote assessment of disease and relapse, software platform for data collection
REC	Research ethics committee
RTA	Reflexive thematic analysis
SCT	Self-Categorisation Theory
SEPRS	Self-Efficacy for Personal Recovery Scale
SIM	Social identity map
SIAH	Social identity approach to health
SIM-tool	Social identity mapping tool
SIMIC	Social identity model of identity change
SISR	Single item stages of recovery
SIT	Social identity theory
SIA	Social identity approach
SMS	Short message/messaging service
SWEMWBS	Short Warwick–Edinburgh Mental Wellbeing Scale
TA	Thematic analysis
TTM	Transtheoretical model of change
UID	Unique identifier
WHO	World Health Organization

Publication and dissemination

Publications

Deakin, E., Ng, F., Young, E., Thorpe, N., Newby, C., Coupland, C., Craven, M. and Slade, M. (2022) Design decisions and data completeness for experience sampling methods used in psychosis: systematic review. BMC Psychiatry, 22(1), 1-18.

Presentations

Deakin E (2022) How is data completeness influenced by the design of experience sampling studies? Institute of Mental Health annual research day, Nottingham, May 18.

Deakin E, Slade M, Craven M, Coupland C (2019) Digital approaches to data collection in people recovering from psychosis, 13th ENMESH Conference, Lisbon, June 6-8.

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Posters

Deakin E, Ng F, Craven M, Slade M (2023) development of a model of social identity change in recovery from psychosis and potential applications to clinical intervention and assessment, Refocus on Recovery, Nottingham, September 6.

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Deakin E, Mendez Villalon A, Ng F, Craven M, Coupland C, Young E, Slade E (2019) Measures, scheduling and participant support, design decisions for an experience sampling study, MindTech symposium, London, December 6.

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Podcast

Deakin E (2022) How does group membership help psychosis recovery? The Clinical Research Podcast, NIHR Nottingham Biomedical Research Centre, August 9. https://anchor.fm/nottmresearch/episodes/How-does-group-membership-help-psychosis-recovery-e15llfh

Chapter 1: Introduction

This introductory chapter provides a brief overview of what will be covered in this thesis. The chapter describes the context and rationale for the research. The thesis structure and the author's contribution to the study are outlined.

1.1 Context

1.1.1 Identity

This thesis examines identity change in recovery from psychosis. What constitutes a change in a person's identity has been discussed since the origins of western philosophy (Barresi and Martin, 2011). Questions frequently posed by philosophers concern how an individual person can be identified, as well as what is considered sufficient and necessary for a past or future being to be the same as someone that exists in the present time (Olson, 2022).

Philosophers have posited different theories about what criteria need to remain in order for identity to remain unchanged rather than someone being considered a different person (Noonan, 2003). Advocates of the psychological continuity view suggest that identity persistence consists of a type of psychological relation (Schechtman, 1994). According to this view, individuals in the future time inherit their mental features from an individual at the current or previous time, ensuring the same person exists at different time points.

Psychological theorists have developed different theories specifying what kinds of psychological features are essential in order for identity continuity to occur (Nichols and Bruno, 2013). Theories of psychological identity include narrative identity, trait theory and social identity theory (SIT). Each theory posits different criteria for how an individual person is identified and also what is sufficient and necessary for identity continuity. These theories are described in detail in Section 3.2.

SIT will be used to inform the thesis. SIT defines social identity as the sense of self a person gains from viewing themselves as a member of social groups (Turner et al., 1987). Social identity is an individual's knowledge that they belong to certain social groups, coupled with the emotional and value significance they experience from group membership (Tajfel, 1978a). Each group membership is represented in the mind of an individual as a social identity (Hogg, Terry and White, 1995). Social identities are fluid, and how individuals express their social identity is variable (Ethier and Deaux, 1994) and changes depending on the environment (Bentley et al., 2020). A detailed description of SIT is provided in Section 3.2.3.

1.1.2 Recovery

Two broad conceptualisations of recovery have emerged: clinical recovery and personal recovery. Clinical recovery has emerged from professional-led research (Slade, 2009). It is observable and rated by clinicians not patients, and the definition does not vary between individuals (Slade and Wallace, 2017). Clinical recovery is often measured in terms of symptomatology. It is seen as improvement in health outcomes such as remission in symptoms and maintaining basic functioning (Liberman and Kopelowicz, 2002).

Personal recovery has emerged from narratives of individuals who have experienced mental illness and used mental health services (Slade, Amering and Oades, 2008). It involves the development of new meaning and purpose in one's life as a person grows beyond the catastrophic effects of mental illness. Recovery is described as a deeply personal, unique process of changing one's values, attitudes, goals, skills, roles and feelings in order to live a satisfying and contributing life (Anthony, 1993). Personal recovery has been described as the subjective process of taking control of one's illness and one's life, taking personal responsibility for one's own recovery and having optimism for the future (Roberts and Wolfson, 2004). A systematic review of recovery in mental illness has been undertaken. The resulting CHIME framework (connectedness, hope, identity, meaningfulness and empowerment) identifies redefining and rebuilding a positive sense of identity as a key recovery process (Leamy et al., 2011). Personal recovery is the conceptualisation of recovery that will be used throughout the thesis.

A criticism of personal recovery is that it does not consider the social context in which the individual is situated (Onken et al., 2007). Much of the recovery literature has focused on individualistic understandings of recovery (Wyder et al., 2022). Recovery processes are often described as occurring in isolation, when recovery should be viewed as a dynamic and interactional process between a person and their environment (Price-Robertson et al., 2017).

It has been suggested that Anthony's definition of recovery endorses the clinical recovery model by framing recovery as a problem of the individual and that inviting people with mental illness to take personal responsibility for their own health and wellbeing places responsibility entirely on the individual (Harper & Speed, 2012). Anthony's definition of recovery is criticised by the authors who suggest his definition is dependent on an individual accepting themselves as a person with an illness. This places the emphasis on the individual who must therefore change their values, attitudes, goals, skills, roles and feelings in order to effect positive changes in their own life.

In recent years, the social aspects of recovery have received more attention (Fowler et al., 2019). A Delphi study has found that people with experience of psychosis find environmental factors such as social support to be among the most important facilitators of personal recovery (Law and Morrison, 2014). Topor and colleagues (2011) describe the importance of the contributions of others to a person's recovery, including responsive mental health services and supportive relationships. The authors describe how 'Social recovery' broadens the individualist perspective on recovery by recognising the importance of the social environment and society in the process of individual recovery. They describe the importance of the contributions of others, including responsive mental health services and supportive relationships. The authors conclude that an individual’s inclusion in community life can be facilitated or impeded by various social influences including the contributions of others.

A systematic review and qualitative meta-syntheses has generated a proposed framework for recovery (Dell et al., 2021). The framework defines recovery as a transformation from a negative identity state to a positive state of psychological wellbeing. The authors describe how transformation is contingent upon four conditions including social and environmental conditions. The authors conclude that professionals working in recovery-oriented systems must consider how the objective social relationships as well as subjective self-representations of persons with mental illness interact to impact recovery outcomes.

Recent literature suggests that research needs to focus on improving understanding of the processes involved in recovery (Hampson et al., 2019), about which empirical evidence is lacking (Cruwys et al., 2020). Operationalising recovery as a process, rather than a transition from poor health to good health may provide a clearer view of the barriers to recovery and also how to ensure better health states can be maintained over time (Jatta et al., 2022). The emphasis of this thesis on changes to social aspects of identity is intended to address this issue.

1.1.3 Psychosis

Psychosis is defined as a cluster of major psychiatric disorders in which a person’s perception, behaviour, mood and thoughts are significantly altered (NICE, 2014). People experiencing psychosis may find it difficult to distinguish between what is real and what is not (Arciniegas, 2015). Symptoms include delusions, hallucinations, disorganised or catatonic behaviour and disorganised speech (American Psychiatric Association, 2013) as well as ‘negative symptoms’ such as decreased motivation, reduced speech, lack of interest and spontaneity, and the inability to feel pleasure (Lyne et al., 2018).

Psychosis may be caused by a psychiatric disorder such as schizophrenia (WHO, 2022) or mood disorder (American Psychiatric Association, 2022) a medical illness (Cardinal, 2011) or trauma (Gibson et al., 2016). The WHO estimates the prevalence of psychosis to be three in every 100 people (WHO, 2022).

NICE guidelines recommend rapid assessment and treatment when someone presents to mental health services with a possible psychotic illness (NICE, 2020). Treatment usually involves antipsychotic medication, talking therapies such as CBT and social support (NHS, 2022). Some novel treatments for psychosis are also in development including virtual reality therapy (Meins et al., 2023) and therapeutic use of cannabidiol (CBD)(Chesney et al., 2021). The WHO estimates however that only 29% of people who experience psychosis symptoms will access mental health services (2022). The WHO also emphasises the importance of social support for people with psychosis including support to develop and maintain personal, family, and social relationships.

Social disability is a feature of psychosis (American Psychiatric Association, 2013). Social disability related to psychosis can manifest in impaired social functioning including social withdrawal, social avoidance and inability to participate in desired social activities (Addington et al., 2003) and occupational challenges including difficulties with employment, self-care and relationships (Hitch et al., 2013).

People who experience psychosis are reported to be one of the most stigmatised groups in society, they are subject to negative public perceptions, including negative stereotyping (Wood et al., 2014). Stigma has been found to be associated with reduced levels of wellbeing in those with experience of psychosis (Eliasson et al., 2021).

Experiencing psychosis can also be associated with changes in the way people view themselves, both as individuals and in relation to others (Conneely et al., 2021). Individuals with psychosis face profound challenges as they attempt to maintain a positive identity through the course of illness (Cowan et al., 2021). The applicability of dominant models of identity to people who have experienced psychosis has been questioned (Gergel and Iacoponi, 2017). Literature has also suggested that people with psychosis have lost their sense of self (Roe and Davidson, 2005) and focus on the all-encompassing nature of illness identity (Estroff, 1989). A detailed understanding of how identity changes in people experiencing psychosis is therefore needed.

1.1.4 Policy and clinical practice

The need for mental health services to provide high quality recovery-oriented mental health services has been identified as an international (World Health Organization, 2021) and national priority (Department of Health, 2011). Recommendations include person-centred services in which care is based on individual perspectives and priorities (World Health Organization, 2022). Although the importance of building a positive sense of identity has been identified as a key process in recovery, identity change currently receives little attention in treatment, possibly due to a lack of clarity or consensus about what identity change in people living with psychosis consists of (Conneely et al., 2021).

1.1.5 Personal motivation

The thesis author is an Occupational Therapist (OT) who has worked with people with experience of psychosis in a number of different roles. She has been drawn to roles which focus on the use of group interventions to encourage social inclusion. The focus in this thesis on social identity groups builds on the author's interest in how groups and social processes can influence recovery. An interest in how people can be supported to leave behind their illness identity and to live a life beyond mental health services was also a motivation.

1.1.6 Summary

Redefining and rebuilding a positive sense of identity has been identified as a key process in personal recovery from psychosis. Despite this, little is known about what identity change is, or how identity change occurs in personal recovery. This thesis uses SIT to explain identity change in recovery and to develop a model of social identity change in recovery from psychosis. SIT conceptualises each individual within their own set of social group memberships (Hogg et al., 1995). This situates recovery and identity change within each individual's social environment. The resulting model could help inform clinical practice and lead to the development of novel interventions to support identity change processes.

1.2 Thesis structure

1.2.1 COVID-19 implications

The Unfold study design, implementation and thesis structure have been significantly affected by the COVID-19 pandemic and associated social distancing restrictions. The original Unfold study (Unfold 1) was closed by the study sponsors at the beginning of the first national lockdown in March 2020. It was not possible to reopen Unfold 1 its original form as the pause in recruitment meant that it no longer fitted into PhD timelines. There were also issues concerning data validity due to social distancing restrictions, and participant and researcher safety. This is discussed in detail in chapter 7.

The study was redesigned and reopened (the newly designed study is hereafter referred to Unfold 2). The Unfold 2 study design was informed by NIHR guidance for reopening a study during the pandemic (NIHR, 2020). This ensured Unfold 2 was viable, safe and within available NHS capacity. The thesis aims and objectives were modified to ensure that the study could open without being affected by ongoing social distancing restrictions.

1.2.2 Study aims

The thesis presents the design and results of Unfold 1. This is followed by the Unfold 2 methods and results.

Unfold 1 aims

Aim 1 (Methods): To assess digital data collection methods to evaluate prospective assessment of identity change.

The objectives relating to Aim 1 were:

Objective 1.1: To use active and passive approaches to data collection and make recommendations for use in future research.

Aim 2 (Identity): To characterise the processes involved in developing an identity as a ‘person in recovery’ with particular attention to social identity and sense of wellbeing.

The objectives relating to Aim 2 were:

Objective 2.1 (Change processes) To explore the role of social identity change processes in recovery from psychosis.

Objective 2.2 (Identity and wellbeing) To investigate the relationship between social identity change and eudaimonic wellbeing

Unfold 2 aim

To characterise the processes involved in developing an identity as a ‘person in recovery’ for people with experience of psychosis who are in the Rebuilding and Growth recovery stages.

Unfold 2 objectives

1. (Change processes) To explore the role of social identity change processes in recovery from psychosis

2. (Relationships) To investigate the relationships between social identity change, wellbeing and recovery

3.(Change theory) To develop a theory of social identity change in recovery from psychosis

1.2.3 Organisation of the thesis

This thesis is comprised of ten chapters. These are summarised as follows.

Chapter 1 introduces the thesis and situates the work within the existing policy and research context.

Chapter 2 presents a narrative review of digital approaches to measurement considered for use in data collection. The review identifies criteria considered in selecting digital technologies. A narrative review was then carried out to identify the main classes of digital technology used for data collection in mental health. Each class of digital technology was then appraised in relation to the identified criteria. The RADAR-base app was then selected for use in Unfold 1.

Chapter 3 outlines different philosophical and psychological conceptions of identity. The chapter describes the decision to use the social identity approach for the thesis. SIT is described in detail as the theory of identity used in this thesis. The relationship between social identity, health and wellbeing is described.

Chapter 4 describes the systematic review of experience sampling (ESM) methods used in psychosis. The two aims of the review were to develop a typology of design choices used in digital ESM studies and to synthesise evidence relating data completeness to different ESM design choices. The results of the review are discussed in relation to how the findings inform the data collection methods for Unfold 1.

Chapter 5 describes the philosophy of pragmatism as the underpinning epistemology of the thesis. Pragmatism is discussed in its relation to mixed methods studies. The decision to adopt a mixed methods design is discussed, as is using pragmatism to allow the effective integration of qualitative and qualitative data.

Chapter 6 describes the methods used for Unfold 1. The study design, methods and the procedures for data analysis are described.

Chapter 7 presents the findings from the Unfold 1 study until the point when it was closed prematurely due to COVID-19. The reasons why the study design was no longer feasible are detailed. The modifications needed in order for the study to reopen are discussed in line with NIHR guidance.

Chapter 8 describes the methods used in the Unfold 2 study. A rationale is presented for the use of stage models as a framework for understanding identity change. The aims of the Unfold 2 study are then presented. The design of the Unfold 2 study is described, incorporating amendments described in Chapter 7.

Chapter 9 presents the results of the Unfold 2 study. It describes the participant demographics and standardised measures. Qualitative results and quantitative results are described individually before being integrated using the pillar integration technique.

Chapter 10 gives a discussion of Unfold 2 followed by a broader discussion of the results of the thesis as a whole and how they relate to wider literature. The main knowledge contributions are discussed in relation to the thesis objectives and the overall strengths and limitations of the thesis are outlined. The research and clinical implications are outlined.

1.3 Student contribution

The thesis author had primary responsibility for the design and implementation of Unfold 1 and Unfold 2. These studies were conducted with regular input from the supervisory team.

Chapter 2: Digital approaches to data collection: Narrative review

This chapter presents a narrative review conducted to appraise existing digital technology, which was used as an approach to collecting data in Unfold 1. Digital technologies are introduced in relation to Mobile and Wearable health (Section 2.1) and were then considered in relation to the level of data capture (Section 2.2), data use (Section 2.3) and the range of digital data collection methods (Section 2.4). The RADAR-base app was then selected for use in Unfold 1.

Objectives

A narrative review is a scholarly summary along with interpretation and critique (MacLure, 2005). The aim of a narrative review is "an authoritative argument, based on informed wisdom that is convincing to an audience of fellow experts" (Greenhalgh et al, 2018, p.e12931). The review was conducted in order to appraise existing digital technology use as an approach to collecting data about the daily life of people living with psychosis.

The objectives were:

Objective 1: (Technology selection) identify criteria to consider in selecting digital technologies for data collection

Objective 2: (Technology identification) identify the main classes of digital technology which have been used for data collection in mental health

Objective 3: (Technology appraisal) appraise each class of digital technology in relation to the identified criteria and select technology to use in the Unfold1 study

The field is new, fast-moving and with little consensus, making an overview difficult. To organise this complexity, three characteristics of data collection are identified: level of data capture, usage and methods.

Level of data capture refers to the comprehensiveness of data captured.

Usage is defined as whether data collection is intended primarily for personal use versus primarily for use by others.

Methods refers to the range of digital data collection methods and their use in health.

2.1 Mobile and Wearable Health

Digital health interventions illustrate the range of technologies used for data collection. Examples of digital health interventions are Mobile health (Mhealth) and Wearable Health (Wearables). Mhealth and Wearables are categories of the overarching domain of Ehealth which is the use of information communication technologies (ICT) in support of health and health related fields, including health-care services, health surveillance, and health research (United Nations, 2016) . Mhealth has been defined as the provision of health services and information via mobile and wireless technologies (K4Health, 2017). MHealth technologies utilise functionalities of mobile devices such as short messaging service (SMS), global positioning systems (GPS), and smartphone applications (Apps) (Gire et al., 2017). The term Wearable refers to electronic technologies or computers that can be worn on the body in the form of clothing or accessories (Tehrani and Michael, 2014). Wearables often have accompanying Apps and are used in conjunction with smartphones (Naslund et al., 2015).

Mhealth and Wearables are used in a variety of different health interventions (Gire et al., 2017) and include self-management (Ben-Zeev et al., 2015) and personal health tracking (World Health Organization, 2018). In health research, a personal health tracker can either be used as an intervention to be applied across a cohort or as an instrument to measure activity (Rooksby et al., 2014). It is the use of digital technologies for measuring activities in real time that will be appraised in this review.

2.1.2 Personal health tracking

Personal health tracking has seen a significant rise in popularity with the rise in availability of self-tracking tools (Sharon, 2017). The market for health Apps has been valued at USD 1.1 billion (£909,830,900.00) in 2021 and is expected to expand by 17.6% from 2022 to 2030 (Grand View Research, 2021).

Self-tracking devices indicate a future in which individuals will become more involved in the management of their own health (Sharon, 2017). New healthcare models are emerging to extend and supplement traditional healthcare models and empower patient self-care (Swan, 2009). Personal health tracking is expected to play a key role in the move toward Personalised Healthcare (PHC) (Flores, 2013). PHC is a model of targeted, preventive, and participatory healthcare. One PHC model describes the different ways in which a person may be active in their own health care (Swan, 2009). These include involvement in treatment, research, tracking and measuring. Health outcomes of the model include normalisation, self-expression and improvement as well as cure. Self-tracking is directed at aspects of life other than health (Lupton, 2013). This allows a much more complex and complete picture than if data were only collected at regular intervals (Sharon, 2017). The PHC model is in keeping with the WHO principles. The WHO constitution defines health as “a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity” (WHO, 1946, p.1).

PHC extends the temporal nature of health surveillance (Lupton, 2012) as technology offers an unprecedented opportunity to monitor and measure individuals (Swan, 2009). One of the biggest benefits is that tracking makes it possible to collect individuals’ data continuously (Sharon 2017). Personal health tracking has been described as the contemporary end of a long line of monitoring and recording (Lupton, 2012), however personal health tracking is done by the patient and for the patient. It is carried out continuously rather than at regular intervals when a patient attends a clinic. Health information is generated that also benefits clinical decision making and research (Sharon and Zandbergen, 2017).

PHC is an NHS priority. The NHS aims for an increase in prevention, with patients taking greater responsibility for their own care (NHS, 2014). The NHS also aims to make better use of digital technology and data (NHS, 2019). NHS Digital, the Information Technology partner of health and social care systems, is tasked with delivering PHC related targets. One aim of NHS digital is to empower the public to make informed choices about how they can manage their own health and care. The NHS aims to change the way digital technology is used is in the areas of patient engagement, self-care and prevention (Honeyman et al., 2016). One recommendation is the use of Wearable technologies and Apps that allow people to manage their own health.
Use of such technologies will also allow clinicians to monitor patients' health remotely, which will benefit clinical decision making and research (Sharon, 2017).

Personal health tracking in psychosis

A meta-analysis of cross sectional studies has investigated endorsement of Mhealth among people with psychosis (Firth et al., 2015). The study concluded that there is a broad scope of clinical applications of Mhealth for this client group. The most popular application among participants was health tracking or monitoring of symptoms in real time. The authors note that ability to use health tracking Apps in order to gain real time feedback may be one of the features that has led to their popularity among people with psychosis.

In a review of Mhealth and Ehealth interventions in serious mental illness, interventions were arranged into four categories: relapse prevention and illness self-management; promoting adherence to treatment and/or medications; psychoeducation and supporting health; and symptom monitoring (Naslund et al., 2015). Of 13 studies that met inclusion criteria, seven interventions used smartphones, and many relied on automatic prompting for participants to provide reports on their symptoms at specific times per day. One smartphone App continuously collected data on movement, location, physical activity and social interactions in combination with prompts for participants to answer questions (Grünerbl et al., 2012). Largely, the studies were conducted to test feasibility and acceptability which was shown to be consistently strong across all studies (Naslund et al., 2015) .

Implications for Unfold 1

The Unfold 1 study adopted PHC focused constructs. Technology was not used to measure symptomatology.

Technology used in PHC was used for data collection in Unfold 1. Use of digital technology in health monitoring is common. This implied digital technology could have high levels of acceptability when used in data collection.

Digital technology use was defined as empowering in a PHC context. The process of data collection and the collected data are both intended for the patient. When the same technology is used for research, questions will be raised concerning whether technology use is empowering in this context.

2.2 Level of data capture

The World Health Organization (WHO) have identified two monitoring methods in personal health tracking: self-monitoring and active data capture (2018). Self-monitoring includes sensors and Wearables and describes the collection of a clients' health data via a device operated by the client. Examples of this are Wearables and fitness trackers such as the Fitbit (Fitbit, 2018). Use of a Fitbit results in the collection of passive data (Barnett et al., 2018) using built-in sensors. Active data capture involves the user carrying out a particular action (Barnett et al., 2018). An example of this used by the World Health Organization is the App CycleTel, which is a family planning App intended to be used by women. The App informs the user of her fertile days after she enters dates relating to her menstrual cycle (K4Health, 2017).

The level of activity required by the user in the data collection process has implications for the comprehensiveness of data captured. The makers of Fitbit state that the device tracks “every part of someone’s day” (Fitbit, 2018). In order for the device to be used to its full data collection potential, however, both active and passive data collection is required. Different facets of a person’s life (Li et al., 2010) including activity, exercise, and sleep can be monitored passively. Some facets such as food intake require the wearer to input information actively via the App (Fitbit, 2018).

Level of active data capture can also have implications for whether a device can be used effectively. If the user of CycleTel does not enter the relevant data then the device will be unable to accurately predict her fertile days (K4Health, 2017). If the wearer of a Fitbit does not actively enter data, then the device can still be used to collect passive data. This will however result in a reduction in the number of facets on which data is captured (Li et al., 2010).

2.1.2 Lifelogging

Beyond the field of healthcare, non-traditional sources of biomedical data can be collected. Examples include data on environment or lifestyle (Sharon, 2017). A practice which involves personal data collection through digital technologies is lifelogging. Although there is no universal definition, lifelogging is the process of carrying out different types of digital self-tracking and recording of everyday life (Selke, 2016b). Although monitoring health is one facet of lifelogging, it has also been used as an aid to memory and for location tracking (Selke, 2016a).

One lifelogging concept is ‘total capture’, where the lifelogger collects as many kinds of data as possible to achieve a complete record of everyday life (Sellen and Whittaker, 2010). The concept has emerged from a desire to create an outsourced human memory and to collect a comprehensive archive (Gemmell et al., 2002). A small number of lifeloggers have sought to achieve this. One such person is Gordon

Bell. From 1998 until 2007, Bell was the leader and prime subject of a Microsoft research experiment called MyLifeBits (Gemmell et al., 2006) lifelogging every aspect of his life, including temperature and heart rate. Inspiration for the MyLifeBits project has come from Memex (Gemmell et al., 2006).The Memex was an all-inclusive personal information system designed in 1945 in which an individual could store their books, records and communications. Although never actually built, the system was designed to be built into a desk and mechanised for speed and flexibility. Bell began lifelogging using his PC and described how the process evolved with technological advances, including Global Positioning System (GPS) trackers and wearable cameras (Bell, 2014). A central feature of lifelogging is that data are collected and stored for use by the participant. Reflecting on current and future uses of lifelogging data, Gordon Bell states that it is the lifeloggers themselves who should benefit from the logging and not a third party (Bell, 2014).

Lifelogging has evolved with technological advancements so that passive data collection is now a central feature (Gemmell et al., 2004). Bell stated that he eventually gave up the lifelogging project with the inception of the smartphone which changed the landscape and made lifelogging almost implicit (Bell, 2016). This may refer to devices being routinely carried with a person and the accuracy of the sensors (World Health Organization, 2018). A feature of modern smartphones is that some on-board sensors are always active (Aranda-Jan et al., 2014), meaning that they are continuously available (Technopedia, 2018). Smartphones therefore have the capacity to collect some forms of data passively and continuously. A similar shift has been observed in data collection for health tracking where technological advances have caused a shift from active to passive data collection (Rooksby et al., 2014).

Another variant of lifelogging is selective capture. Selective capture includes blogging, digital photography (Sellen and Whittaker, 2010) or using social media (Karapanos et al., 2016) . These methods involve effortful capturing of a specific event at the discretion of the lifelogger.

Like personal health monitoring it involves active data capture (World Health Organization, 2018) but is not restricted to the domain of health (Selke, 2016b). Table 2.1 illustrates some examples of different lifelogging approaches.

Table 2.1 Categories of lifelogging approaches

	Total Capture	**Selective capture**
Effortful data collection	MyLifeBits Memex	Photography Blogging Social media
Passive data collection	Wearable camera Lifelogging Apps	Global Positioning Systems (GPS) monitoring Activity monitoring via Wearable

Use of lifelogging techniques in health research

Lifelogging techniques have been used to collect participant data in research studies. Studies illustrate varying levels of data capture, employing one or more type of data collection and involving passive or active involvement of the user. One ‘lightweight’ study, investigating lifelogging in senior citizens, captured only one type of passive data (Joho et al, p.9). The method involved asking participants to carry a smartphone with them for three weeks in order to collect data based on their location using GPS. In contrast, a study using active as well as passive methods of data capture recruited three students enrolled on a lifelogging course (Nagaoka et al., 2016). For passive data capture a wrist-band activity tracker and GPS location tracker were used. For active data capture participants also took a daily photograph of their choice as well as one of their receipts to log expenditure.

Implications for thesis

1 Passive data approaches were used for data collection. Active methods were also be used but they were carefully chosen so as not to be too burdensome for participants.

2 Smartphones were used in the collection of data for Unfold 1.

3 Total data capture is not possible. It would have caused a high level of burden and disruption to participants' lives. Unfold 1 was a naturalistic study which aims to capture participants' unchanged behaviour and methods of total capture would not allow this. Study design included a defined set of processes and outcome variables.

2.3 Data use

2.3.1 The Quantified self

The Quantified Self illustrates how data collected via digital technologies is used. Quantified Self refers to a class of practices that help people to collect and reflect on personal information (Choe et al., 2014). While there is a crossover between lifelogging and the Quantified Self, one way of distinguishing between them is that lifelogging is indiscriminate and aims at total capture (Sellen and Whittaker, 2010), whereas with the Quantified Self, understanding the collected data is a key goal (Gurrin et al., 2014). The Quantified Self encompasses health and wellbeing but also extends beyond, for example covering personal finance, personal communications and life photography (Rooksby et al., 2014).

The Quantified Self-movement was founded in 2007 by Gary Woolf and Kevin Kelly in San Francisco (Quantified Self Institute, 2016). The stated aim of self-tracking is to identify patterns that remain hidden when relying solely on human senses (Sharon and Zandbergen, 2017).

The stage model of personal informatics (Li et al., 2010) is the most commonly used model for understanding how people use digital technology to collect personal data (Epstein et al., 2015). The model has five stages and was designed to demonstrate 'a comprehensive list of problems that users experience' during the process of collecting and reflecting on personal information (Li et al., 2010).

Table 2.2 Stages of the Model of personal Informatics (Li et al. 2010)

Preparation stage	Users determine what information is required and how it will be recorded
Collection stage	Data collection
Integration stage	Users consider and interact with the information
Reflection stage	The user reflects on their personal information
Action stage	where people choose what to do with their new personal insights

The stage based model has been criticised for failing to take into account tracking that is done for reasons other than goal setting (Epstein et al., 2015). The model has been described as failing to consider the agency of the self-tracker and their motivations to self-track (Rooksby et al., 2014). The term 'lived informatics' has been coined to describe the way in which individuals build the practice into their everyday lives. It might be difficult to understand lived informatics if the way in which individuals build the practice into their everyday lives is ignored (Rooksby et al., 2014). Aside from goal driven tracking, which has been termed 'Directive tracking', other styles of personal tracking have been identified such as 'Documentary tracking'*;* where people are interested in documenting their activities, rather than changing them.

The Model of Lived Informatics describes the way in which individuals build self-tracking into their everyday lives (Rooksby et al., 2014). The model identifies three initial motivations for tracking:

- The desire to change behaviour
- For rewards or social engagement
- Curiosity regarding data and habits

The model describes a number of processes, which occur simultaneously alongside tracking. These include reflecting on the data, interpreting the data and Integrating findings from the data (Epstein et al., 2015). The model also describes how deciding to track, tool selection and lapsing often occur simultaneously and repeatedly as the self-tracker stops tracking and subsequently engages with different tools (Rooksby et al., 2014).

Using data from researcher-supplied technology contrasts with the lived informatics approach (Rooksby et al., 2014). When digital tools are used for data collection in research, the participant takes on one role, the role of tracker. In studies where technology has been supplied by researchers, it is often found that participants did not use technology as required, which affected technology use and impacted on the data set (Wilson et al., 2018). Studies which have allowed participants flexibility and choice in the use of technology have had more successful outcomes (Nagaoka et al., 2016).

2.3.2 The qualified self

Limitations with personal informatics have been identified. First it has been said to provide an externalist account of human beings; not valuing the self that produces behaviours but valuing the behaviours themselves (Rapp and Tirassa, 2017). Second, the idea that the truth about a person lies in numerical data has been described as inherently limiting (Lupton, 2013). Third, the ‘self’ has been said to be reduced to a set of behaviours or dates and numbers which has been called “algorithmic identity” (Sharon and Zandbergen, 2017).

The rhetoric of commercial self-tracking is orientated towards ‘Directive’ (goal driven) tracking despite lived informatics research demonstrating the diverse reasons a person may choose to self-track (Epstein et al., 2015). An example of this is on the homepage of the Fitbit website which reads ‘Know yourself to improve yourself’ (Fitbit, 2018). The next line on the page demonstrates that the ‘self’ that can be better understood through use of the Fitbit refers to a set of past behaviours including exercise, sleep and weight (Rapp and Tirassa, 2017). Similarly, using fertility Apps has been described as another method of learning about oneself (Lupton, 2015). Apps such as CycleTel however are inherently goal driven as their aim is to inform users of their fertile days (K4Health, 2017).

The lived informatics model has demonstrated how self-trackers continually reflect throughout the data collection process (Epstein et al., 2015). Self-trackers actively engage with their data, ascribing value and meaning to the data they generate (Sharon and Zandbergen, 2017). Throughout this process they move beyond quantitative data collection, integrating the data to create meaningful insights (Swan, 2013). An ethnographic study of self-trackers has shown one of the ways in which self-trackers attribute meaning to the practice of data gathering is by using self-tracking as a communicative and narrative practice (Sharon and Zandbergen, 2017). The Quantified Self therefore takes shape through qualification (Davis, 2013). This process has been termed the ‘qualified self’ (Swan, 2013). The numbers are interpreted and re-contextualised into a subjective narrative which becomes a process of identity construction (Sharon and Zandbergen, 2017).

In research using researcher supplied technology, qualitative data has been collected in addition to passive sensor data in order for data to be meaningful to researchers, and to enable them to convert it into information. In one study, researchers found it difficult to interpret wearable camera data collected by participants suffering chronic pain. They asked participants to annotate the data during playback of the camera data, which then enabled researchers to analyse the data successfully (Wilson et al., 2018).

2.3.3 Use of Personal Informatics in health research

Due to advancements in wearables and other digital technology (Li et al., 2010), the popularity in Personal Informatics (PI) is rising and now has a worldwide network of thousands (Rapp and Tirassa, 2017). The Quantified Self-tracker is simultaneously the participant, practitioner and beneficiary of the study (Swan, 2009). When PI tools are used in research the participant only takes on the one role of self-tracker. This has implications for data collection and management. Personal informatics tools have been used in research involving participants at different stages of the process (Li et al., 2010). One study involved participants at all stages from the ‘Collection stage’ to the ‘Action stage’. The study investigated lifelogging in students enrolled on a lifelogging class and aimed for the participants to reflect on their data in order to set quantifiable goals (Nagaoka et al., 2016). Participants changed the way in which they tracked and found ways to fit data collection around their lives as the study progressed. As studies of lived informatics have predicted, there were variations in the types of data collected from each participant due to each participant finding different tools useful and interesting.

Using data from researcher-supplied technology contrasts with the lived informatics approach (Rooksby et al., 2014). Lived informatics models illustrate how self-trackers use personal informatics tools in idiosyncratic ways in order to meet their own aims (Epstein et al., 2015). In another study PI tools have been supplied by researchers to be used by participants for data collection purposes only. Wearable cameras were used to explore day to day patterns of functioning for seven days in 13 adults over the age of 65 who had been living with persistent pain (Wilson et al., 2018). The cameras took pictures automatically every minute. Participants were not engaged in the selection of PI tools or intended to be involved in any reflective process (Li et al., 2010). Participants were required to wear the camera for seven days without the flexibility that the lifelogging students were allowed during the data collection stage (Nagaoka et al., 2016). Participants often removed the camera if it interfered with their daily activities, causing an incomplete data set (Wilson et al., 2018).

Studies have shown that in order to make sense of and to communicate their findings, self-trackers engage in a process of qualification of their quantifiable data (Swan, 2013). In research involving PI tools, qualitative data has been collected in addition to passive sensor data in order for it to be meaningful to researchers. Researchers using wearable cameras found data difficult to analyse without participant involvement due to the large amount of decontextualized visual data (Wilson et al., 2018). One solution the authors suggested was to record participant audio during playback of the data (Wilson et al., 2018). The analysis mirrors PI practices of using qualitative and quantitative data in order to make data meaningful.

Implications for thesis

1. It was made clear at the stage of recruitment that the data is to be used by the researcher. This was written clearly into the study description. This was to avoid confusion that may have arisen from utilising data collection methods where the data is usually for the use of the person collecting the data.
2. It was also made clear at the recruitment stage that technology needs to be used in the way described in participant information. The flexible way technology is often used by individuals was not appropriate for collecting data in a research context.
3. An end of participation meeting or interview with each participant took place. It focused on the qualification of data through interpretation and annotation by the participant. This was to assist the researcher converting collected data into information that can be used to meet study aims.
4. The study used participants’ own smartphones. Smartphone ownership and usage will be inclusion criteria for the study.
5. Interpretation of digital data generally takes place through qualification, so a qualitative arm of the study was necessary. This involved a sequential design whereby qualitative data collection follows quantitative data collection.

2.4 Methods

Smartphones will be used for active and passive data collection in the Unfold 1 study. This is due to high levels of feasibility and acceptability of smartphone use among participants with psychosis (Naslund et al., 2015). This is also because Unfold 1 was designed to collect naturalistic, observational data. If participants are regular smartphone users, they will not be required to alter their behaviour with the exception of when carrying out active data capture. Similarly, the option of providing participants with a smartphone was rejected because this is likely to change participant behaviour.

Participants' own smartphones will be used. The model of lived informatics demonstrates that digital technology is woven into individual's lives in a flexible way, often unique to each individual (Rooksby et al., 2014). Researcher-provided technology has been shown to be less effective at data collection in research studies. Smartphone ownership among people who have experienced psychosis has been shown to be similar to that of the general population (Firth et al., 2015) which was 78% of UK adults in (OFCOM, 2018). Use of personal devices also has the potential to be less noticeable and therefore less stigmatising than researcher-provided technology.

2.4.1 Platform requirements

After appraising digital technology, the following criteria have been identified:

- Compatible with smartphones
- Capacity to collect active as well as passive data
- Real time data capture
- 'Always on'
- Runs in the phone background allowing usual device usage to continue

Table 2.3 describes some platforms that meet the criteria and appraises them in more detail.

2.4.2 Platform appraisal

Table 2.3 Potential technology platforms for data collection in Unfold 1

Platform	**Description**	**Strengths**	**Weaknesses**
Hub of All Things (HAT)	The Hub of All Things (HAT) is designed to help the trade and exchange of personal data. HATs are private data accounts that let individuals store their own data for personal use. HAT potentially provides a mechanism for collecting and processing data. For Unfold 1 each participant could have an individual micro server on which their data could be stored (Hub of All Things, 2019). The researcher piloted the HAT on her own smartphone to assess suitability for Unfold 1.	Easy to install Compatible with Android and iOS operating systems. Enables passive monitoring Data collected from Facebook, Twitter, Fitbit and GPS.	No capacity for active data capture Data owned by participant Data can be viewed by each participant. This may cause a change in participant behaviour which is not desired for a naturalistic observational study. When piloted by the researcher, the App required a high amount of phone memory.
Purple Robot	A sensor data acquisition platform for collecting information about the user and their immediate surroundings in real time (Schueller et al., 2014).	The platform has been used successfully in health research with people with psychosis (Kerz et al., 2016).	Requires additional coding which will take more time and resources than are available for the study.

RADAR-base (Remote Assessment of Disease And Relapses)	RADAR-base is a platform designed to collect data from Wearables and mobile technologies. The main focus of RADAR-base is integration of data streams from Wearables to collect sensor data in real time and store, manage and share the collected data with researchers for retrospective analysis (Ranjan et al., 2019).	RADAR-base provides both passive and active data collection It has been designed for health research and used previously in mental health research (Stewart et al., 2018).	RADAR-base is only currently available for use on smartphones with an Android operating system.
Qualtrics	Qualtrics provide experience management software for collecting and analysing data. Surveys can be set up and sent to selected smartphone numbers (Qualtrics, 2019).	Nottingham University has a licence for Qualtrics use.	Qualtrics has no capacity for passive data collection. The platform only generates prompts and surveys requiring active data collection.
Bespoke platform	Bespoke systems have been created for collecting data from people with psychosis for research studies. An example of this which has been used with people with psychosis is the CrossCheck system (Ben-Zeev et al., 2015).	Benefits of a bespoke system is that it could carry out all the necessary data collection for Unfold1 as desired.	Time restrictions of the PhD do not allow for development of a bespoke system. This would also be likely to cost more than the PhD budget allows.

‘Off the shelf’ Apps	‘Off the shelf’ Apps could be purchased or downloaded for free and used to collect data. Apps designed to help users with smartphone addiction can monitor App usage. An example of this is the QualityTime App. QualityTime logs the amount of time a smartphone user spends on each App. Time spent using emails/messaging services/call logs could be used to measure social contact (Google, 2019).	Free to download Other smartphone addiction Apps are available (Google, 2019).	An additional App will be required (e.g., Qualtrics) in order to carry out active data collection. The data can be viewed by the participant, which may cause them to alter behaviour. The Quality Time App does not log who participants were communicating with. Only currently available for use on smartphones with an Android operating system.

2.4.3 Platform choice

The Platform chosen for data collection use in Unfold 1 was RADAR-base. RADAR-base is a research platform developed in the UK intended to support the capture of temporal health-related data securely. The RADAR- base (Remote assessment of disease and relapse) is an Mhealth platform for generalised data collection from Wearables and smartphone devices. The main function of the platform is to integrate data streams from devices to collect real time sensor data. The platform also stores, shares and manages collected data with researchers for data analysis (Ranjan et al., 2019).

RADAR-base is able to collect both passive and active data. It collects passive data on real time movement, location, audio call App and text use. An application runs in the background of a smartphone, requiring no or minimal input from participants. For use in active data collection, RADAR-base includes a questionnaire application, which can be used for the delivery of questionnaires. Configurable schedules and questionnaires can be set by researchers so that measures can be sent to participants at pre-set times. The platform has been used successfully to collect passive data including heart rate, movement, activity levels, exercise, and sleep patterns in participants diagnosed with major depressive disorder (Stewart et al., 2018). It has also been used to administer patient health questionnaire to the same participants. RADAR-base has been used to collect data from populations with diagnoses of multiple sclerosis, depression and epilepsy (Ranjan et al., 2019). The platform is utilised across a number of other research studies.

A deployment of RADAR-base was acquired in-house at the University of Nottingham. A server has been agreed for purchase at the University of Nottingham funded by the Biomedical Research Centre explicitly to support data collection.

Chapter 3: Identity

This chapter describes philosophical (Section 3.1) and psychological (Section 3.2) conceptions of personal identity and identity change. The social identity theory is described in detail as the theory of identity that will be used in this thesis. The relationship between social identity, health and wellbeing is discussed in Section 3.3.

3.1 Philosophical conceptions of identity

Identity is what distinguishes one object from another (Sollberger, 2013). Philosophers have questioned what makes an object what it is and what preserves that object across time since the origins of western philosophy (Shoemaker and Tobia, 2022). Philosophical questions regarding identity typically focus on what makes an object what it is and how much change an object can undergo while remaining that same object.

3.1.1 Personal identity

In western philosophy, personal identity theory comprises a range of views on the relationship between mind and body (Olson, 2022). Understanding identity persistence and change depends on the nature of personal identity over time (Noonan, 2003). One question frequently asked by philosophers is the evidence question. The question relates to how an individual person can be identified; what specific evidence is required to distinguish one person from another (Swinburne, 1973). Two responses to the question have arisen, quantitative identity and qualitative identity.

Quantitative identity

Quantitative identity concerns the relation an object bears only to itself. It implies that a person can only be identified by locating them in time and space (Sollberger, 2013). One advocate for quantitative identity was 17th century philosopher Gottfried Wilhelm Leibniz. Leibniz argued that humans can be described in terms of a concept of substance, specifically a numeric-quantitative, identification: to say that *a* and *b* are numerically identical is to say *a* and *b* are one thing and not two (Leibniz, 1969). This is known as Leibniz's law and implies that no two objects have exactly the same properties. This law implies that it would be impossible to recognize individuals as the same individuals at different timepoints. In order for two things to be considered identical, they must be absolutely the same. According to quantitative identity theory, identity change over time is impossible and an individual at different time points constitutes two separate individuals.

Qualitative identity

Qualitative identity is specified by detailed, conceptual or substantial attributes (Sollberger, 2013). To say that *a* and *b* are qualitatively identical is to say that *a* resembles *b* (Olson, 2022). Two things sharing a qualitative identity share properties which make them qualitatively identical. Objects can vary in the degree to which they are identical. An example of this is the categorisation of plants and flowers: a rose is qualitatively the same as a lily because they have the shared property of being a flower. It is likely however that two roses will have greater qualitative identity than a rose and a lily due to having more shared properties. Flowers can therefore be categorised into different types, depending on their shared properties. Philosophers have described this categorisation as assigning a type (the concept, e.g. flower) to the individual token (the individual instance of the concept, e.g. rose) (Peirce, 1958). In relation to personal identity, qualitative identity is concerned with a person's individual characteristics (Sollberger, 2013).

3.1.2 Identity continuity and change

An inherent feature of personal identity is a sense of temporal continuity (Sani, 2008). This concerns the idea that a person remains inherently the same person throughout their life, even though they may experience qualitative changes. For example, they may dye their hair or have a change of career but still feel that they are the same person as before. Another question frequently posed by philosophers is the persistence question. This concerns what is considered sufficient and necessary for a past or future being to be the same as someone that exists in the present time (Olson, 2022). This question concerns what personal identity over time actually consists of. Philosophers have posited different theories about what criterion need to remain in order for identity to remain unchanged rather than someone being considered a different person (Noonan, 2003). There are three main criteria proposed: the simple view, the brute physical continuity view and the psychological continuity view (Olson, 2012)

The simple view posits that personal identity is unanalysable and distinct from everything experienceable and observable (Noonan, 2003). Brute physical continuity views state that a person is the same biological organism that has the same body. Advocates of the psychological continuity view suggest that persistence consists in a type of psychological relation (Schechtman, 1994). Individuals in the future time inherit their mental features from an individual at the current or previous time. Psychological theorists have developed differing theories specifying different kinds of psychological features deemed essential and what kind of continuity occurs (Nichols and Bruno, 2013). The psychological continuity view is the view that most people feel intuitively drawn towards (Nichols and Bruno, 2013). Three psychological theories of identity that pose different criterion for identity continuity are trait theory, narrative identity and social identity theory, which are now discussed.

3.2 Psychological conceptions of identity

3.2.1 Trait theory

Trait theory of personality suggests that personality consists of broad dispositions called traits. Traits are dimensions of personality that can influence a person’s behaviours as well as their thoughts and feelings (McCrae and Costa, 2003). The field has approached consensus on a taxonomy of personality traits called the five factor model (John and Srivastava, 1999). The model organises broad individual differences in social and emotional life into five categories, labelled as: openness to experience, conscientiousness, neuroticism, extraversion and agreeableness. A dispositional signature consists of traits which are non-conditional, decontextualised and broad. Traits constitute the most stable and recognisable aspect of psychological individuality, often viewed as broad dimensions of individual differences. Traits are used to categorise people by personality type. For an individual, each trait falls on a point along a spectrum and combined scores contribute a personality type (Matthews et al., 2003).

Personality traits have been shown to remain relatively stable across the individual lifespan (Roberts and Mroczek, 2008). Traits held by an individual aged 30 are a good predictor of personality traits that same individual will hold aged 80 (McCrae and Costa, 1982). Changes have been observed in longitudinal studies with a retest interval of 20 years or more (Ardelt, 2000) and longitudinal time interval has a negative relation to trait consistency (Roberts and DelVecchio, 2000). This indicates that although changes in personality traits do occur, this takes several years.

A criticism of trait theory is that it fails to take the context of the individual into account, as traits are not dynamic and remain consistent across different contexts (Mischel, 1973). Another criticism is that trait theory does not explain how individual traits result in individual behaviours. Although some studies have shown how different traits correlate with specific behaviours, there is no conceptual theory for how each trait translates into specific behaviours (Fleeson and Jayawickreme, 2015).

3.2.2 Narrative identity

Narrative approaches to psychology suggest individuals understand their identity as ongoing stories. These stories may be explored by an evolving and internalised life story (McAdams, 2001). Narrative identity reconstructs autobiographical past and imagines a future in order to give purpose, meaning and unity to an individual's life (McAdams and McLean, 2013). Narrative identity functions to provide a person with a sense of purpose, temporal continuity and coherence (Hammack, 2008).

Change is central to the construction of life stories (McAdams, 2019). Narrative identity change can be observed in the telling and re-telling of a story (McAdams, 2001). In order to examine the extent to which narrative identity shows continuity and change, the extent to which a story changes or stays the same from one telling to the next can be assessed (Adler, 2019).

It can be extremely difficult to discern identity stability and identity change in life stories (McAdams, 2019). One reason is that the conceptualisation of persistence and change in narrative identity is not very well understood (Adler, 2019). Research has shown that it can be difficult to identify stability and change in life stories and that it is also difficult to identify precisely what stability or change means (McAdams, 2019).

3.2.3 Social identity

Social Identity Theory (SIT) is a social psychological theory of intergroup relations (Hogg et al., 1995). SIT defines social identity as the sense of self a person gains from viewing themselves as a member of social groups (Turner et al., 1987). A social group is a collection of individuals who perceive themselves to be members of the same social category (Brown and Ross, 1982). Social identity is an individual's knowledge that they belong to certain social groups, coupled with the emotional and value significance they experience from group membership (Tajfel, 1978b).

Each group membership is represented in the mind of an individual as a social identity (Hogg et al., 1995). Groups are objects of intense psychological identification and investment (Sani et al., 2015). Social identity groups are cognitive entities, meaningful to the individual (Tajfel, 1978c). Group memberships are internalised and incorporated into a person's view of who they are, so they become central to a person's sense of self (Ng et al., 2018). Memberships inform a person's actions, thoughts and feelings (Reicher et al., 2012). Individuals often have a collection of group memberships that vary in overall importance to their concept of self (Hogg et al., 1995). Group memberships help define the individual self and form the building-blocks of people's social identities (Iyer et al., 2009). If a person belongs to multiple social groups, an individual's sense of self is composed of multiple social identities (Tajfel and Turner, 1979).

Self-categorisation theory

An extension of SIT is Self-Categorisation Theory (SCT). SCT describes categorisation processes as the basis for group behaviour (Hogg et al., 1995). SCT explains the social cognitive underpinnings of group behaviour in terms of the individual cognitive process of self-categorisation (Abrams and Hogg, 1990). The theory posits that social identity is a cognitive component of the self and the self is perceived as a set of cognitive representations (Turner et al., 1987). SIT and SCT are referred to together as the social identity approach (Hogg et al., 1995).

Categorisations are cognitive tools that classify, order and divide the social environment (Brown and Ross, 1982). The creation and internalisation of self-categorisations leads to the formation of groups (Turner et al., 1987). During the self-categorisation process, an individual assigns people, including themselves, into a contextually relevant category known as the in-group and corresponding group known as the out-group. In-group versus out-group combinations include American versus non-American (Haslam et al., 1999), substance user versus non substance user (Bathish et al., 2017), or a football team supporter versus supporter of an opposing team (Van Hiel et al., 2007). Categorisation of self and others into in-groups and out-groups defines a person's social identity (Turner et al., 1987).

Social identity salience

Social identities are fluid, and how individuals express their social identity is variable (Ethier and Deaux, 1994). Identity changes depending on environment (Bentley et al., 2020). SCT assumes that that social identity is context specific. Particular identities can be 'activated' in certain situations. This is called identity salience. Salience of a group membership is its psychological significance in a given environment (Oakes, 1987). Social identity salience is described as the definition of the self in terms of group membership shared with other people (Haslam et al., 1999). When a particular social identity is salient, people become attuned to the similarities between themselves and other members of the in-group and individuals think and act in terms of those beliefs (Turner et al., 1994). This results in individuals evaluating themselves in a specific way (Turner et al., 1987) as identity salience informs self-perception (Oakes, 1987). An example of this is a woman who describes herself as a worker when she is surrounded by colleagues in her working environment but at home her social identity of being a mother becomes salient and she feels more defined by the significance of this role.

Implications for thesis

Social Identity Theory was used as the theoretical framework for this thesis. This was chosen as identity change is clearly defined within SIT. Changes to a participant's social identity groups will be measured, as well as how participants evaluate these groups. Another reason why SIT has been chosen is that the theory describes social identity as fluid. The fluidity of social identity means that changes are likely to be observed. A final reason is that SIT defines identity as context specific and recovery is an inherently social process (Price-Robertson et al., 2017). By selecting a theory of identity that considers social context, social changes and processes in identity change in recovery from psychosis may be observed.

3.3 Social identity, health and wellbeing

Social identity influences an individual's health and wellbeing. A meta-analysis has shown that social relationships protect against premature death to the same degree as smoking cessation (Holt-Lunstad et al., 2010). Interventions that increase identification with different groups have an effect on both physical and mental health (Steffens et al., 2019). The positive effect that social identification has on health can be seen to predict recovery from severe mental illness (Cruwys et al., 2020) and depression (Cruwys et al., 2013), and is linked to reduced primary care attendance (Cruwys et al., 2018).

Social identities provide psychological resources that are critical to health and wellbeing (Haslam et al., 2021), such as sense of control, self-esteem sense of meaning and sense of belonging. These resources protect an individual against threats to their health (Greenaway et al, 2016). Protection is from negative psychological affects as well as physiological effects (Praharso et al., 2017). The positive impact of social groups on health and wellbeing is known as the social cure (Haslam et al., 2018).

Another benefit of identification with a group is social support (Jetten et al., 2009). Social support refers to acts in which individuals and groups provide resources to others (Haslam et al., 2012). Identification with social groups plays a key role in determining whether people give and receive social support. Social identity provides the basis for benefiting from social support (Haslam et al., 2004). One of the critical factors defining relationships is the degree to which the groups or individuals concerned perceive each other to share a social identity (Turner et al., 1987). The dynamics of support are always structured by identity-based relationships (Haslam et al., 2012). Social support does not automatically provide positive outcomes (Haslam et al., 2012). Social support between individuals without a shared social identity can have a negative effect on a person's wellbeing (Haslam et al., 2012). Group identification provides a precondition for positive social relationships that are based on respect, trust and support, which paves the way for positive mental states (Sani et al., 2012). Receiving social support from in-group members has been found to help an individual to maintain levels of wellbeing after a stressful life event (Jetten et al., 2001). It has also been associated with improved health (Schwarzer and Leppin, 1991).

3.3.1 Illness identity groups

Categorisation into an illness identity group can have a negative effect on a person's level of wellbeing. Psychological Wellbeing (PWB) is defined as a form of happiness consisting of pleasure and virtue. This has recently been reframed in terms of pleasure and psychosocial meaning by psychologists (Deci and Ryan, 2008). PWB differs from hedonic wellbeing which refers to the pursuit of pleasure (Huta and Ryan, 2010). It is based upon how good one feels about one's own life (Bauer et al., 2008).

Psychological Wellbeing is linked to the conditions of the groups to which an individual belongs (Jetten et al., 2017). Social groups provide health benefits only when membership is underpinned by social identity (Praharso et al., 2017). Social identity is the source of social psychological resources that are critical to health and wellbeing. This is because social identity provides the platform for a sense of psychological connection to other in-group members (Haslam et al., 2021). It is not merely group membership that provides benefits, but rather the sense of social identity afforded by group membership that provides wellbeing benefits (Greenaway et al., 2016).

In order to achieve and maintain positive social identity, a person must establish positively valued regard for their groups (Turner and Reynolds, 2010). Positive social identity is based on favourable comparisons made between a person's in-group and corresponding out-group (Brown and Ross, 1982). Illness groups can be negatively evaluated by group members (St. Claire and Clucas, 2012). People diagnosed with mental illness have been defined as occupying a low-status group (Cruwys and Gunaseelan, 2016).

Members of low-status groups evaluate their status less positively than members of high-status groups. Therefore membership of a group which has low status may negatively affect group members' self-concept (Ellemers et al., 1993). Perceived hostility from high status groups, as well as the feeling of being 'outnumbered' by higher status group members, can lead to reduced levels of wellbeing (Van Laar et al., 2010). Members of a low-status group may aim to protect their health and wellbeing by seeking out membership in a higher-status group (Turner and Reynolds, 2010).

3.3.2 Life change as social identity change

Social identity plays a significant role in how an individual manages life changes (Ng et al., 2018). Life changes result from events and experiences that disrupt a person's established patterns and routines (Jetten et al., 2009). These can occur due to a broad range of circumstances, including anticipated life events, which are often sought out and welcomed and unanticipated life events. An example of an anticipated life event is starting university (Iyer et al., 2009). Unanticipated life events are often associated with loss of group membership, for example an unexpected illness (Haslam et al., 2021).

Life events often involve a transition from one identity to another (Praharso et al., 2017). Change in group memberships often occurs as a result of life changes. An individual may lose some social identities as a result of the transition, or the transition may provide opportunities for identification with additional social groups (Jetten et al., 2009). The social group memberships and subsequent social support available prior to the life change are unlikely to be the same after the transition, which can result in a short-term decrease in a person’s level of wellbeing (Praharso et al., 2017).

3.3.3 Social Identity Model of Identity Change (SIMIC)

The Social Identity Model of Identity Change (SIMIC) was developed to explain the role that social identity processes play in adjustment to life change (Haslam et al., 2021). The model addresses identity change resulting from life events which have caused a significant amount of adjustment and a marked disturbance in identity continuity (Jetten et al., 2009). Life changes where SIMIC has been applied include pursuit of higher education (Iyer et al., 2009), migration (McIntyre et al., 2016) and recovery from trauma (Helgeson and Zajdel, 2017). The purpose of SIMIC is to provide a testable framework for understanding how responses to life changes are influenced by social identity processes (Haslam et al., 2021). SIMIC assumes that life changes involve changes to social group memberships and corresponding social identity. SIMIC seeks to model the nature of this change in ways that inform theory and practice, helping to explain how social identity change affects health and wellbeing (Jetten et al., 2009).

The SIMIC model presents three processes by which a person’s level of wellbeing can be protected against life changes:

1. Through multiple group membership
2. The social identity continuity pathway
3. The social identity gain pathway

The model has hypotheses relating to each process. Processes and related hypotheses are described in Table 3.1.

Table 3.1 Hypotheses of the SIMIC model

Social identity process	Hypothesis	Result
Multiple group membership (Belonging to multiple groups prior to occurrence of life change)	**H1:** Multiple group memberships before life change will be associated with enhanced health and wellbeing after life change	Improved health and wellbeing
Social identity continuity pathway (Maintaining old group memberships)	**H2:** The extent that people belong to multiple groups will increase the likelihood of maintaining pre-existing groups to support social identity continuity	Improved health and wellbeing
Social identity gain pathway (Acquiring new group memberships)	**H3:** The extent that people belong to multiple groups will increase the likelihood of joining new groups to support social identity gain	Improved health and wellbeing

The social identity continuity pathway

SIMIC describes how the number of group memberships prior to life change is an important predictor in whether an individual copes successfully with identity change (Jetten and Pachana, 2012). This is thought to be for two reasons:

1. A person’s old identity network provides a basis for social support
2. The network provides a platform on which to build new social identities (Jetten and Pachana, 2012).

A study that investigated wellbeing after a stroke found that participants who reported belonging to a higher number of social groups before their stroke reported higher levels of wellbeing after the stroke. This effect was mediated by individual’s ability to maintain their membership of those social groups after the stroke. The findings are therefore consistent with the argument that if someone has multiple social identities before a life transition they are more likely to maintain them, which protects their level of wellbeing (Jetten and Pachana, 2012).

Social identity gain pathway

The ability to take on new relationships following a life changing transition can be a way for an individual to maintain levels of wellbeing after life change (Jetten et al., 2009). An adaptive response to life change could involve self-categorising in terms of a new group and deriving a meaningful social identity from this group membership (Iyer et al., 2009). For example, a change in relationships over time has been observed in students starting university, whose levels of wellbeing increased once they identify as a university student (Iyer et al., 2009). The identity gain pathway has been tested in a longitudinal study of people diagnosed with depression. Those who acquired no new group memberships had a 41% increased risk of relapse in depression symptoms. This risk declined as people became more socially connected and relapse rates among those who acquired one, two, and three or more group memberships were significantly lower (Cruwys et al., 2013).

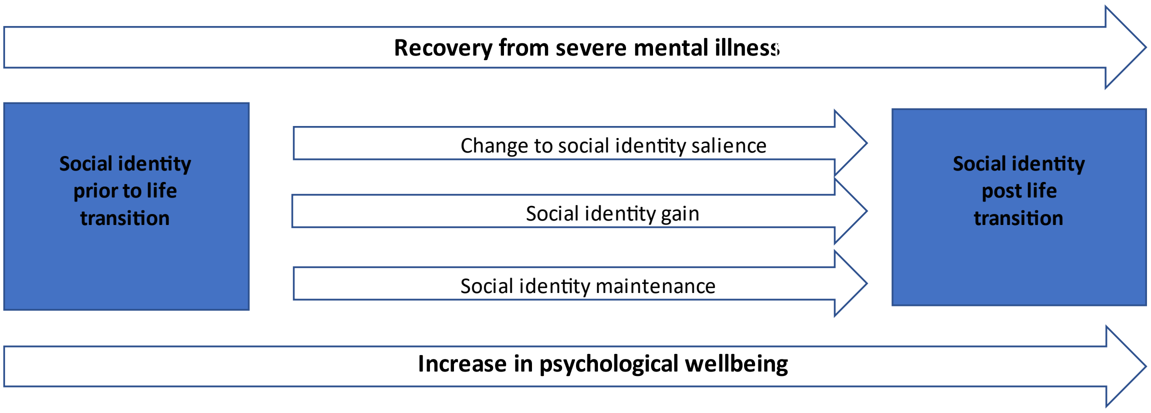
Recovery as a life event

SIMIC could be used to explain mechanisms involved in identity change in recovery from psychosis. The model has been applied to understanding identity transition caused by recovery from other chronic health conditions, where life change has been defined by persistent, and often unpredictable, course of illness. Identity transition has been shown to involve a move away from illness or trauma-focused identities (Helgeson and Zajdel, 2017). Unanticipated life events including illness are often associated with loss of group membership (Haslam et al., 2021), and identity change in people with psychosis can be caused by lost relationships and roles (Conneely et al., 2021). This can be seen in people with psychosis, where social exclusion from community groups is a common feature (Wood and Alsawy, 2018), and loneliness through lack of social groups is a significant barrier to recovery (Badcock et al., 2020).

Conclusion and Implications for thesis

Self-categorisation theory stipulates that social identity change occurs when a person self-categorises in and out of social identity groups. By categorising into additional social identity groups or by or maintaining social identity groups a person may experience an increase in psychological wellbeing. The positive effect that social identification has on health can also be seen to predict recovery from severe mental illness. These processes are illustrated in Figure 3.1.

Figure 3.1 Social identity change processes



Unfold examined the relationship between social identity change and psychological wellbeing. Social identity processes relating to group memberships were investigated. These included changes to the number of social identity groups participants belong to, and the relationship that any changes to the number of social identity groups may have to psychological wellbeing. These findings may indicate the applicability of the SIMIC model to people recovering from psychosis.

Unfold focused on changes to the level of group positivity and changes to the level of group supportiveness and importance of a person’s social identity groups as they recover. Changes in group positivity and group supportiveness were considered in relation to level of psychological wellbeing. This could demonstrate if group positivity and group supportiveness protect the level of psychological wellbeing of a person recovering from psychosis.

Chapter 4: Experience sampling methods used in psychosis: Systematic Review

4.1 Introduction

Digital technology approaches to data collection in psychosis were identified in Chapter 2. A key methodology utilising digital technology for real-time data collection is the Experience Sampling Method (ESM). This chapter presents a systematic review of design decision and data completeness for ESM methods used in psychosis. The findings can be used to inform the design of the Unfold 1 study. This systematic review has been published (Deakin et al, 2022) and is shown in Appendix 9. The thesis author planned and designed the review, carried out the literature screening and analysed the data with support from the supervisory team.

4.1.1 The experience sampling method

ESM is an intensive longitudinal research method (Bolger and Laurenceau, 2013a). The term ‘ESM’ is often used interchangeably with other terms, such as Ecological Momentary Assessment (Shiffman et al., 2008). For the purpose of this review, the term ESM will be used to encompass all forms of real-time data collection.

ESM is conducted in real world settings as a participant goes about their daily life (Palmier-Claus et al., 2019). Participants complete self-report questions about transient experiences at multiple times, typically followed by questions relating to current environment or context (Kimhy and Vakhrusheva, 2019). Participants are asked questions about their current or very recent state (Shiffman et al., 2008). Existing measures can be modified for use in an experience sampling design (Runyan et al., 2018) or measures are developed specifically for individual studies (Kimhy et al., 2012). ESM has been used with a diverse range of populations and a wide range of settings. Examples include the effects of social media use on the wellbeing of young adults (Faelens et al., 2021) and the intentions of healthcare staff to leave their professions (Blanco-Donoso et al., 2021).

Prior to the advent of digital technologies, ESM involved filling in a diary or booklet (Shiffman et al., 2008). More recently, most ESM designs are computerised and allow researchers to identify the exact time a momentary assessment was completed (Burke et al., 2017). The use of ESM studies has increased considerably in recent decades (Trull and Ebner-Priemer, 2020), partly due to increasing smartphone availability (Janssens et al., 2018).

4.1.2 Advantages of the experience sampling method

ESM can provide an accurate assessment of phenomena as they occur in the context of a person’s life (Palmier-Claus et al., 2019). For example levels of wellbeing (Faelens et al., 2021) or perceived closeness in friendships (Pouwels et al., 2021). It allows researchers to gain more ecologically valid insights into the impact of daily events, which is difficult to measure under laboratory conditions (Conner and Mehl, 2015). Responses are less subject to retrospective recall biases as participants do not rely on memory to answer questions (Solhan et al., 2009). This allows assessment of behaviour and experiences to take place in a more ecologically valid way (Trull and Ebner-Priemer, 2009).

ESM can be used to examine temporal precedence between variables (Palmier-Claus et al., 2019). By asking participants to report experiences over a period of time, researchers can investigate fluctuations between variables which may not be captured using other methods (Bolger et al., 2003).

4.1.3 ESM in psychosis research

ESM has been used widely in mental health research (Kimhy et al., 2012). A review of the use of ESM in mental health research has identified a number of applications including improving understanding of symptoms and social interactions, identifying causes of symptom variation and evaluating treatments (Myin-Germeys et al., 2018).

ESM has been used in psychosis research. It is a valid approach when capturing mental health states in participants with schizophrenia (Ben-Zeev et al., 2012b). It has also been shown to be a reliable method when used with this population (Palmier-Claus et al., 2012). ESM studies recruiting people with psychosis have been used to investigate symptoms such as paranoia (Monsonet et al., 2020), auditory hallucinations (Jongeneel et al., 2020) and sleep disturbances (Mulligan et al., 2019). ESM has been evaluated for use in assessing people with psychosis after they were discharged from hospital (Moitra et al., 2021), and also to understand daily habits and social interactions (Granholm et al., 2020).

4.1.4 Data completeness in ESM research

Data completeness is a particular challenge in ESM. Missing data is common in research using ESM methods (Depp et al., 2019). Data incompleteness can occur for a number of reasons, such as participants finding ESM burdensome and time consuming (Palmier-Claus et al., 2019) leading to reduced adherence to the study protocol, resulting in reduced data quantity (Fuller-Tyszkiewicz et al., 2013) and quality (Rintala et al., 2019). Incomplete data sets can cause important aspects of experience to be overlooked by researchers and also bias statistical models used for analysis (McLean et al., 2017).

People with psychosis have been shown to be less adherent to ESM study protocols than the general population (Rintala et al., 2019). Studies that recruit people with psychosis have higher rates of participant withdrawal, resulting in fewer participants included in final analyses (Vachon et al., 2019).

4.1.5 ESM design

Conducting an ESM study involves making several design decisions (Janssens et al., 2018). For example, deciding when and how frequently participants answer questionnaires. A questionnaire prompt may be sent to participants at pre-defined intervals (time contingent protocol), scheduled at random times (signal contingent protocol) or carried out when a predefined event has occurred (event contingent protocol) (Wheeler and Reis, 1991). Studies can also use hybrid designs, which combine sampling protocols (Myin-Germeys et al., 2018). Setting the frequency of questionnaire prompts involves consideration of participant burden as well as how rapidly the target phenomenon is expected to vary (Shiffman et al., 2008).

There is evidence that design decisions influence completion rates. For example longer questionnaires have been associated with higher levels of participant burden (Eisele et al., 2020). Protocol adherence has been shown to reduce over time, and also to be dependent on the time of day a questionnaire is received (Rintala et al., 2019). A systematic review has investigated compliance with study protocols and retention in ESM studies in participants with severe mental illness (Vachon et al., 2019). The review found that frequent assessments and short intervals between questionnaires reduce data completeness, and increasing participant reimbursement increases data completeness (Vachon et al., 2019).

There is a need for greater consistency in the design of ESM studies (Myin-Germeys et al., 2018). ESM is a collection of methods and is usually reported in relation to general characteristics such as ‘ambulatory assessment’ rather than a defined set of design options (Shiffman et al., 2008). When designing an ESM study, researchers have insufficient evidence on which to base design decisions (Eisele et al., 2020). Designs of ESM studies are often based on individual research questions (Janssens et al., 2018), leading to a large heterogeneity of designs (Vachon et al., 2019). Additional methodological research is needed in order for studies to be replicable and standardised (Myin-Germeys et al., 2018).

Developing this consistency in design is impeded by the absence of a typology of design decisions. No typology for ESM design choices currently exists. A typology could help to define and classify ESM research methods (Beissel-Durrant, 2004), increasing both methodological rigour in individual studies and the ability to compare or combine findings.

4.2 Review aims

The aim of this systematic review is to characterise the design choices made in digital ESM studies monitoring the daily lives of people with psychosis.

The objectives in relation to ESM studies involving people with psychosis are:

(1) to develop a typology of design choices used in digital ESM studies (Design typology)

(2) to synthesise evidence relating data completeness to different ESM design choices (Data completeness).

4.3 Method

4.3.1 Data sources and search strategy

A systematic search was conducted using six data sources. The search strategy was developed in collaboration with two information specialists with expertise in systematic review searches. These data sources and associated search strategy are described below.

Electronic databases

The following five electronic databases were searched from January 2009 to July 2021: The Cochrane library, Medline, Embase, PsycInfo, and Web of Science. The search terms are described in Table 4.1.

Table 4.1 Systematic review search terms

	Search terms	**Domain**
1	‘Ecological Momentary Assessment’ OR ‘*Monitoring’ OR ‘Ambulatory Data Collection’ OR ‘Self-Assessment’ OR experience sampl*” OR ‘sampling method*’ OR ‘momentary assessment’ OR ‘ESM ‘OR ‘EMA’ OR ‘momentary intervention*’	Real time data collection methods
2	‘data adj2’ OR ‘captur*’ OR ‘collect*’ OR ‘real?time’ OR ‘time series’ OR ‘acqui*’ OR ‘obtain*’ or ‘gather*’ OR ‘entry’ OR ‘entries’ OR ‘input*’ ‘daily diary method’ OR ‘daily diary stud*’ OR ‘track*’ OR ‘monitor*’ OR ‘assess*’ OR ‘measur*’ OR sensing OR sense OR ‘self?report*’	Data collection
3	‘*Technology’ OR ‘*software’ OR ‘mobile applications’ OR ‘ Cell Phone’ OR ‘Telemedicine’ OR ‘wearable electronic devices’ OR ‘ fitness trackers’ OR ‘Text Messaging’ OR ‘Telemedicine’ OR ‘Smartphone*’ OR ‘smart-phone*’ OR ‘cell phone*’ OR ‘mobile phone’ OR’ App’ OR ‘Apps’ OR ‘Mobile application*’OR ‘Mhealth’ OR ‘m-health’ OR ‘ehealth’ OR ‘e-health or wearable*’ OR ‘remote’ OR ‘Personal digital assistant*’ OR ‘Software’ OR ‘mobile	Digital technology

	technolog*’ OR ‘mobile device*’ OR ‘mobile electronic device*’ OR ‘cellular telephone*’ or ‘cellular phone*’	
4	‘Psychotic Disorders’ OR ‘Schizophrenia’ OR ‘psychoses’ OR ‘psychosis’ OR ‘psychotic’ OR ‘schizo*’	Psychosis
	1 AND 2 AND 3 And 4	

The search terms were modified for each database. For example, Medical Subject Headings (MeSH) terms used for experience sampling in the Cochrane library included ‘Monitoring, Ambulatory’ rather than two separate terms ‘Monitoring’ OR ‘Ambulatory’ used in EMBASE. Also, the Cochrane library used the MeSH term ‘Wearable Electronic Devices’ which was ‘Wearable Devices’ in PsycINFO.

The many different terms used in the literature to describe experience sampling methods required broader terms associated more generally with data collection, such as ‘diary study’, ‘input’ monitor’ or ‘measure’, which are not generally associated with technology.

Also ‘sensing’ is associated with technology used in passive data collection, but a number of studies use active and passive data collection alongside each other or used the term sensing more generally to refer to the active or passive use of mobile sensors.

Table of contents

The table of contents for the following nine journals were hand searched: Journal of Medical Internet Research; Journal of Medical Internet Research (Mental health); Journal of Medical Internet Research (Mhealth and Uhealth); Psychiatric Services; Psychological Assessment; Schizophrenia Bulletin; Schizophrenia Research; International Journal of Methods in Psychiatric Research; and Psychiatric Rehabilitation Journal. These were searched from 1990 to January 2021 These journals were chosen as they regularly published recovery-related papers.

Web searches

Web-based searches were conducted using:

- Google Scholar
- ResearchGate
- Academia.edu

They were searched using the terms ‘experience sampling and psychosis’, ‘ecological momentary assessment’ and ‘psychosis’, ‘experience sampling’ and ‘schizophrenia’ and ecological momentary assessment and ‘schizophrenia’. Due to the large number of results found on Google Scholar only the first five pages of results (i.e. 50 hits) were searched.

Grey literature searches

Grey literature searches were conducted using OpenGrey. This was conducted using the same search terms used for the web-based searches.

Hand searching

Reference lists of included papers were hand-searched. Backward citation tracking was conducted by hand-searching the reference lists of all included papers. Forward citation tracking of papers citing included studies was conducted using Scopus and Google Scholar.

Expert consultation

A panel of five experts with expertise in experience sampling methods was consulted for additional studies meeting the inclusion criteria.

4.2.2 Eligibility criteria

Inclusion criteria:

- Participants: papers that reported on participants with a clinical or research diagnosis of psychosis, either as a category or by specific diagnosis, e.g. schizophrenia
- Methods: Studies using ESM to monitor participants with psychosis
- Studies which used digital technology to administer ESM. As the aims of the thesis were to assess digital data collection methods for people with psychosis, studies that did not use digital technology were excluded

- Studies which included experience sampling as part of an intervention
- English language full text articles, reviews and conference abstracts were included in the review
- Papers published from January 2009 to July 2021
- Studies which reported the completeness of data or where it was possible to calculate the completeness if it was not reported

Additionally, the following exclusion criteria applied:

- Studies recruiting non clinically diagnosed adults, i.e., participants self-reporting psychosis without clinical or research validation

4.2.3 Data extraction and appraisal

Eligible citations were collated and uploaded to EndNote, and duplicates were removed. The titles of all identified citations were screened for relevance against the inclusion criteria by the thesis author who rated all of the studies for inclusion. Data were extracted into an Excel spreadsheet developed as a Data Abstraction Table for the review.

Subgroup analysis was undertaken for studies included in Objective 2 (Data completeness). Subgroup analysis was not undertaken for Objective 1 (Design typology) because the aim was to develop an exhaustive typology (Bailey, 1994). The methodological quality of the included studies was initially assessed using the Critical Appraisal Skills Programme (CASP) checklist for assessing the quality of a cohort study (Critical Appraisal Skills Programme, 2018). The tool rates whether the results of the study are valid, and if results are applicable to a local population. The tool has 12 questions which can be answered "yes", "no" or "can't tell".

The quality ratings were reviewed by the thesis author, and a sample of 30% of study titles were also rated by a secondary reviewer. Concordance was not high during title screening, and consensus was difficult to reach by discussion. The reviewers felt that the CASP did not accurately capture the content of the ESM studies. Multiple checklists were also required for different study designs. For example, the cohort study checklist was not appropriate for case control studies. Reviewer discussion identified that a checklist was required that more accurately captured reporting of design decisions specific to ESM studies, and that was applicable to all included studies.

As a result, an alternative quality rating approach was implemented. In the absence of a typology for reporting of ESM studies (Moher et al., 2010), recommended reporting criteria for ambulatory studies (Trull and Ebner-Priemer, 2020) were used. Studies were assigned points based on whether they had reported elements of the study design recommended by the guidelines. Examples of recommended reporting criteria include ‘explanation of the rationale for the sampling design’ and ‘full description of the hardware and software used to collect data’. Corresponding to the number of items on the reporting criterion, the maximum possible score was 12 points. Studies scoring 0 to 6 were arbitrarily considered to be low quality, and studies scoring 7 to 12 were considered high quality. This rating was carried out by the thesis author.

4.2.4 Data analysis

To meet Objective 1 (Design typology), design decisions were iteratively identified from the included papers. A preliminary typology of design decisions was developed by analysts who were familiar with the field of ESM. This preliminary typology was used as headings in the initial version of the Data Abstraction Table (DAT). The constant comparative method (Glaser and Strauss, 1967) was used to refine the preliminary typology, by combining inductive category coding with simultaneous comparison of incidents observed (Goetz and LeCompte, 1981). Included papers were coded using existing DAT headings, and further or combined categories were iteratively identified as the thesis author became more familiar with the data, and as subsequent included papers reported new design decisions (Dye et al., 2000). The DAT was then structured using all identified design decisions and corresponding data extracted from each study (Glaser, 1965). Extending and combining of the preliminary typology was achieved through discussion amongst the primary analysts and the wider research team.

To meet objective 2 (Data completeness), the outcome of data completeness was defined as the percentage of questionnaires completed by participants in each study out of a possible total allowed by each study protocol. This was taken directly from the paper where possible. Where percentage of data completeness was not reported, completeness was calculated by converting the total questionnaires completed during the study into a percentage using the total possible questionnaires allowed by each study protocol. The percentage represents the total data completeness for each study. Each study had a different number of questionnaires to report and different number of participants The percentage therefore includes variation between participants and within participants as questionnaire completion was completed over time. Each of the categories from the typology were used as predictor variables. Additional predictor variables included in the analysis were mean age of study participants and percentage of male participants.

In order to carry out a meta-analysis or meta regression of completeness, a standard error was required. Standard error is influenced by the number of participants in the study, the number of questionnaires in the study and the number of questionnaires completed. These were not consistently reported in the included studies. If these were obtained, the meta-analysis or meta regression would have had standard errors that reflected the standard errors on number of participants in the study or number of questionnaires in the study or the number of questionnaires completed. Each standard error has limitations and can give biased estimates of predictors.

It is problematic to analyse such summary data without the standard error being requested from individual study authors (McKenzie et al., 2021) or requesting the whole datasets from the authors for an Individual Participant Data (IPD) analysis.

In order to combat this bias, a weighted regression was carried out. This approach assumes that the completeness is a summary statistic from a study with unknown variance and this standard error. Each completeness percentage statistic is weighted by how many participants were in each study. The number of questionnaires (denominator variable) was also included as a predictor to see if this predicted completeness. The completion outcome is analysed as a standard regression but where each estimate of completeness is given weight dependent on its sample size.

Predictor variables were entered into the weighted regression model. Design features not used in any included study, e.g. ESM protocol: signal contingent, were excluded. For non-continuous predictor variables, cut-points were used to produce broadly equal sized categories, such as participant gender (0% - 32% male, 33%-65% male, 66%-100% male). For each predictor variable, the first category was then used as the reference category and each of the other categories individually and where relevant in grouped combinations was compared with the reference category.

A p-value for each predictor was calculated using the ANOVA function comparing the difference in model fit (R squared value) for each predictor and the intercept model (i.e. no variables). Significant predictors were then further explored by comparing beta values in their models with their corresponding p-values. These were reported and tabulated to see the impact on completeness and to explore which differences between categories of the predictor were significantly associated with completeness. Throughout the thesis, statistical significance will be interpreted as 0.05. Multiple testing will be accommodated by using a Bonferroni adjustment.

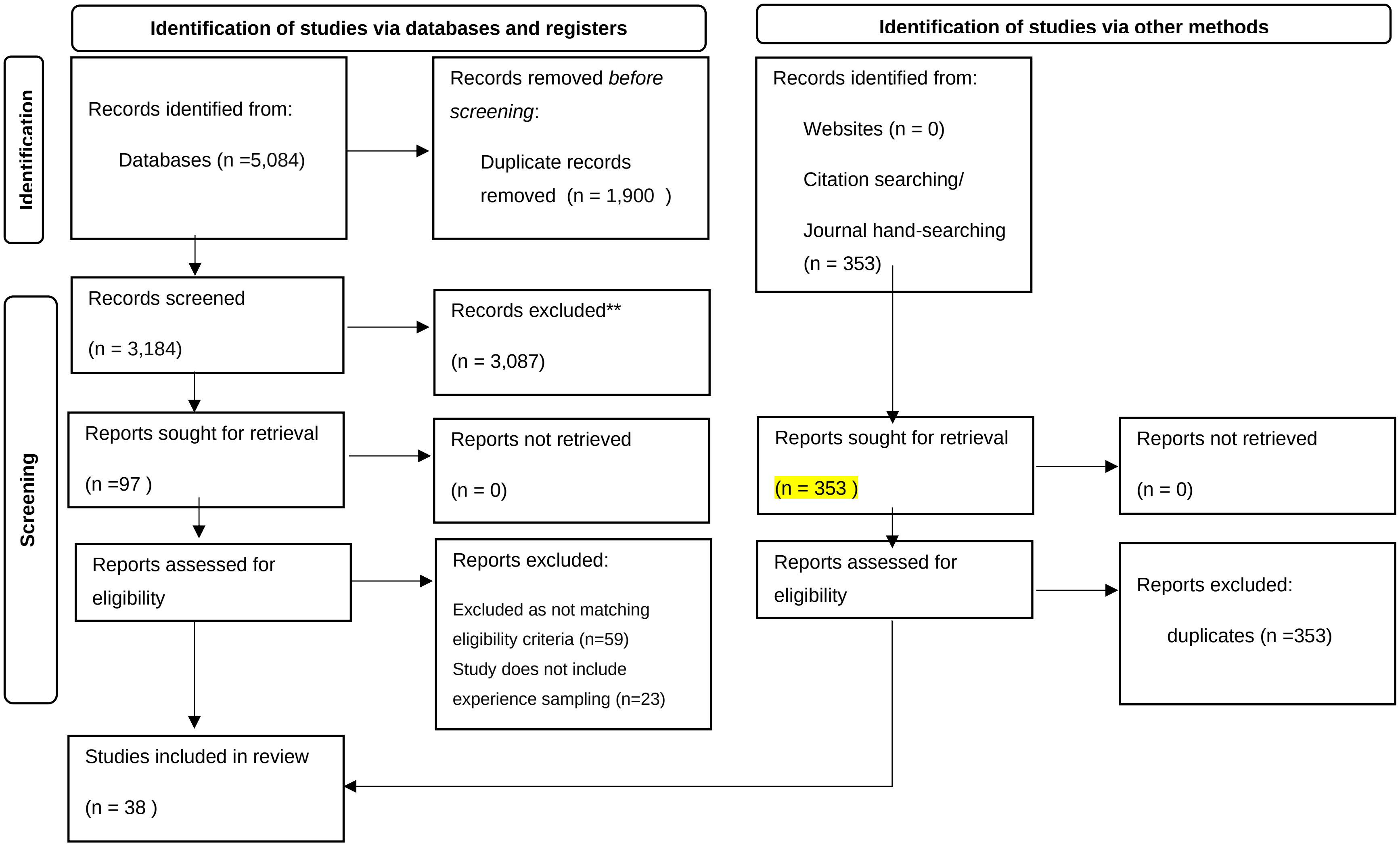
The Bonferroni adjustment is a statistical method used to address multiple comparisons within a study (Bland and Altman, 1995). When multiple statistical tests are conducted, the chances of obtaining a Type 1 error (false positive) is increased. A Bonferroni adjustment can help to prevent this occurring.

A Bonferroni adjustment is carried out by dividing the desired significance level (0.05) by the number of comparisons made. This then provides the adjusted significance level (Chen et al., 2017).

4.3 Results

The search process and total number of articles included in the review are shown in Figure 4.1 (Page et al., 2020).

Figure 4.1 Flowchart of study selection process



4.3.1 Included publications

Included publications are summarised in tables below grouped into high quality (table 4.2) and low quality studies (table 4.3).

Table 4.2 Summary of high quality included papers

Reference (full list in Appendix 8)	**Sample size** (n)	**Length of data collection period** (days)	**Daily time period per day** (hours)	**Frequency of notification** (n per day)	**Hardware used**	**Data completeness**
1	24	7	13	6	PDA	88%
2	24	7	Not reported	6	PDA	97.70%
3	130	7	12	4	PDA	130/190 participants completed 2 full days or more.
5	26	14	12	7	PDA	60%
11	51 participates with First episode psychosis, 46 at risk mental state, 53 controls.	6	Not reported	10	Data collection platform	51/59 participants completed more than 20 valid responses.
13	N=150 51 First episode psychosis (FEP) 46 At risk mental	6	Not reported	10	Data collection platform	90.9%

	state (ATMS) 53 Controls					
14	65	28	12	4	PDA	28%
15	N=49 N=22 (schizophrenia) N=27 (HC)	7	Personalised to each participant	5	Smartphone application	87%
18	24	6	12	4	Smartphone application	69%
25	171	7	12	7	Smartphone application	85%
31	34	6	12	10	Smartphone application	72
33	97	10	15	6	Electronic device	97 participants completed > 20 questionnaires
34	47	6	Varied	10	Smartphone application	41 participants completed at least 18 out of 60 questionnaires
38	95	6	14.5	10	Electronic device	56%

Table 4.3 Summary of low quality included papers

Reference (full list in Appendix 8)	**Sample size** n	**Length of data collection period** (days)	**Daily time period per day** (hours)	**Frequency of notification** (n per day)	**Hardware used**	**Data completeness**
4	145	7		4	PDA	72.10%
6	24	7	13	6	PDA	98.10%
7	32	6	15	10	PDA	27 participants completed more than half of questionnaires
8	31	2	12	10	PDA	81%
9	53 people schizophrenia and 58 controls	6	13.5	7	Data collection platform	72.10
10	22	7	Personalised for each participant	5	PDA	77.40%
12	N=40	3	12	10	PDA	89.80%
16	59	5	Not reported	10	Data collection platform	98.4%
17	199	7	12	4	PDA	72.10%

19	31	7	9	4	PDA	80%
20	20	1.5	12	10	PDA	79%
21	73	1.5	12	10	PDA	74%
22	76	6	13.5		Data collection platform	71%
23	15	10	10	4	Smartphone application	76%
24	56	6	12	4	PDA	90.2%
26	141	7	12	4	PDA	69%
27	31	9	Varied	10	Smartphone application	88.5% provided ⩾30 valid responses
28	173	30	Varied	3	Smartphone application	80
29	64	21	21	6	Smartphone application	61.5
30	384	30	12	4	Smartphone application	60
32	173	30	12	3	Smartphone application	76.5

35	71	6	Not reported	10	Smartphone application	71/80 completed > 10% questionnaires
36	110	6	15	10	Electronic device	13 participants excluded as less than 20 responses completed
37	100	7	12	7	Smartphone application	85%

The 38 included publications comprised cohort studies (n=22, 58%), case control studies (n=14, 37%), a crossover trial (n=1, 3%) and a pilot randomised controlled trial (RCT) (n=1, 3%). There were 21 (55%) studies which used the term ‘experience sampling’ (ESM) to describe the method of digital data collection, 13 (34%) studies used the term ‘ecological momentary assessment’ (EMA), and one (3%) used each of ‘computerised ambulatory monitoring’, ‘self-assessment’, ‘mobile phone-based assessment’ and ‘computerised ecological momentary assessment’ (EMAc).

Studies collected data on participant experiences, including what participants observed, encountered, or undertook (n=11, 29%), immediate environment or context (n=19, 50%), current behaviour (n=12, 32%) and cognitive data relating to specific researcher-set tasks (n=1, 3%).

4.3.2 Quality assessment scores

All 38 studies were assessed for quality. Overall, 14 (37%) were evaluated as high quality and 24 (63%) as low quality.

4.3.3 Participants

The 38 included studies recruited a total of 2,722 participants with psychosis. Overall 51% (n=1,380) of participants were male. The mean age was 41 years. Other participant demographic variables were reported inconsistently across studies. Data were collected from 2,643 (97%) participants in the community and 79 (3%) were inpatients at the time of data collection. Participants had diagnoses including schizophrenia, spectrum disorder, psychosis, non-affective psychotic disorder, bipolar disorder, schizophreniform disorder, schizo-affective disorder, delusional disorder, or psychotic disorder not otherwise specified (NOS), depression with psychotic symptoms, delusional disorder and first episode psychosis.

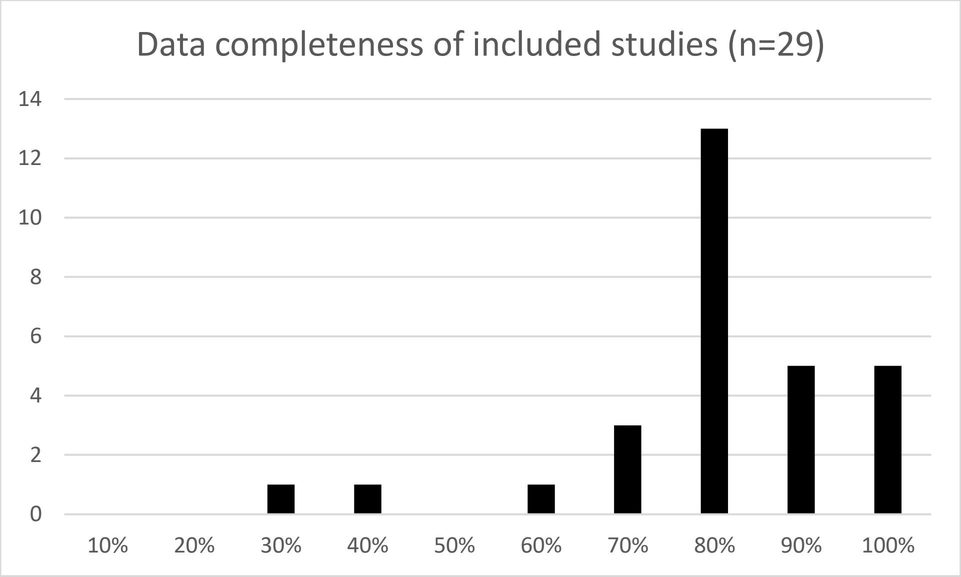
4.3.4 ESM Design

The mean study duration was 9.3 days (range 2-30). Participants responded to a mean number of 6.8 (range 3-10) questionnaires per day for a mean number of 12.3 (range 9-15) hours per day. The included studies comprised 27 (71%) signal-contingent, seven (18%) time-contingent, three (8%) stratified, no event-contingent protocols were identified, and one study was not classifiable due to insufficient design description. 16 (42%) studies used Personal Digital Assistants, 14 (37%) used smartphones, five (13%) used an online data collection platform and three (8%) a bespoke electronic device. 34 (89%) studies used devices provided by the research team, no studies used participant-owned devices and 2 (5%) provided smartphones for use in the study if participants did not have their own. 6 (16%) studies used questionnaires derived from validated scales, 19 scales (50%) were developed for individual studies, and 8 (21%) studies used a combination of both. Questionnaires were available for participants to answer for a mean of 15 minutes (range 5-60). The mean completion time was estimated to be 3.5 minutes (range 2-5). Training in completion of ESM questionnaires was provided for participants in 33 (87%) studies. Contact with researchers during data collection was initiated by participants in 2 studies (5%), initiated by researchers in 15 (39%) studies, and initiated by either researchers or participants as required in 5 studies (13%). Where the number of studies does not total 38 it is because insufficient design details were reported.

4.3.5 Data completeness

Percentage of data completeness was obtained for 29 studies. The remaining nine studies expressed data completeness as either a percentage or number of participants who completed more than a predefined threshold amount, meaning it was not possible to determine the exact data completeness percentage. Data completeness across included studies in summarised in Figure 4.2. The X axis represents percentage of data completeness, and the Y axis represents frequency.

Figure 4.2 Data completeness of included studies



4.3.5 Objective 1: Typology of design choices used in ESM studies

Analysis of included publications identified 24 design decisions. These are shown in Table 4.4.

Table 4.4 Design decisions (n=24) identified in included papers

Design category	**Design decisions**
Study context	Study design
	Sample size
	Data collection setting
	Recruitment setting
ESM Approach	ESM protocol
	Type of prompt
	Technology used
	Device ownership
	Time taken to complete measures
	Type of data being collected
	Design of the questionnaire
	Other data collected
	Total length of time sampling took place

ESM implementation	Questionnaire availability
	Data collection frequency
	Study duration
	Terminology used
	Data access
	Accepted response rate
	Contact with research team during data collection
	Participant training
	Additional support
	Participant reimbursement
	Participant characteristics

Three superordinate themes were identified from the designs: Study context, ESM approach and ESM implementation. These are described below and listed in Table 4.3, 4.4 and 4.5 respectively, along with identified design choices that relate to each superordinate category.

Superordinate theme 1: Study Context

The Study Context theme describes decisions made when designing an ESM study which are not ESM-specific decision. These are shown in Table 4.5.

Table 4.5 Design typology theme 1: Study context

Theme	Definition	Categories
1.1 Study design	Design of the overall study within which the ESM study is nested	Cohort Case control Crossover trial Pilot RCT
1.2 Sample size	Intended number of participants completing ESM measures	Continuous: N
1.3 Data collection setting	Location of ESM data collection	Hospital (currently an in-patient) Community (not an in-patient)
1.4 Recruitment setting	Location of participant recruitment	Hospital Community Hospital and community

Superordinate theme 2: ESM Approach

ESM approach describes the design decisions relating specifically to experience sampling and are shown in Table 4.6.

Table 4.6 Design typology theme 2: ESM Approach

Theme	**Definition**	**Categories**
2.1 Data collection method		
2.1.1 ESM protocol	Data collection trigger	Event-contingent assessments: carried out when a predefined event has occurred, for example attending a social event. Signal-contingent assessments: scheduled at random times. Time-contingent assessments: involve prompting the individual to make an assessment at pre-defined intervals Hybrid assessments: a combination of more than one data collection trigger
2.1.2 Type of prompt	Alert to promote participant response	Auditory (beep) Vibrate Visual prompt
2.1.3 Hardware used	The hardware used to collect data	Personal Digital Assistant (PDA) Online data collection platform Smartphone
2.1.4 Software used	The software used to collect data	Smartphone application
2.1.5 Device ownership	Owner of the device used to collect data	Provided by researcher Pre-owned by participant

2.2 Measures		
2.2.1 Questionnaire completion time	Total time taken by participants to complete one round of questions	Continuous: minutes
2.2.2 Type of data	Type of data being collected	Cognitive data Behavioural data Experience data Context data
2.2.3 Questionnaire design	Were questions derived from psychometrically validated scales?	Derived from validated scale/scales Uses non-validated scales
2.2.4 Other data collected?	Was other participant data collected during the ESM data collection period?	Yes No
2.3 Schedule		
2.3.1 Measurement duration	Time period within each day that data collection takes place, i.e., gap between earliest and latest time	Continuous: hours
2.3.2 Questionnaire availability	How long was the questionnaire available for participant response after each prompt?	Continuous: minutes
2.3.3 Data collection frequency	Number of prompts per day	Continuous: numerical value
2.3.4 Length of time in study	Length of time ESM data collection is conducted	Continuous: days

Superordinate theme 3: ESM Implementation

The theme of ESM implementation is shown in Table 4.7.

Table 4.7 Design typology theme 3: ESM implementation

Theme	**Definition**	**Categories**
3.1 Terminology	What was the method of data collection called in the study?	Experience Sampling Methods or ESM Ecological Momentary Assessment or EMA Ambulatory assessment Computerised ambulatory monitoring Mobile phone-based assessment Self-assessment Computerised ecological momentary assessment (EMAc)
3.2 Data		
3.2.1 Data access	Who can access collected ESM data?	Researchers Participants Clinicians
3.2.2 Accepted response rate	Amount of questionnaires completed in order to be eligible for inclusion	Continuous: %

3.3 Participation		
3.3.1 Participant training?	Was training provided for participants prior to commencing ESM data collection?	Yes No
3.3.2 Contact with research team	Who initiates additional contact between the research team and participants during the ESM period?	Researcher Participant Either
3.3.3 Additional support	Support offered to participants by the research team after commencing data collection	None Initial contact after commencing data collection Technical support Technical support on request Motivational support Emotional support
3.3.4 Participant reimbursement	Compensation provided to each participant	Continuous: £

4.3.6 Objective 2: Predictors of data completeness

Percentage of data completeness was obtained for 29 studies, either from the original papers or calculated by the researcher. Only these 29 were included in the final analysis. The remaining 9 studies expressed data completeness as either a percentage or number of participants who completed more than a predefined threshold amount, meaning it was not possible to determine the exact data completeness percentage.

A weighted regression of design decisions included in the typology was conducted, and the significance of each design choice as a predictor of data completeness is shown in Table 4.8.

Table 4.8 Weighted regression of design choices as predictors of data completeness for included studies (n=29)

Design Choice	**Significance** (overall p-value)
1.1 Study design	0.221
1.2 Sample size	0.159
1.3 Data collection setting	0.737
1.4 Recruitment setting	0.741
2.1.1 ESM protocol	**0.021**
2.1.2 Type of prompt	0.310
2.1.3 Hardware used	0.078
2.2.2 Type of data	0.978
2.2.3 Questionnaire design	0.540
2.2.4 Other data collected?	**<0.001**
2.3.1 Measurement duration	**0.033**
2.3.2 Questionnaire availability	0.210
2.3.4 Length of time in study	**0.021**
3.2.2 Accepted response rate	**0.035**
3.3.2 Contact with research team	**0.014**
3.3.3 Additional support	0.390
Participant gender	0.435
Participant mean age	0.450

Denominator what's this?	0.165
2.1.5 Device ownership	0.320
3.1 Terminology used	0.984
3.2.1 Data access	0.869
3.3.4 Participant reimbursement	0.313

Bold = $p<0.05$

The regression identified six candidate predictors of data completeness: ESM protocol, length of time per measurement, total time in the study, research team contact, accepted response rate and collecting other data. If a Bonferroni adjustment were applied however, this would set statistical significance at $p=0.002$ and therefore only 'Other data collected' would be statistically significant.

The findings from the weighted regression for specific values of these six candidate predictors are shown in Table 4.9.

Table 4.9 Weighted regression for candidate predictors of data completeness for included studies (n=29)

Design Choice	**Beta-value**	**Standard error**	**P**
2.1.1 Protocol			
Signal contingent	reference		
Time contingent vs Signal contingent	-11.82	4.24	**0.010**
Hybrid vs signal contingent	-0.25	5.18	0.962
2.2.4 Other data collected			
Yes	reference		
No vs yes	19.26	3.57	**<0.001**
2.3.1 Measurement duration (hours)	-2.16	0.94	**0.033**
2.3.4 Length of time in study (days)	-0.438	0.18	**0.021**
3.2.2 Accepted response rate (% of questionnaires)	68.07	28.70	**0.035**
3.3.2 Contact with research team			
Researcher initiated	reference		
Participant initiated vs Researcher initiated	-17.49	5.06	**0.004**
Both vs Researcher initiated	-4.84	7.85	0.549

Bold = p<0.05

Table 4.8 shows that using a time contingent protocol rather than a signal contingent protocol was significantly associated with reduced data completeness by around 12%. Greater data collection burden was consistently associated with reduced data completeness: every extra hour in measurement duration reduced data completeness by 2%, every additional day enrolled in the study reduced data completeness by 0.5% and collecting extra data alongside ESM data reduced data completeness by 19%. Finally, researcher-initiated contact with participants increased data completeness by 17.5% when compared to participant-initiated contact

4.4 Sensitivity analysis

The analysis was repeated only including the 10 studies rated as high quality that expressed the data completeness as a percentage. The weighted regression is shown in Table 4.10.

Table 4.10 Weighted regression of design choices as predictors of data completeness for high quality studies (n=10)

Design Choice	**Significance** (overall p-value)
1.1 Study design	0.234
1.2 Sample size	**0.012**
1.3 Data collection setting	NA (all community)
1.4 Recruitment setting	NA (all community)
2.1.1 Protocol	0.697
2.3.3 Data collection Frequency	0.589
2.2.2 Type of data	0.204
2.2.3 Questionnaire design	0.453
2.2.4 Other data collected	**0.006**
2.3.2 Questionnaire availability	0.119
2.3.4 Length of time in study	0.595
2.3.1 Measurement duration	0.133
3.2.2 Accepted response rate	0.506
3.3.2 Contact with research team	0.669
3.3.3 Additional support	0.693
% male	0.331
Mean age	0.636
2.1.2 Type of prompt	NA (only one category)
2.1.3 Hardware used	**0.045**
2.1.5 Device ownership	NA (only one category)
3.1 Terminology used	0.735
3.2.1 Data access	0.675
3.3.4 Participant reimbursement	0.935

Bold = $p<0.05$

Table 4.10 shows candidate predictors of data completeness in studies assessed as high quality (Sample size, other data collected and hardware used).

Table 4.11 Weighted regression for candidate predictors of data completeness for high quality studies (n=10)

Design Choice	**Beta-value**	**Standard error**	**p**
Sample size			
0-49 participants	reference		
50-99 participants vs 0-49 participants	-23.55	8.02	0.022
100+ participants vs 0-49 participants	8.20	5.74	0.196
Other data collected			
Yes	reference		
No vs yes	28.47	7.71	0.006
Hardware used			
Personal Digital Assistant	reference		
Data collection platform vs Personal	10.00	8.86	0.302
Digital Assistant	1.49	7.96	0.858
Smartphone application Personal	-24.90	9.87	0.045
Digital Assistant			
Electronic device Personal Digital			
Assistant			

Bold = $p<0.05$

Table 4.11 shows the results of a weighted regression for candidate predictors of data completeness for high quality studies (n=10).

4.5 Discussion

This systematic review identified design decisions used in experience sampling studies of people with psychosis. The resulting typology identified three superordinate themes relating to design decisions in ESM studies: Study context, ESM approach and ESM implementation. Weighted regression was then used to identify six candidate design decisions from the main analysis that predicted data completeness: ESM protocol, other data collected, length of time in study, measurement duration, accepted response rate and contact with the research team. Of these predictor variables 1 variable (other data collected), was also found in the sensitivity analysis of high quality studies.

4.5.1 Theme 1: Study context

The study context comprises design decisions that are not exclusive to ESM studies. Sample size is a design choice identified in this category. The number of participants necessary to address the study aims is an important design decision to consider when planning an ESM study (Trull and Ebner-Priemer, 2020). It is recommended that the sample size for ESM studies is based on a power calculation to ensure the study is sufficiently powered to detect effects being studied (Bolger and Laurenceau, 2013b). People with psychosis have been shown to be less adherent to ESM study protocols than the general population (Rintala et al., 2019). Higher rates of participant withdrawal may be expected (Vachon et al., 2019). Attrition is something which researchers need to consider to ensure that, on completion of the study, the remaining sample size and the number of questionnaire responses are sufficient to address study aims.

Another design choice relating to the study context is the data collection setting. ESM studies are designed to assess phenomena as they occur within real world settings (Trull and Ebner-Priemer, 2009), in order to capture experiences as they occur in the context of participants lives (Oorschot et al., 2009). One benefit of ESM is that it can be used to assess the relationship between a participant’s immediate environment and the variables of interest (Palmier-Claus et al., 2011). Therefore, it is important that the data collection setting allows the aims of the study to be met.

The importance of the data collection setting can be illustrated by ESM studies that have collected data from participants in hospital. Carrying out data collection in a hospital setting may alter or limit the range of responses made by participants compared to a community or more ‘real life’ setting (Trull and Ebner-Priemer, 2020). ESM studies which have taken place in a hospital setting have aims specifically relating to inpatients. One study has focused on changes to psychosis symptoms in the initial period after starting medication as an inpatient (So et al., 2013), and another was testing the feasibility of ESM methods in an inpatient setting (Kimhy et al., 2014). Therefore, researchers need to consider the data collection setting and its relevance to the study aims when designing an ESM study.

4.5.2 Theme 2: ESM approach

The ESM approach describes the ESM-specific design decisions. Four ESM protocols were included in the typology. Event-contingent assessments, Signal-contingent assessments, Time-contingent assessments, and hybrid assessments. Three ESM protocols are commonly cited in ESM literature (Himmelstein et al., 2019). A questionnaire prompt may be sent to participants at pre-defined intervals (time contingent), scheduled at random times (signal contingent) or carried out when a predefined event has occurred (event contingent) (Wheeler and Reis, 1991). ‘Hybrid assessment’ has been used to describe combined protocols.

A sampling protocol is often selected based on the variables of interest (Janssens et al., 2018). Choice of protocol may depend on whether the variables are discrete, relating to distinct events such as social interactions, or continuous events with less identifiable parameters, such as mood (Shiffman et al., 2008). Discrete events are well suited to event contingent protocols as they have definable beginning and end points. Rather than waiting for a signal or prompt, participants fill out a questionnaire when a discrete event occurs. Time contingent and signal contingent protocols are better suited to measurement of continuous variables. Participants are not required to identify the beginning or end of a pre-defined event in order to complete a questionnaire in time contingent or signal contingent designs (Myin-Germeys et al., 2018).

Signal and time contingent protocols can be carried out at fixed or flexible time points (Myin-Germeys et al., 2018). Some authors described their signal contingent designs as stratified (Hartley et al., 2014) or semi-random (Janssens et al., 2018). In stratified sampling, questionnaires are sent at random time points within pre-programmed time windows. These parameters are unknown to the participant (Harvey et al., 2021). An example of this would be a protocol with a range of 90 min within which at least one beep occurred with a minimum of 15 minutes and a maximum of 3 hours between each beep. The intention of the stratified protocol is to balance the requirement for collecting variable and valid data with participant burden (Hartley et al., 2014). The data may be more variable than a time contingent protocol, as the timing of the signal cannot be anticipated by participants. Participants will therefore be less likely to alter their daily life or habits to incorporate the sampling.

Another design choice relating to ESM approach is whether the digital technology used for data collection was provided by the researchers or participants used their own smartphones. The present review found there to be no significant difference in data completeness between studies which provided a device and those in which participants used their own phone. There is conflicting opinion about this in ESM literature (Trull and Ebner-Priemer, 2020). Disadvantages of using participant-owned devices may include increased distractions from other applications on the phone and decreased uniformity of study procedures (Meers et al., 2020). Advantages may include reduced study costs and also reduced requirement for participants to meet researchers face to face (Hofmann and Patel, 2015), which could reduce participant burden. A meta-analysis on ESM protocol compliance in substance users also found no difference in adherence rates for participants who used their own phone compared with participants who used researcher provided devices (Jones et al., 2019).

The typology identifies different types of prompts to alert participants to respond to questionnaires. The kind of alert available and its use is dependent on the type of digital technology used in the study. The type of prompt used to alert participants to questionnaires may be more easily controlled by researchers in studies using pre-programmed devices. PDAs can be locked by researchers after being programmed for the study (Palmier-Claus et al., 2011), meaning that participant cannot alter the settings. There may be more variability in how devices are used for data collection if participants use their own device. Most ESM studies are now carried out using smartphone apps (Myin-Germeys et al., 2018). Many apps are programmed to emit an auditory signal or beep to alert the participant to complete a questionnaire (Thai and Page-Gould, 2018). Participants have the ability to silence their device or alter the type of signal e.g. to vibrate rather than beep. This may influence whether they respond to questionnaire prompts, influencing protocol adherence.

The typology identified measures used for ESM studies that were derived from psychometrically validated scales and others that were not validated. Many of the measures which were not validated were created by the research team for the purpose of the study. In ESM studies, researchers have often selected items from longer, validated measures and adapted the questions to fit the study time frame (Trull and Ebner-Priemer, 2020). This is often due to the lack of validated measures available for use in ESM studies (Fisher and To, 2012). Researchers should consider that adding “right now” to a questionnaire item does not necessarily mean that it is appropriate for measuring momentary states (Kimhy and Vakhrusheva, 2019). Measuring momentary experiences is different from measuring phenomenon included in cross-sectional questionnaires that occur generally and retrospectively (Myin-Germeys et al., 2018). When considering what questionnaires to use in ESM studies, researchers should take into account the momentary nature of the phenomena and develop items that accurately capture how they are experienced over the course of the study duration (Varese et al., 2019).

4.5.3 Theme 3: ESM implementation

ESM implementation describes the ways in which the ESM methods were applied within studies. The typology identified different terminology used to describe ESM methods. Two of the identified terms, ‘ESM’ and ‘EMA’ are often used interchangeably (Vachon et al., 2019). Study authors often acknowledge interchangeability and state their decision to use particular terms in study introductions. Others use both terms combined: ‘ESM/EMA’ (Bos et al., 2015).

ESM and EMA have originated from different research traditions (Trull and Ebner-Priemer, 2009). ESM originates from a mental health research background and was developed to understand mental processes (Csikszentmihalyi and Larson, 2014). EMA has originated in behavioural medicine (Stone and Shiffman, 1994), and focuses on behavioural and cognitive processes in natural settings. ESM and EMA are often discussed in relation to their similarities, which include collecting self-reports about behaviour cognition or emotions in real time in participants daily lives (Trull and Ebner-Priemer, 2013).

Due to their different backgrounds, a way to distinguish between them may be the type of data that is collected. According to their origins, ESM studies would traditionally collect experience data and EMA studies would collect behavioural or cognitive data. Of the included papers in this review, the terminology did not relate consistently to the type of data that would be expected from each method. ESM studies were used to collect behavioural or cognitive data (Ben-Zeev et al., 2012a) and some studies the authors described as using EMA involved the collection of data about participant experiences (Reininghaus et al., 2016).

Better definition of terms could allow for meaningful distinctions to be made between design decisions. The lack of uniformity might create an additional challenge to the design of ESM studies by preventing researchers from selecting the most appropriate method.

Participant training and monitoring from researchers and also financial reimbursement are often used by researchers to increase protocol adherence (Trull and Ebner-Priemer, 2020). No difference was found in protocol adherence between studies that reported providing participants with training prior to commencement of data collection and studies which did not report that training had been provided (Jones et al., 2019). This finding could be due to the lack of reporting guidelines in ESM research, meaning that studies which did provide training did not always report it (Trull and Ebner-Priemer, 2020). This could also be because training is not sufficient to improve protocol adherence (Vachon et al., 2019), and other strategies are also required. The typology also identified support offered to participants once data collection has commenced. This is a common method of encouraging protocol adherence (Rintala et al., 2019). It can take the form of technical support, motivational support or emotional support.

This study found no significant association between data completeness and reimbursement to participants. However, reimbursement can involve a number of different strategies, including providing added incentives to participants who achieve high levels of protocol adherence, withholding payment if compliance falls below a certain threshold, and providing payment at regular face to face meetings (Trull and Ebner-Priemer, 2020). The value of participant reimbursement has been found to be positively associated with protocol adherence (Vachon et al., 2019). However, the authors note that they did not consider the strategy used to provide the incentives. Instead, a total incentive was calculated for each study. Another study investigated studies which provided reimbursement proportional to the number of questionnaires completed. No increase in protocol adherence was found (Jones et al., 2019). The difference in findings indicate that more research is needed in this area, particularly on the influence of different reimbursement strategies on data completeness.

4.5.4 Applicability to different populations

Design choices included in the typology are consistent with those described in suggested ESM reporting guidelines for research in psychopathology (Trull and Ebner-Priemer, 2020). This suggests that the typology can be applied across different mental health populations. Future research is required to validate the typology for use with transdiagnostic groups. For example, when being used to collect data from participants with depression, ESM is well suited to measuring discrete variables such as self-harming behaviours (Armey et al., 2015).This suggests that event contingent protocols may be used more frequently with this population (Shiffman et al., 2008).

4.5.5 Data completeness

Variations in the ESM protocol predicted data completeness. Using a signal contingent protocol compared to a time contingent protocol was shown to increase data completeness by around 12% ($p<0.01$). This is in contrast with previous research which has shown that signal contingent sampling may be perceived as more burdensome by study participants (Piasecki et al., 2007) leading to lower levels of adherence compared to other protocols (Walsh and Brinker, 2015). The authors suggest that higher levels of predictability afforded by time contingent protocols may increase adherence as participants are able to integrate responding to questionnaires into their daily routine (Walsh and Brinker, 2015). Knowledge of when to expect the questionnaire prompts may allow participants to plan their daily tasks in accordance with the scheduled questionnaires (Vachon et al., 2019).

A study of ESM in participants with substance dependence found that participants may prefer to isolate themselves, or to be in a quiet environment, when responding to questionnaires (Serre et al., 2012). In this case, the additional burden of anticipating the signal at a certain time and finding a quiet environment may account for lower data completeness with a time contingent protocol. Using an event contingent protocol has been shown to predict a higher level of data completeness compared to signal contingent protocols in a student population (Himmelstein et al., 2019). In this review, there were no studies included in the analysis that used an event contingent protocol. Future research could investigate adherence to event contingent protocols of people with psychosis. As there are advantages and disadvantages to each ESM protocol and inconsistent findings regarding their effects on data completeness, it has been suggested that the choice of protocol should be based on the requirements of the study (Vachon et al., 2019). This may involve choosing a protocol that is based on the nature of the variables of interest (Shiffman et al., 2008).

Design decisions relating to scheduling were found to influence data completeness. Longer study lengths and longer daily measurement duration predicted lower levels of data completeness. For every day participants were enrolled in a study, data completeness reduced by 0.5% (p=0.021). Similarly, every additional hour of measurement duration per day reduced data completeness by 2% (p=0.033). These findings are consistent with previous research. A study analysed predictors of adherence to ESM protocols in a pooled data set of 10 ESM studies. The sample consisted of 1,717 participants, of whom 15% had experienced psychosis. The results showed that ESM protocol adherence declined over the duration of study days. (Rintala et al., 2019).

Some studies have customised the time period per day that sampling took place for each participant. This has included personalising the daily measurement period to each participant’s waking hours (Ben-Zeev et al., 2012c). Sampling took place for the same number of hours per day for each participant but began and ended at different times. This review only included the total number of hours per day sampling took place in the analysis. Future research could investigate the relationship between personalised scheduling and data completeness.

Participants who did not carry out other data collection activities in addition to responding to ESM prompts completed 19% more questionnaires compared with those who completed additional data collection activities (p<0.001). This finding is in contrast to a study showing that participants who were asked to provide a saliva sample at the time they filled out ESM questionnaires did not complete significantly less questionnaires compared participants enrolled in ESM studies which did not include additional data collection activities (Rintala et al., 2019).

The difference in findings may be because of differences in the nature of study procedures. A number of different methods of data collection have been identified. Self-report methods such as ESM require participants to carry out a particular action, whereas other types of ambulatory assessment involve the automatic collection of ambient data via built-in device sensors (Barnett et al., 2018). Different ambulatory methods place different demands on participants and therefore different degrees of burden. ESM may create high levels of burden (Eisele et al., 2020). Questionnaires may also be missed by participants (Vachon et al., 2019) or completed incorrectly (Eisele et al., 2020) , which would not occur in ambient data capture.

Another factor that may account for the difference in findings is the scheduling of study procedures. The saliva samples were collected at the same time as the ESM questionnaire was carried out. The signal emitted for participants to respond to the questionnaire may also have served as a reminder for them to provide the saliva sample.

Longer data collection periods, both per day in total study length, and additional data collected all predict lower data completeness. This indicates that data completeness may be associated with lower assessment burden. This was also found in the sensitivity analysis of higher-quality studies. Study duration may increase participant burden (Eisele et al., 2020), which has been shown to increase throughout the duration of the study (Piasecki et al., 2007).

Monitoring participants once ESM has commenced has been recommended in order to encourage protocol adherence (Trull and Ebner-Priemer, 2020). Support from researchers during the data collection phase is either initiated by researchers or by participants. Researcher initiated contact with participants throughout the duration of the study increased data completeness by 17.5% compared to participant-initiated contact (p=0.014). These findings support active researcher support once data collection has commenced. This is something which may be particularly beneficial if participants find the study procedures burdensome.

After a Bonferroni adjustment, only the variable ‘Other data collected’ was statistically significant. This indicates that the level of significance of the other variables was not robust enough withstand criteria for significance when considering multiple comparisons.

4.5.6 Sensitivity analysis

Three design decisions were found to predict data completeness in high quality studies: sample size, other data collected, and hardware used. Studies in the middle size range (50-99 participants) were found to have less complete data sets than smaller (0-49 participants) and larger studies (100+ participants). Reasons for this may be that smaller studies were easier for researchers to offer active support to participants. The main analysis has shown that active support from researchers increases data completeness. This is something that may have been easier to achieve in smaller studies. In studies with over 100 participants, researchers may need to rely on participant-initiated support which has been shown to predict less complete data sets.

Three design decisions which were found to predict data completeness in the main analysis did not predict data completeness in high-quality studies: type of protocol used, length of time in study and measurement duration. This may be because the quality of the included studies influences the findings. In order to clarify this, more high-quality ESM studies need to be conducted.

4.5.7 Strengths and limitations

One strength of this study is the rigorous search strategy. This was designed in collaboration with two information specialists with expertise in conducting systematic review searches in the field of mental health. Another strength is the use of several analysts with differing expertise. Areas of expertise include clinical expertise, mental health services research and technology research and design.

Several limitations can be identified. Studies were only included which reported data completeness, or studies where it was possible to calculate this. Studies that did not report this could have been included for Objective 1, which may have increased generalisability of the findings. The title, abstract and full paper sifting was only carried out by the thesis author, which may introduce inclusion bias. In the absence of an appropriate quality checking tool, recommended reporting guidelines were used instead, which may not have been fully capturing quality. Finally, a meta regression could not be carried out, and the weighted regression that was conducted instead does not account for given estimates of variance, meaning that conclusions drawn from the analysis need to be interpreted with caution.

The sensitivity analysis is limited by the small number of included studies, so findings rely on a very small number of studies included in each category. The sensitivity analysis confirmed collecting data in addition to ESM data predicts lower data completeness.

4.5.8 Conclusions

The study addresses a knowledge gap related to design decisions for ESM studies recruiting people with psychosis. The identification and classification of design decisions may provide knowledge for researchers designing ESM studies. Identification of design decisions which predict data completeness may enable researchers to make informed design decisions in order to increase chances of collecting a more complete data set.

The typology of design choices used in ESM studies identifies key design decisions to consider when designing and implementing an experience sampling study. The typology could be used to inform the design of future experience sampling studies in transdiagnostic mental health populations. The review also identifies a number of predictors of data completeness. This knowledge could help future researchers to increase the likelihood of achieving fuller data sets.

Future research might seek to add additional design choices to the typology and to refine design decisions as the field advances. Future research may also examine how the typology is used by researchers when designing ESM studies. Researchers may also focus on how design decisions shown to predict completeness can be used in study designs to increase chances of a fuller data sets.

Implications for thesis

ESM was used for data collection in Unfold 1. It is a valid and reliable method when used in studies recruiting people with psychosis and is an appropriate method for the frequent sampling required to detect changes to wellbeing and social contact.

Specific choices about the ESM design in this thesis which follow from this review were:

1. No additional data was collected from participants alongside ESM questionnaires.
2. The number of consecutive days of ESM was as small as possible. As adherence to ESM protocol declines for each day participants were enrolled, the number of consecutive days of ESM sampling will be kept short in order to ease burden and increase the chances of a full data set.
3. The researcher initiated contact with participants after data collection commences. As levels of data completeness have been shown to be lower in this population, efforts will be made by the researcher to increase adherence to the ESM protocol using active support. Participants will be contacted regularly by the researcher after data

collection has commenced to offer support and to encourage adherence with the study protocol.

4. A time contingent protocol was used to measure social contact and level of wellbeing. This is because of the nature of the variables of interest. Wellbeing is a continuous variable, and this was an appropriate protocol to measure this (Shiffman et al., 2008). Social contact is a discrete variable which may be suited to an event contingent protocol. The study was unable to show whether event contingent protocols predict data completeness in this population. Therefore, the time contingent protocol was used to capture both types of variables.

Chapter 5: Methodology

This chapter describes the underpinning epistemology of the thesis. This will be informed by the philosophy of pragmatism. The chapter outlines how pragmatism informed the research methods used.

5.1 Pragmatism

The knowledge claims made by research methods are informed by philosophy. Epistemology is what constitutes acceptable knowledge (Blaikie and Priest, 2017). It refers to the theory of knowledge, which incorporates:

- What knowledge is
- When one has acquired knowledge
- How knowledge can be gained (Johnson, 2017)
- The relationship between the knower and the known (Benton and Craib, 2011).

The epistemological position is concerned with how we justify knowledge, and comes from the discipline of the researcher and the theories of knowledge they have read (Carter and Little, 2007). Research methods and questions are consequently reflections of a researchers' epistemological understanding of the world (Feilzer, 2010). A researcher's epistemological perspective defines what can be known, which influences the creation of knowledge. Researchers therefore have a responsibility to make their epistemological position clear and to conduct research that is consistent with this position (Madill et al., 2000).

In order to address the aims of this thesis, knowledge was required in order to develop a useful theory of social identity change in recovery from psychosis. In order to develop this theory, qualitative and quantitative data were required, including knowledge of changes to a participant's number of social identity groups, as well as how participants evaluate these groups.

This thesis will be informed by the philosophy of pragmatism. Pragmatism is a set of philosophical tools that have been used to address problems (Biesta, 2010). It is a theory of truth focusing on the outcomes and meanings of an action or event (Denzin, 2012). The central belief is that there is a connection between knowing the meaning of a premise and knowing what consequences to expect as a result of the premise being true (Misak, 2004). Pragmatism turns the focus away from what thoughts and beliefs are, to what they do (Kim and Sjöström, 2006).

Pragmatism is not a single philosophical approach. It is a diverse philosophical perspective (Hall, 2013). It represents a range of positions concerning the nature of knowledge and truth within the domains of daily life and science (Kim and Sjöström, 2006). Charles Sanders Peirce, William James and John Dewey are considered the most important of the classical pragmatists (Johnson et al., 2017). It is the philosophy of the classical pragmatists that informs this thesis, particularly the following features of classical pragmatism:

- Rejection of metaphysical dualisms
- Endorsement of a practical theory
- Belief in human experience as a theoretical starting point
- Truth viewed as fallible

An alternative philosophical approach considered for this thesis was positivism, which is associated with the data of experience and experimentation, defined by the pursuit of objectivity accuracy and neutrality of values (Majeed, 2019). This was not appropriate for this thesis because of the subjective nature of social identity. Another approach considered was constructivism, which aims to understand and reconstruct constructs held by the researcher and study participants (Guba and Lincoln, 1994). This was not adopted because of the need to combine both observable and experiential aspects of social identity groups.

5.1.1 Pragmatism feature 1: Rejection of metaphysical dualisms

A fundamental feature of the pragmatist philosophy is the rejection of epistemological dualism. Dualism concerns the notion that mind and matter are separate entities. (Nussbaumm and Putnam, 2003). Dualism has given rise to the problem that consciousness and thought are perceived as different from the physical world, therefore there is not a consensus on how to perceive a being who has both mind and body (Robinson, 2020). A dualistic view of reality assumes that questions of knowledge have to begin with the mind in order to question how the mind can comprehend the material world outside of itself (Biesta, 2010). Mind/matter dualism provides a basis for modern epistemology by implying one has to justify how the mind can access the outer world (Stent, 1998).

Pragmatism avoids issues of reality by accepting that there are both singular and multiple realities open to empirical inquiry (Feilzer, 2010). By rejecting philosophical dualisms, pragmatists reject the notion that there are fundamental truths rooted in the nature of reality (Kim and Sjöström, 2006). Pragmatists believe in the notion of intersubjectivity; there is a single real world but also that all individuals have unique interpretations of that world (Morgan, 2007).

Peirce’s rejection of dualism is illustrated by the pragmatic maxim. The maxim states:

> *“Consider what effects, that might conceivably have practical bearings, we conceive the object of our conception to have. Then, our conception of these effects is the whole of our conception of the object” (Peirce, 1878, cited in Peirce and Buchler, 1986, p.66)*

The maxim identifies an alternative procedure for analysing concepts. According to the maxim, the goal of any enquiry is to justify the beliefs that arise as a result. The maxim allows investigation of what particular truths may make in reality (Johnson and Onwuegbuzie, 2004). Within the maxim, Peirce connects meaning to what is tangible, rejecting metaphysics and focusing on ascertaining meaning from potentially abstract concepts (Talisse and Aikin, 2008).

This orientation aligns with research into social identity and wellbeing. It has been shown that the number of groups a person belongs to (Brook et al., 2008), as well as the quality of the connection a person has to their groups (Ellemers and Jetten, 2013), can predict better health and wellbeing. Knowledge of group quality as well as group quantity will be sought in order to address the study aims. Viewing social identity through the lens of traditional metaphysics may be problematic as the study requires knowledge derived from both participant consciousness and also the physical world. The pragmatist epistemology enables both types of knowledge to be considered in order to achieve the study aims.

5.1.2 Pragmatism feature 2: Endorsement of practical theory

Actions are prioritised over philosophising in pragmatism, and practical theories are endorsed (Teddlie and Tashakkori, 2003). The pragmatist view of knowledge has been described as 'antirepresentational', arguing that research should no longer aim to most accurately represent reality, but should instead focus on producing knowledge that is useful (Feilzer, 2010). To 19th century philosopher William James, pragmatism was a theory of truth that was based on practicality (Kim and Sjöström, 2006). He proposed that truth should have a practical and functional consequence, saying no concept consists of anything other the potential difference it could make (James, 1904). The pragmatic method is an approach to interpret different ideas and notions by tracing their practical consequences in order to judge whether the notion is 'true' (Kim and Sjöström, 2006). James referred to the practical consequences as the *"cash value"* (James, 1904, p.685), meaning an idea or concept is 'true' in as much as it is useful or practical.

Focus on a practical theory was later echoed by Dewey who believed that to discover the meaning of an idea we must find out its consequences (Dewey, 1921). For James the practical value of an idea was a way of solving metaphysical disputes arising from epistemological dualisms, saying unless some practical difference would follow from one or the other side's being correct, the dispute is meaningless.

The assumption that research should produce a practical theory aligns with the study aims of producing a model of social identity change for people recovering from psychosis. The knowledge is intended to be useful as the research aims are derived from the researcher's experience of clinical work in mental health services and the need for a better understanding of social identity in order to improve treatment.

5.1.3 Pragmatism feature 3: Views truth as fallible

Pragmatism views the concept of 'truth' as provisional, transient and evolutionary (Kim and Sjöström, 2006). Another feature of the pragmatist epistemology agreed upon by classical pragmatists is the concept of fallibilism (Burke Johnson et al., 2017). Fallibilism means that it is recognised that a well-supported belief may ultimately turn out to be false and that all possibility of error cannot be avoided (Hookway, 2013). Reaching absolutely certain and final knowledge is therefore not possible for a pragmatist (Martela, 2015).

Fallibilism grounds pragmatism's orientation to the tentative nature of knowledge (Bernstein, 1983). This fallibilism is reflected in how Peirce understands the method of science; to be embedded within the epistemological position of fallibilism (Martela, 2015). He stated that reasoning:

> "*Should not form a chain which is no stronger than its weakest link, but a cable whose fibres may be ever so slender, provided they are sufficiently numerous and intimately connected*" (Peirce, 1869, p.141).

When a truth turns out to be incorrect, or unexpected, further investigation can be made which may uncover an alternative truth. Other versions of the truth may come to replace a truth which is disproved.

According to Dewey, outcomes of inquiry are not definite solutions to the problem; they are viewed as assertions that may become warranted (Johnson & Onwuegbuzie, 2004). Assertions cannot be warranted until after actions have been taken (Hall, 2013). Any assertions generated must be tested in real life. Transferability requires inquirers to work back and forth between the specific results and their general implications in order to reach a version of the truth (Morgan, 2007). Humans must continually engage in cycles, moving from a state of doubt to a state of belief. The fallibilist notion of truth can therefore be linked back to experience. This occurs continually as different truths are tested and corroborated (Hall, 2013).

Considering the truth as fallible aligns with the dynamic nature of social identity. Social identity is context specific. Particular identities can be ‘activated’ in certain situations, resulting in individuals evaluating themselves in a specific way (Turner et al., 1987). When a specific social identity becomes salient, individuals think and act in terms of those beliefs (Turner et al., 1994). Identity salience can influence how a person thinks, feels, and acts in different situations (Haslam et al., 2021). A person’s sense of self changes as salient identity changes (Turner et al., 1994). For this reason, it will be assumed that knowledge about participants’ social identities gained from the study is just one version of the social identity of each participant. Participants’ salient identities may be dependent on how they experience their role as a participant. The social identity described by each participant during the study may be different from how they would describe their social identity in a different context.

5.1.4 Pragmatism feature 4: Belief in human experience as a theoretical starting point for generation of knowledge

Rejection of the mind/body starting point for knowledge generation implies rejection of the assumption that there is an external system that will explain beliefs (Morgan, 2007). The classical pragmatists had a different theoretical starting point to traditional metaphysics. Rather than starting from a mind/body position the theoretical starting point is lived experience (Burke Johnson et al., 2017). The world is not seen as something to be observed, but something within which humans live their lives, existing in the world primarily as actors (Martela, 2015). To search for knowledge is to set it at work within the stream of experience (James, 1907). Dewey believed that metaphysical theories of knowledge should be replaced by a theory that regards the knower of the world as an agent within that world (Putnam, 2010).

For pragmatists, human experience is the basis for truth (Kim and Sjöström, 2006). The mind and the world interact constantly through human experience (Hall, 2013). Pragmatists' view of the world relates to an existential reality. It consists of different layers, some objective, some subjective, and some a mixture of the two (Feilzer, 2010). Dewey describes how experience does not consist of dualisms such as mind/world or subject/object, but is one single and continuous interaction consisting of huge diversity (Hildebrand, 2016). Dewey classed experience as an indefinite series of interactions, describing his own metaphysis as consisting of human sufferings, enjoyments, trials, successes and failures; all within the range of human experience (Biesta, 2010).

Pragmatism allows the incorporation of both experiential and observable knowledge. Pragmatism has influenced Unfold through placing emphasis on experiential and observable knowledge when understanding social identity. Although the quantity of social identity groups is believed to have some effect on health and wellbeing, this is not enough to gain sufficient knowledge about social identity, as knowledge is required on how group membership is experienced (Bentley et al., 2020).

5.2 Mixed-methods research

Mixed methods research (MMR) is defined as 'The type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of qualitative and quantitative viewpoints, data collection analysis inference techniques) for the purpose of depth and breadth of understanding and corroboration' (Creswell and Plano Clark, 2018, p.3.). Mixed methods research can be used to provide a more complex understanding of a phenomenon that would otherwise not have been accessible by using only one approach (Creswell & Plano Clark, 2011; Morse & Niehaus, 2009).

A paradigm can be defined as the framework of a shared scientific theory and shared common sense beliefs necessary for science to come into existence (Benton and Craib, 2011). One definition of 'paradigm' identified by 20th century philosopher Thomas Kuhn is that they are epistemological stances or distinct belief systems about how research questions are asked and answered. (Kuhn, 1970).

Qualitative and quantitative methods were originally viewed as the two main research paradigms (Burke Johnson et al., 2007). Qualitative methods are defined as the techniques associated with collecting, analysis and interpretation of narrative information. Many qualitative researchers subscribe to a worldview known as constructivism (discussed in Section 5.1). Quantitative research involves techniques associated with collecting, analysis and interpretation of numerical information (Teddlie and Tashakkori, 2009).

Methodological purists have asserted that qualitative and quantitative research have different paradigmatic assumptions and therefore cannot be combined (Greene, 2008, p.12). This is because quantitative and qualitative paradigms have different conceptions of what constitutes truth and reality (Howe, 1988). Incompatibility concerns epistemological assumptions underpinning qualitative and quantitative research, often construed as a clash (Johnson and Onwuegbuzie, 2004, p.16) between a broadly interpretivist approach and positivism/post positivism (Bryman, 2006). Quantitative research methods are often underpinned by the positivist/post positivist notion of a single truth waiting to be discovered by value-free objective inquiry (Yvonne Feilzer, 2010). By contrast, qualitative purists, often called interpretivists or constructivists, believe in multiple constructed realities. For interpretivists, context-free generalisations are neither possible nor desirable (Johnson and Onwuegbuzie, 2004).

Pragmatism justifies the use of qualitative and quantitative data in a study (Johnson et al., 2016). Rather than treating different assumptions as a barrier to mutual understanding, pragmatists accept intersubjectivity as a key element of social life (Morgan, 2007). An intended consequence of advocating pragmatism as an underpinning philosophy is to disrupt the reliance on a metaphysical version of the philosophy of knowledge as a lens for examining social research (Morgan, 2014). Pragmatists claim that all research paradigms aim to find the truth. Objective and subjective enquiry both aim to produce knowledge that represents reality (Feilzer, 2010). The pragmatist antirepresentational view of knowledge could be a way of resolving this epistemological issue.

The pragmatist position states that it is acceptable to mix different types of data in studies which call for both in order to answer the research question (Teddlie and Tashakkori, 2009). The typical opposition between quantitative and qualitative approaches to problem-solving are obstacles to finding solutions (Johnson et al., 2017). The pragmatist position sees longstanding epistemological debates as misguided, and encourages researchers to ignore the centrality of human experience (Morgan, 2007). Pragmatism does not ignore the relevance of epistemology. It does, however, reject assumptions within the metaphysical paradigm, as they constrain assumptions about the nature of knowledge as relating to mind or body (Morgan, 2007). Pragmatism views knowledge as both constructed and based on the reality of the world one experiences and lives in (Teddlie and Tashakkori, 2009).

The use of pragmatism as an underlying philosophy for mixed methods research has been criticised. Some see pragmatism as a simplistic philosophy which can be interpreted as ‘doing what works’ (Johnson and Onwuegbuzie, 2004). When used as an underlying philosophy for mixed methods research, pragmatists have been criticised for saying nothing about their epistemological position (Lincoln, 2010). Use of the term ‘pragmatism’ has been trivialised and sometimes been used synonymously with doing whatever works in order to advance researcher agendas (Hall, 2013). Relatedly, there is a danger in advocating pragmatism as a philosophy for mixed-methods research in that pragmatism as a philosophical stance is conflated with the everyday meaning of pragmatism (Denscombe, 2008). Using pragmatism in this way has been described as utilitarian and fails to acknowledge the philosophical foundation (Denscombe, 2008) and could lead to it to be considered a-paradigmatic (Greene, 2008). Therefore, in this thesis the term pragmatism will always have the philosophical rather than everyday meaning.

Advocating pragmatism as a philosophy in mixed methods research can lead to an indifference towards theoretical disputes and the philosophical questions such disputes articulate (Lipscomb, 2008). A more precise understanding of pragmatism is required to understand it as a philosophy for MMR (Biesta, 2010).

Mixed methods research requires researchers to thoughtfully address competing values, methods, methodologies (Johnson, 2017). It offers the possibility of meaningful engagement with a dialogue across different perspectives and different ways of knowing (Greene, 2015). Although pragmatism offers an immediate and useful position methodologically and philosophically, it should not mark the end of philosophical debates (Johnson and Onwuegbuzie, 2004). Successfully using pragmatism as an underlying philosophy depends on the extent to which pragmatism is viewed as a philosophical paradigm (Biesta, 2010), rather than seen as ‘doing what works’.

5.3 Use of pragmatism and mixed methods research in Unfold

This thesis will go beyond doing what works in order to engage with the philosophical basis of pragmatism and its implications for the generation of knowledge. Pragmatism treats qualitative and quantitative data as epistemologically the same. For this reason, a convergent mixed methods design will be adopted. Quantitative data and quantitative data will be used to generate knowledge on the phenomena of social identity. Both types of data will be collected at the same time and each type of data will be used to access different layers of social identity.

Another design decision that emerged from the pragmatist position that qualitative and quantitative data are epistemologically the same is the use of the abductive research strategy to enable effective integration of the data sets. Integration describes the interaction between the qualitative and quantitative data components of a mixed methods study (O'Cathain et al., 2010). Integration occurs when quantitative and qualitative data is merged in such a way as to be mutually informative, resulting in findings that are greater than the sum of the individual components (Woolley, 2009). Integration should result in qualitative and quantitative data that is interdependent in order to address the research question (Guetterman et al., 2015). The two data sets will be integrated in order to create knowledge about social identity and psychosis which would not be accessible with a single method study. When mixed methods designs do not engage with the philosophical underpinnings, this can result in failure to effectively integrate the data sets. This can result in keeping data sets separate during analysis, discussing each data set separately and only juxtaposing findings from each data set. (Feilzer, 2010). This would not be appropriate in a study informed by pragmatism which considers the two data types in relation to their similarities. Separation would be inappropriate as the qualitative and quantitative strands will have been used to address different 'layers' of the same phenomenon and so need to be effectively integrated in order to gain sufficient knowledge of social identity.

A research strategy is a procedure for generating new knowledge (Blaikie and Priest, 2017). Distinct research strategies include induction, deduction and abduction. The inductive research strategy seeks to establish universal generalisations to be used as explanations (Benton and Craib, 2011). The deductive research strategy aims to test theories, eliminate false ones and uphold the surviving one (Benton and Craib, 2011). Abduction is the process of working back from an observed consequence to a probable antecedent or cause (Denzin, 2017). Abduction ‘moves back and forth between induction and deduction—first converting observations into theories and then assessing those theories through action’ (Morgan, 2007).

A way of ensuring data is integrated effectively is to use abductive reasoning in the integration process. A pragmatic researcher is required to work back and forth between different research strategies and with different epistemological assumptions (Morgan, 2007). Abduction can serve as a point of connection between qualitative and quantitative data (Teddlie and Tashakkori, 2012). It is an inference from a body of data to an explaining hypothesis. The hypothesis itself is not an absolute truth but a “tentative solution” (Burks, 1946, p.305). With the abductive approach, the research process starts with unexpected observations (Kovács and Spens, 2005). This means that it can be used to integrate the two data sets when juxtaposition or difference occurs. Adoption of the abductive research strategy will allow assertions to be tested through the action of integration.

Implications for thesis

This chapter has described how a pragmatist epistemology has influenced the design of the Unfold study. A list of the features of pragmatism and the design decisions arising from them can be found in table 5.1.

Table 5.1 Implications of using pragmatism on the study design

Pragmatism feature	Implications for study design
Rejection of metaphysical dualisms	Qualitative and quantitative data were combined in a mixed methods study design in order to address the study aims.
Endorsement of practical theory	A model of social identity change in psychosis was developed.
Views truth as fallible	Knowledge generated from this thesis was considered one version of the truth which may come to be replaced in the future as other social identity theories and models are developed and tested.
Belief in human experience as a theoretical starting point for generation of knowledge	The mixed methods study gave equal weight to qualitative and quantitative data. A dedicated Public and patient involvement group was formed to inform the study design.
Considers qualitative and quantitative data the same epistemologically	A convergent mixed methods design was used Abductive reasoning was adopted during the integration process

Chapter 6: Methods for Unfold 1

Chapter 6 describes the aims and objectives of the Unfold 1 study, the study design, study procedures and the procedures for data analysis.

6.1 Aims, objectives and hypotheses

Unfold 1 had two aims.

Aim 1 (Methods): To assess digital data collection methods to evaluate prospective assessment of identity change.

The objectives relating to Aim 1 are:

Objective 1.1 (Data collection): To use active and passive approaches to data collection and make recommendations for use in future research.

Aim 2 (Identity): To characterise the processes involved in developing an identity as a ‘person in recovery’ with particular attention to social identity and sense of wellbeing.

The objectives relating to Aim 2 are:

Objective 2.1 (Change processes) To explore the role of social identity change processes in recovery from psychosis

Objective 2.2 (Identity and wellbeing) To investigate the relationship between social identity change and eudaimonic wellbeing

Two hypotheses relating to Objective 2.2 were tested:

Hypothesis 1: Increase in social contact with members of social groups over time precedes increased sense of eudaimonic wellbeing

Hypothesis 2: Participants who maintain group memberships from baseline to follow-up will report higher levels of eudaimonic wellbeing than those who do not maintain group memberships

6.2 Design

Unfold 1 is a longitudinal mixed methods study with a convergent design. In longitudinal research, the researcher repeatedly collects and analyses data on three or more occasions. This method is well suited to investigating phenomena that change over time (Bamattre et al., 2019).

Longitudinal studies are complex in their design and implementation (Ployhart and Ward, 2011). Researchers who wish to design and carry out a longitudinal study face a number of challenges including:

- Methodological and design decisions including appropriate spacing of the repeated measurements and managing participant attrition.
- No guarantee that change in the variables will occur simply because they were measured on multiple occasions over time (Ployhart and Vandenberg, 2010).

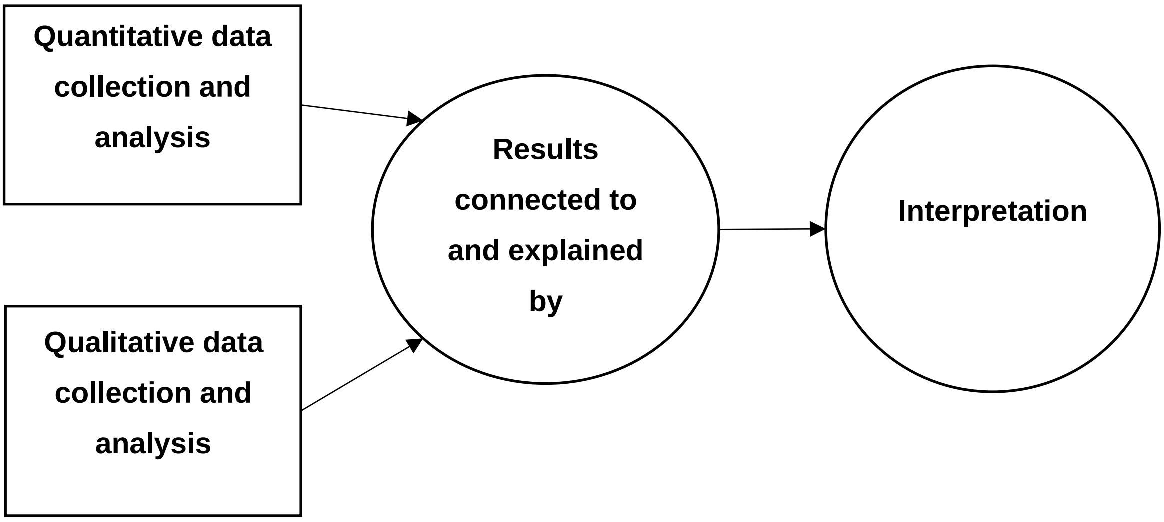
To alleviate some of the design complexities, another design considered for Unfold 1 was a retrospective design. In a retrospective design the study takes place after the event that is being observed (Euser et al., 2009). Participants could be asked to recall their experiences of social identity change as it occurred in their past. A retrospective design allows exclusion of those who have not experienced changes to social identity prior to data collection taking place.

A disadvantage of the retrospective design is that data may be subject to recall bias (Solhan et al., 2009). Recall bias is an error due to differences in completeness or accuracy of recall (Spencer et al., 2017). For this reason, the retrospective design would not be appropriate to meet the aims of the study. When carried out effectively, longitudinal studies are able to capture the dynamic nature of variables and their relationships (Chan, 1998). A prospective design is required to detect changes to social identity and wellbeing over time as participants recover from psychosis. Therefore, a prospective design will be used for Unfold 1.

A mixed methods approach to data collection is needed. Chapter 5 outlined the definition of mixed methods research and identified how mixed methods research can be used to provide a more complex understanding of a phenomenon that would otherwise not have been accessible using a single design (Creswell & Plano Clark, 2011; Morse & Niehaus, 2009). In Chapter 2, it was argued that social identity research has shown that a person’s identity is defined by the number of groups they belong to (Brook et al., 2008), as well as the quality of the connection they have to these groups (Ellemers and Jetten, 2013). Collection of only quantitative data could provide a general understanding of a person’s social identity change in terms of the number of social identity groups and how this may change between two timepoints. Collection of only qualitative data could provide knowledge of participant’s experiences of this change. Collecting only one of these two types of data will not allow for knowledge to be gained which will provide a full understanding of social identity change. Knowledge of both group quality and group quantity will therefore be sought, in order to achieve complete and corroborated results (Creswell and Plano Clark, 2018). By engaging in both forms of data collection, knowledge can be obtained about social identity change in recovery from psychosis that would not be accessible through collection of only one type of data (Shannon-Baker, 2015).

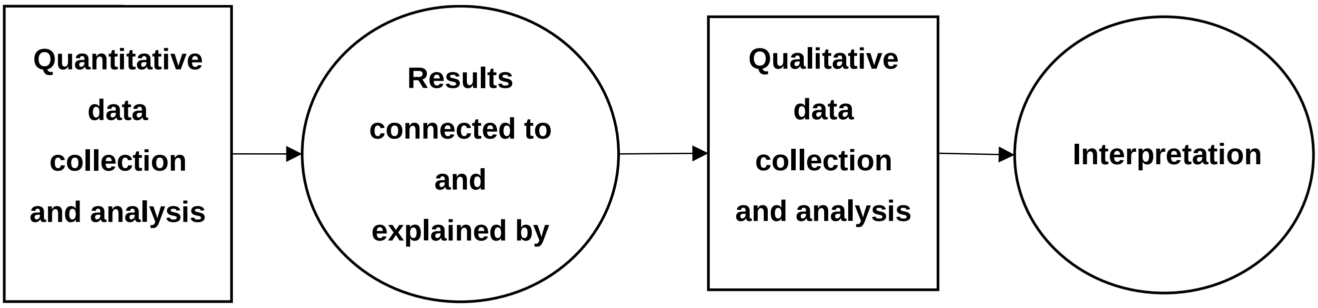
In a convergent mixed methods design, the qualitative and quantitative phases of the study occur in parallel, ending at approximately the same time (Teddlie and Tashakkori, 2009 p.120). This design is illustrated in Figure 6.1.

Figure 6.1 Convergent design



Another mixed methods design considered was the explanatory sequential design. In an explanatory sequential design, the first phase constitutes collection of quantitative data which is then analysed. The first phase is then followed by the collection and analysis of qualitative data in order to expand on the quantitative results. The qualitative phase is designed to follow on from the results of the quantitative phase (Creswell and Plano Clark, 2018). This design is illustrated in Figure 6.2.

Figure 6.2 Explanatory sequential design



An explanatory sequential design was not chosen, because the pragmatist epistemology underpinning the thesis specifies that the quantitative and qualitative data are treated in relation to their similarities. Analysing the two data sets separately without integration implies ontological differences between the two data sets, which the pragmatist position considers unnecessary (Johnson et al., 2017).

A convergent design will be used, where qualitative and quantitative results are brought together and merged so that they can be compared and combined (Creswell and Plano Clark, 2018). This allows for different layers of the same phenomena to be accessed (Yvonne Feilzer, 2010). The convergent design allows the two data sets to be integrated in order to gain sufficient knowledge to achieve the study aims.

The two phases in Unfold 1 comprised:

1. Quantitative data collected about social identity social contact, wellbeing, and recovery

2. Semi-structured interviews conducted about experiences of social identity change and recovery

6.3 Participants

Inclusion criterion

- Participants aged 18-65
- Currently using NHS community mental health services provided by Nottinghamshire Healthcare NHS Foundation Trust
- Meets DSM-5 diagnostic criteria for a psychotic disorder
- Owns and regularly uses a smartphone with an Android operating system
- Fluent in English
- Willing and able to complete self-reported assessments via smartphone
- Able to give informed consent for participation.

Participants aged 18-65 were chosen because this was considered a wide enough age range where recovery and social identity change could occur. Older participants were excluded as they may have been less likely to engage in the social identity groups experienced by a working age population.

Participants who were using community (out-patient) mental health services and who had a diagnosis of a psychotic disorder were included because in longitudinal studies it is important to select a sample who are most likely to exhibit the hypothesised form of change (Ployhart and Vandenberg, 2010).

It was considered likely that those who would make progress in their recovery and those who would experience changes in their social identity would be using mental health services at the time of enrolment.

Due to the need to respond to ESM questionnaire prompts, participants were required to own and regularly use a smartphone. The smartphone was required to have an Android operating system as the RADAR-base App used in the study only runs on this operating system.

Exclusion criteria

- Current inpatient
- Expresses that they are currently experiencing mental health crisis

Inpatients were excluded as it was possible that the role as an inpatient may have had an effect on their ability to develop or maintain other social identities Those experiencing mental health crisis were excluded due to ethical concerns about participants being able to provide informed consent on entry to the study or maintain capacity for informed consent whilst enrolled in the study.

Sample size

A sample size of 50 participants was chosen for the study total. A power calculation is often required at the study design stage (Shulz and Grimes, 2005). A calculation could ensure that a study is powered sufficiently to prevent failure to detect an important effect due to low sample size. A power calculation may also help to avoid ethical issues resulting from enrolling too many participants with the result that there is no scientific value from data from later participants, or too few participants resulting in an underpowered study which does not contribute to the evidence base (Halpern et al., 2002)

A power calculation was not used because Unfold was an exploratory study aiming to explore how ESM methods could be used with people with psychosis. A power calculation may not be appropriate in exploratory studies as there is insufficient data on which to base calculations (Jones et al., 2003). Instead, to decide the sample size NIHR guidance for feasibility studies was drawn upon who recommend a sample size of 40-50 participants (NIHR, 2019). As a result, the findings will be hypothesis-generating rather than confirmatory.

The sample size for qualitative interviews was 10 participants. This number was chosen because this was the number that the researcher and supervisory team believed that central organising concepts would be identified (Braun and Clarke, 2015). It is an idea or concept that captures and summarises the core point of a coherent and meaningful pattern in the data. If the central organising concept of a theme is identified, then the ‘core’ of what a coherent theme is about may be captured. Based on prior experience with conducting qualitative studies with a similar sample, interviews with 10 participants was considered sufficient for central organising concepts to be identified.

In some approaches to qualitative research, saturation has been described as the ‘gold standard’ for deciding sample size (Guest et al., 2006). One definition of saturation is the point in coding when no new codes are found in the data (Saunders et al., 2018). However, the transferability of saturation across all qualitative approaches has been questioned (O’Reilly and Parker, 2013). Tools for guiding sample size should be based on methodological concerns (Malterud et al., 2016).The creators of reflexive thematic analysis (RTA) have argued that saturation only makes methodological sense within a positivist or realist ontology (Braun and Clarke, 2021). In the interpretivist ontology of a qualitative paradigm, saturation has been called a logical fallacy, as new theoretical insights are always possible as long as data continue to be collected (Low, 2019). Coding in RTA stems from engagement with the data, and from situated, reflexive interpretation. It is process-based and evolving (Braun and Clarke, 2021). Therefore, saturation is not consistent with the values and assumptions of RTA.

The pragmatist epistemology asserts there are both singular and multiple realities open to empirical inquiry (Feilzer, 2010). Existential reality consists of different layers, some objective, some subjective, and some a mixture of the two. The pragmatist epistemology allows for both qualitative and quantitative data to be collected and each type of data used to access different layers of social identity. In line with the pragmatist epistemology therefore, qualitative sample size will depend on a situated, interpretative judgement about when adequate data has been generated to enable a rich explanation of patterns related to the phenomena of interest (Sim et al., 2018). This will occur when central organising concepts have been identified.

6.4 Setting

Participants were recruited from community services within Nottinghamshire Healthcare NHS Foundation Trust (NHFT). The Trust provides integrated healthcare services, including mental health services across the county of Nottinghamshire. The community services are for service users aged 18-65 who have mental health difficulties which require the involvement of specialist mental health services.

6.5 Measures

Flourishing Scale

Wellbeing was assessed using the Flourishing Scale. It has been developed to complement existing measures of subjective wellbeing (Diener et al., 2010). It comprises eight items measuring self-perceived success in areas such as relationships, sense of purpose, self-esteem, and optimism. Each item is rated on a 7-point scale ranging from 1 (strong disagreement) to 7 (strong agreement). Final sum scores can range from 8 (low social-psychological prosperity) to 56 (high social-psychological prosperity). High scores signify respondents view themselves in positive terms in important areas of functioning. Flourishing Scale scores have been shown to correlate with similar scales (Diener et al., 2010). Scores on the Flourishing Scale show an acceptable fit to three latent factors of flourishing, positive feelings and negative feelings (Howell and Buro, 2015). The Flourishing Scale has been used in a population of American college students with psychosis. The mean score was found to be 39 out of a possible score of 56 (Oh et al., 2022).

The Flourishing scale was chosen for use in Unfold as it is designed to assess aspects of social–psychological functioning, such as having supportive and rewarding relationships and contributing to the happiness of others. Changes in social-psychological functioning are likely to be present as participants experience social identity change. It is likely that participants who maintained or increase positive social relationships during their recovery will have higher levels of function in social-psychological wellbeing aspects.

The Self-Efficacy for Personal Recovery Scale (SEPRS)

The Self-Efficacy for Personal Recovery Scale (SEPRS) is a 14-item self-report scale measuring an individual's autonomy and responsibility in defining and directing their own recovery (Villagonzalo et al., 2018). It measures a person's confidence in their ability to engage in behaviours relating to recovery. Two items broadly reflect self-efficacy for personal recovery and self-management, and twelve items focus on domains from the CHIME framework. CHIME describes five key aspects of personal recovery: Connectedness, Hope, Identity, Meaning and Empowerment (Leamy et al., 2011). Items are rated on a continuous scale from 0 (not confident I can do this at all) to 100 (highly confident I can do this). Items are averaged to produce the overall score, ranging from 0 (low autonomy) to 100.

SEPRS is a valid and reliable measure, which has been shown to be understandable and acceptable to people who have experienced psychosis. Scale reliability and validity were investigated in a sample of 178 adults with persisting psychosis. The mean score was 65.70 (SD = 19.4) and test-retest reliability was evaluated in a subset of 32 participants. The scale showed high internal consistency (alpha= 0.96), test-retest reliability and convergent validity, including correlating positively with hope, personal recovery, and generalised self-efficacy, whilst showing independence from social desirability, insight, and positive symptoms (Villagonzalo et al., 2018). The SEPRS was chosen for use in Unfold because it captures participant beliefs about their ability to engage in behaviours that support recovery. Developing a positive sense of identity is a behaviour that supports recovery.

Social Identity Mapping Tool (SIM-tool)

The Social Identity Mapping Tool (SIM-tool) assesses an individual's social identity. A participant produces a social identity map (SIM), which visually represents of their social identity groups (Cruwys et al., 2016). The SIM-tool assesses eight aspects of social identity, as listed in Table 6.1

Table 6.1 Social identity constructsge

Social identity construct	**Definition**	**Scoring**
Number of groups	Total number of groups participants generate	0-unlimited
Group importance	Level of importance participant considers each group to have	0-5
Group positivity	How positive participants felt about being a member of each group	0-5
Social contact	Number of days in a typical month that participants engage in an activity related to that group membership	0-30
Group tenure	Number of years of group membership	Years(n)
Group prototypicality	Degree to which participants believed they were ‘like other members in the group’	0-5
Group similarity	How similar participants considered groups	0-5
Group compatibility	How ‘easy versus hard’ it is to be a member of two or more groups	0-5

SIM-tool has been validated with a clinical population of women with mild to moderate depression and a non-clinical population of university students. The SIM-tool has been shown to have good internal consistency, with good convergent and discriminant validity and be easy to use. Social identity constructs represented by SIM-tool have been shown to be significantly associated with the Multiple Group

Memberships scale, which is a measure of group memberships (Haslam et al., 2008) and also Social Network Activity Scale (Brissette et al., 2000), which measures of social network size. SIM-tool has been shown to have high levels of discriminant validity. Social identity constructs measured by SIM-tool are not confounded by social desirability or by personality traits.

To create a SIM, each participant is provided with a sheet of A3 paper and three different sized post-it notes (small, medium and large). Participants were given a detailed verbal definition and examples of social identity groups by the researcher. They were asked to think about different groups and categories they belong to, including ones in which they:

- Have similar opinions about something (e.g. political party, sport team, world views)
- Were born in, or live in the same country
- Do activities together (e.g. gardening, running, arts or crafts, other community groups)
- Are part of the same religion
- Have the same professional qualifications or do the same job (even if you are not necessarily in the same place)
- Are in a close relationship (e.g. a family)
- Have specific roles (parent, grandparent, etc.)

Participants were informed that these are just some examples; there are many other groups that they may feel part of, and that are part of how they see themselves and that there is no right or wrong answer. They were then asked to create a SIM in accordance with the procedures described in Table 6.2.

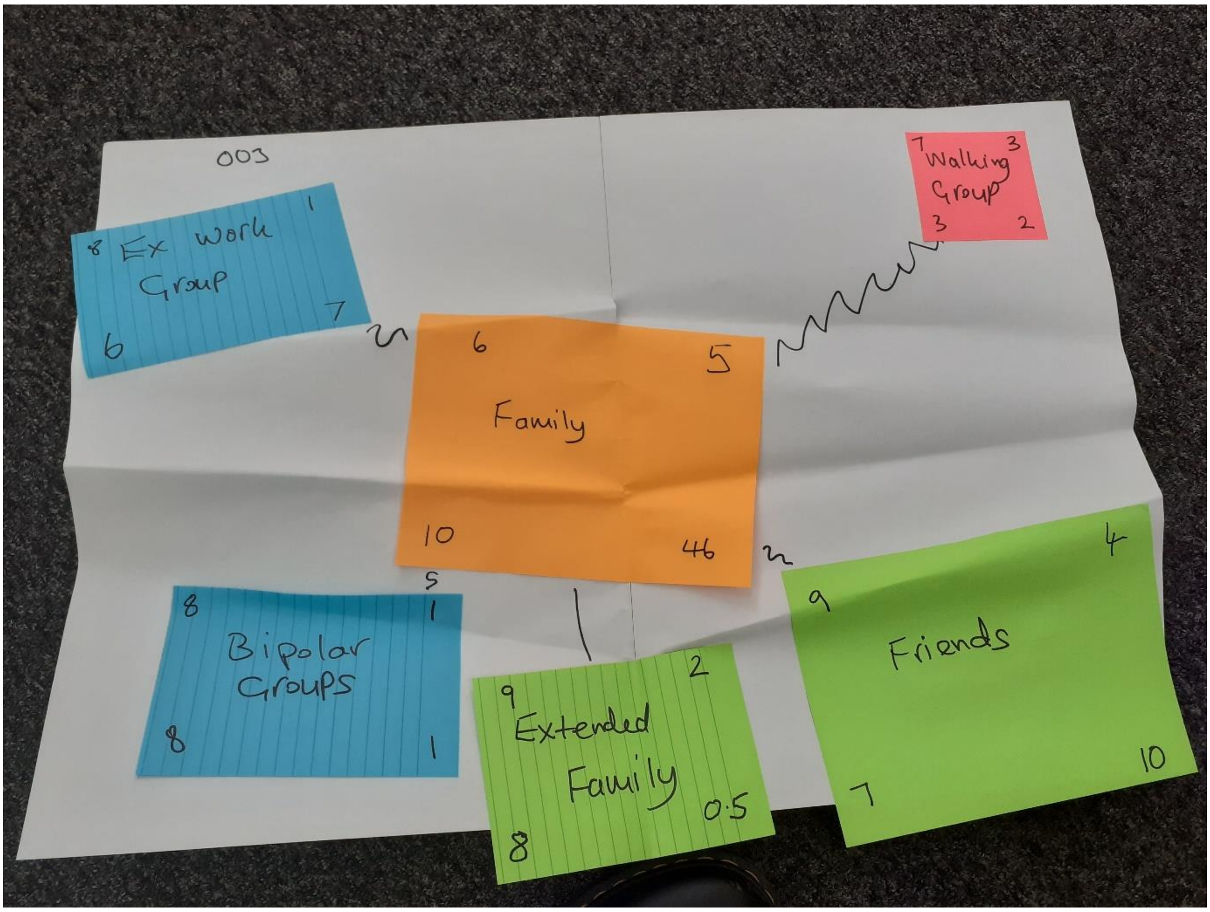
Table 6.2 How participants created their SIM

Order of SIM creation procedures	**Social Identity construct**	**How construct is represented on SIM**
1	Group importance	The names of the most important groups are written on the largest post-it notes, groups of moderate importance on the medium size notes and groups considered least important on the smallest size.
2.	Number of groups	Post it notes are placed on the SIM
3	Group positivity	Participants place group positivity score ranging from 1 (low positivity) to 5 (high positivity) for each group in the top left-hand corner of each post-it.
4	Social contact	Participants place social contact score in the top right had corner of each post-it. This is measured in days per month they have contact with other group members ranging from 0-30
5	Group tenure	Participants place group tenure scores in years for each group in the bottom left corner of the post-it
6	Group prototypicality	Participants place group prototypicality score ranging from 1 (participants felt they were not very much like other group members) to 5 (participants felt they were very much like other group members) in the bottom right-hand corner of each post-it note
7	Group similarity	Distance between groups indicates how different the groups are from each

		other. If two groups are very different from each other (e.g., they do different things, it feels different being a member of each, they have different members), these were placed far from each other on the sheet of paper. If two groups were very similar to each other, these were placed close to each other.
8	Group compatibility	Participants join post-it notes with different lines according to perceived level of compatibility between groups. Straight lines represent very compatible groups, wavy lines represent moderately compatible groups and jagged lines represent incompatible groups.

A completed SIM is shown in Figure 6.3.

Figure 6.3 Completed Social Identity Map (SIM)



Scoring

Social identity constructs used in Unfold 1 were total groups and group positivity. These constructs are scored by each SIM according to the description in Table 6.3

Table 6.3 How social identity concepts are scored and interpreted using SIM-tool

SIM variable	Scoring process	Interpretation
Total groups	Number of post-its in SIM	Total number of groups identified by the participant as groups they belong to which have at least some importance for their social identity
Positive Groups	Number of groups scoring 8,9 or 10 in group positivity	Number of groups identified by the participant as groups they belong to which are a positive aspect of their social identity

The SIM-tool was chosen for Unfold because it is based on social identity theory (SIT) (Tajfel et al., 1979). SIT has shown social identity to be complex and multifaceted. SIM-tool allows a range of different social identity constructs to be captured. The completed SIMs allow for multiple social identity constructs to be represented simultaneously, offering a comprehensive understanding of a person's social identity. Creating a SIM allows social identity groups to be described in relation to each other. These social identity features may be difficult to capture using a single psychometric scale.

6.6 Patient and public involvement

NIHR defines patient and public involvement (PPI) in research as research being carried out by or with members of the public. PPI involves an active partnership between researchers and patients, carers and members of the public that influence and shapes research (NIHR, 2021a). A PPI group was created for the Unfold 1 study, which comprised three people who had experience of mental ill health including psychosis. The PPI group met with the researcher regularly from the study inception to provide advice and give opinions on various aspects of the study design. Design decisions that the PPI group were actively involved in making included are described in Table 6.4.

Table 6.4 Changes made to Unfold study design as a result of PPI input

Issue raised by PPI group	**Changes made to study design**
Refinement of research objectives	Decision to focus on social identity
Choice of measures	Decision to use SIM-tool made after PPI group tested the measure
Active involvement in feasibility test	See Section 6.8 for details of feasibility testing
Development of topic guides for interviews	Decision to include an additional topic guide about using smartphone for data collection.

6.7 Ethical approval

REC approval was obtained from the Health Research Authority (19/LO/1228). All participants gave consent to participate and for their data to be anonymised and used in publications. The consent form is included as Appendix 1.

6.8 Procedures

Data were collected using experience sampling methods, passive smartphone monitoring standardised measures, and semi-structured interviews.

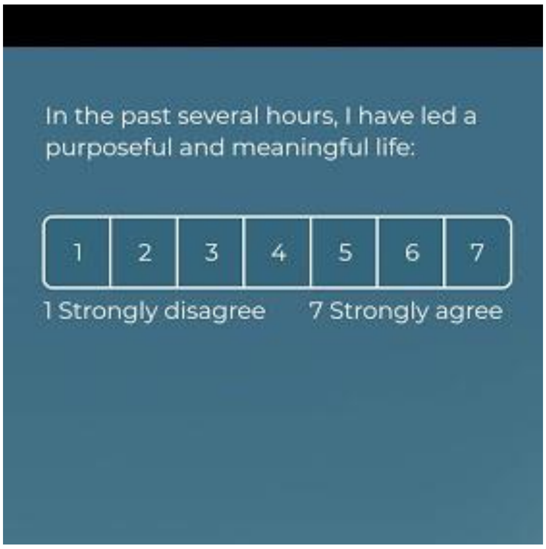
Unfold 1 used ESM, in order to test hypothesis 1. This was administered using the Remote assessment of disease and relapse (RADAR- base).

The Remote assessment of disease and relapse (RADAR-base) is an Mhealth Application (App) for generalised data collection from Wearable and smartphone devices. RADAR-base is able to collect passive as well as active data. The platform has been successfully used in collecting passive data including heart rate, movement, activity levels, exercise, and sleep patterns in participants diagnosed with major depressive disorder (Stewart et al., 2018). It has also been used to administer PHQ-8 (a patient health questionnaire) to the same participants. RADAR-base has been used to collect data from populations with diagnoses of Multiple Sclerosis, Depression and Epilepsy (Ranjan et al., 2019). The platform is currently being utilised across a number of other research studies.

RADAR-base can be installed onto smartphones that have an Android operating system. The App is downloaded from Google Play. After RADAR-base has been downloaded to the participant's smartphone, they then use the smartphone to scan a QR code in order for them to begin receiving questionnaires. Questionnaires are received as notifications on the smartphone at the time of the questionnaire prompt. The notification can take the form of a 'beep' or can be a vibrate or just a visual alert, depending on the participant-modifiable smartphone settings.

RADAR-base was chosen for use in Unfold because it has been used successfully with a variety of clinical groups. The App allows questionnaires to be customised with a choice of answers displayed for participants to choose using their touch screen to select. This reduces the chance of incorrect questionnaire responses as participants do not have to type their response. An example ESM question displayed in RADAR-base is shown in Figure 6.4.

Figure 6.4 ESM question displayed in RADAR-base App



In the past several hours, I have led a purposeful and meaningful life:

Another option for administering ESM questionnaires was to administer them via text message. Advantages of this approach would be that this would be utilising a function that is already on participant's smartphones and they would not have to download an App, and the approach could also be used with other operating systems. Disadvantages of using SMS messages are that participants with psychosis are less compliant with this method, and it takes longer to fill out questionnaires (Ainsworth et al., 2013). This may add to participant burden, which is an issue with ESM methods (Eisele et al., 2020) which may affect level of data completeness. Another disadvantage of using SMS is that due to character limitations, the questionnaires would need to be sent in a number of different messages each time which may further add to participant burden if they are required to respond to multiple messages.

ESM was reviewed in Chapter 4, which identified four design decisions for using ESM in Unfold:

1. No additional data was collected from participants alongside ESM questionnaires
2. The number of consecutive days of ESM was as small as possible
3. The thesis author initiated contact with participants after data collection commences.

4. A time contingent protocol was used to measure social contact and level of psychological wellbeing.

The ESM questionnaire included items about eudaimonic wellbeing, social context, and group identification. In the absence of validated ESM measures, researchers often select items from larger, cross sectional measures and adapt the items and instructions to fit the study timeframe (Trull and Ebner-Priemer, 2020). To measure momentary eudaimonic wellbeing, three items from the Flourishing Scale were adapted for use in the ESM questionnaire (Diener et al., 2010). The ESM version of the scale was used previously by Runyan and colleagues who used ESM to measure links between compassion, eudaimonia, and pro-social behaviour (2019). The authors selected the three top-loading items from the original scale. This is an approach that has been used previously to adapt a larger scale for ESM use (Conner et al., 2015). By selecting the top-loading items from a scale, the authors intended to represent the construct of eudaimonic wellbeing as accurately as possible. The three items were adapted from a ‘universal’ to a more momentary format by phrasing the statement in the past tense and adding the phrase ‘in the past several hours’. The scale for scoring each question was maintained from the original full-length scale, comprising a Likert scale that ranged from 1 (Strong disagreement) to 7 (Strong agreement). The shortened version of the scale demonstrated an adequate level of internal consistency, (Cronbach’s $\alpha = 0.83$) that was nearly as high as that reported for the eight-item version in the original validation study ($\alpha = 0.86$) (Diener et al., 2010).

Participants were asked 2 questions about current social contact. These questions were designed to assess social contact by assessing if participants were around people with whom they shared a social identity.

In the third section of the ESM questionnaire, participants were asked questions about how much they identified with the people they were having social contact with at the time of the questionnaire prompt. Group identification was measured using an unvalidated scale called the Group Identification Measure (Doosje et al., 1995). The scale was developed for use in a non-ESM study measuring perceived intragroup variability between psychology student and students taking other subjects. The measure was chosen for use in Unfold because the questions allow for appraisal of the participant’s current social context. The questions also allow for the ESM questionnaire to be completed in an average time of less than 2 minutes. This is an important consideration for ESM questionnaires as it reduces participant burden and increases adherence (Varese et al., 2019)

The ESM questionnaire is summarised in Table 6.5.

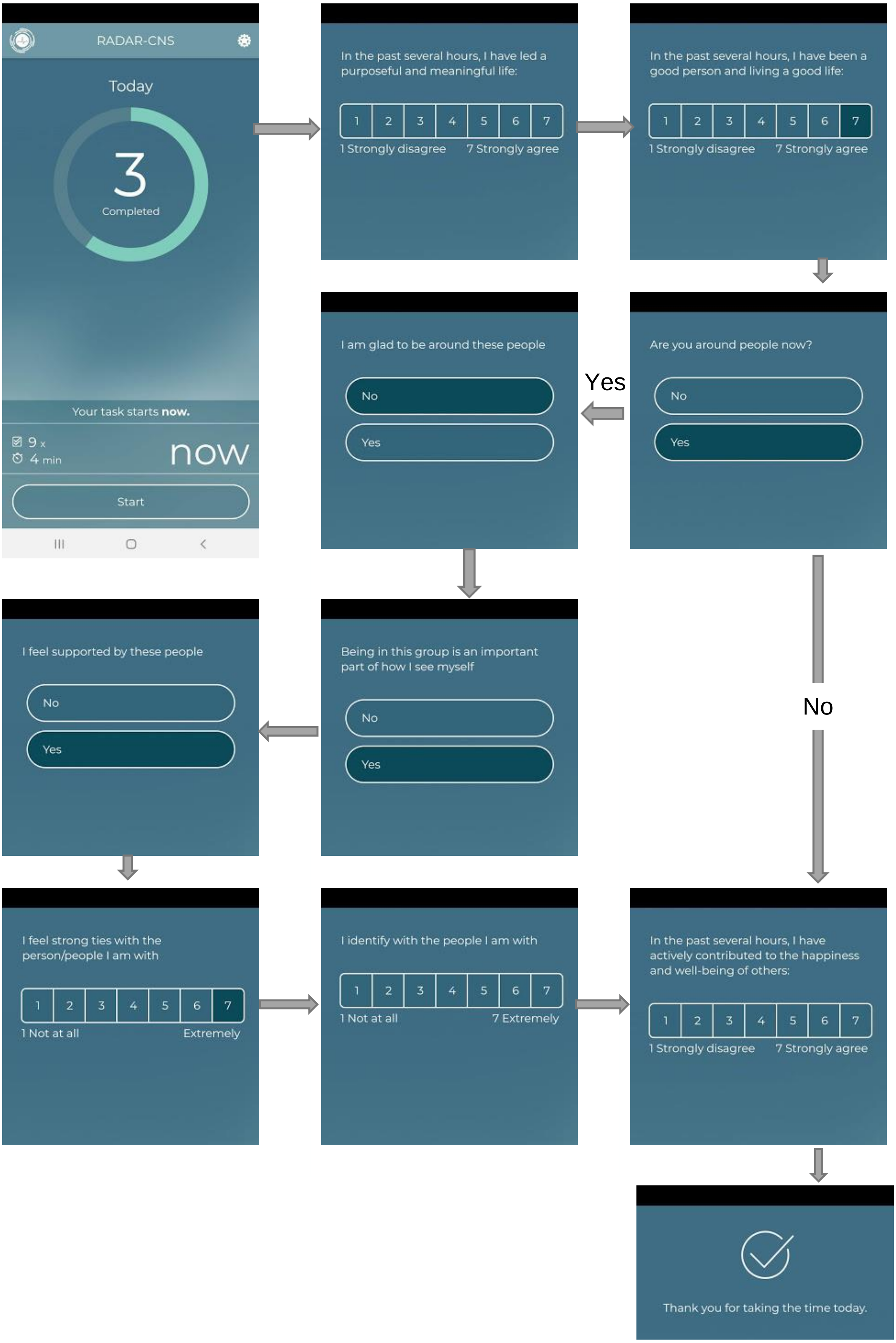
Table 6.5 ESM questionnaire

Construct being measured	Question presented to the participant	Scale option	Sampling frequency	Source
Eudaimonic wellbeing	In the past several hours, I have led a purposeful and meaningful life.	(Strongly disagree) 1 2 3 4 5 6 7 (Strongly agree)	10x per day on 4 consecutive days throughout 4 days out of each month	Flourishing Scale (Diener et al., 2010)
	In the past several hours, I have actively contributed to the happiness and well-being of others.	(Strongly disagree) 1 2 3 4 5 6 7 (Strongly agree)	10x per day on 4 consecutive days throughout 4 days out of each month	
	In the past several hours, I have been a good person and living a good life.	(Strongly disagree) 1 2 3 4 5 6 7 (Strongly agree)	10x per day on 4 consecutive days throughout 4 days out of each month	
Social context	Are you around people now?	Yes or No	10x per day on 4 consecutive days throughout 4 days out of each month	

	I am glad to be around these people	Yes or no	10x per day on 4 consecutive days throughout 4 days out of each month	
Group identification	Being in this group is an important part of how I see myself	Yes or no	10x per day on 4 consecutive days throughout 4 days out of each month	Group Identification Measure (Doosje et al., 1995)
	I feel supported by these people	Yes or no	10x per day on 4 consecutive days throughout 4 days out of each month	
	I feel strong ties with the person/people I am with	Not at all 1 2 3 4 5 6 7 Extremely	10x per day on 4 consecutive days throughout 4 days out of each month	
	I identify with the people I am with.	Not at all 1 2 3 4 5 6 7Extremely	10x per day on 4 consecutive days throughout 4 days out of each month	

Figure 6.5 shows the ESM questionnaire displayed in the RADAR-base App

Figure 6.5 ESM questionnaire in RADAR-base App



In the past several hours, I have led a purposeful and meaningful life:

In the past several hours, I have been a good person and living a good life:

Are you around people now?

I am glad to be around these people

Being in this group is an important part of how I see myself

I feel supported by these people

I feel strong ties with the person/people I am with

I identify with the people I am with

In the past several hours, I have actively contributed to the happiness and well-being of others:

Thank you for taking the time today.

Sampling schedule

When designing an ESM study, it is important to select a sampling strategy that is influenced by the nature of the phenomenon of interest (Varese et al., 2019). It was not known in what timescale social identity change in recovery from psychosis would be observed. Longitudinal studies have identified social identity change in different populations. Social identity change has been observed in a sample of students starting university after four months (Praharso et al., 2017), participants recovering from drug and alcohol addiction after 6 months (Dingle et al., 2019) and people recovering from depression after 6 months.

A person's identity network supports social identity change by providing a platform on which to build new social identities (Jetten and Pachana, 2012). Mental health service users often report fewer social connections than other populations (Pinfold et al., 2015). In a population where the old network is smaller, it may serve as less of a platform than a larger social network. Therefore, it is anticipated that it could take longer to see social identity change in a population with psychosis. The ESM data collection in Unfold therefore took place over 9 months.

The systematic review in Chapter 4 showed that adherence to ESM questionnaire prompts decline over consecutive days of sampling. To increase protocol adherence, the sampling will take place over a small number of consecutive days. The systematic review identified the average number of consecutive days of ESM sampling for included studies as 9.93 days. In Unfold the number of consecutive days will be 4 per month. Participants will receive ten prompts per day which has been shown to be a strategy used successfully in ESM studies recruiting a psychosis population (Ludwig et al., 2020).

Passive monitoring will be used for objective 1.1 (Data collection) and Objective 2.1 (Change processes). This will be carried out using the RADAR-base App. The social identity approach defines social identity as an individual's knowledge that they belong to certain social groups, coupled with the emotional and value significance they experience from group membership (Tajfel et al., 1979). One way in which social identity can change is by gaining new social identity groups (Jetten et al., 2009). Data were collected passively by capturing data on the addition of new contacts saved in a participant’s smartphone. Passive data was collected once per month. It was not possible to differentiate between additions to participant phonebooks from in-group members or from incidental contacts such as a new doctor surgery phone number. Therefore, passive data can only be used as a proxy for new group memberships. It will be used as secondary data to supplement qualitative interview data on social identity change processes.

Prior to the study commencing, the RADAR-base App was tested for feasibility.

Feasibility studies are used to test important parameters required for the design of the main study. These may include outcome measures and participant response and compliance rates (NIHR, 2017).

The feasibility study used two established approaches:

1. Heuristic evaluation
2. Back-end checking.

Heuristic evaluation is an informal method of usability testing, in which a number of evaluators are presented with an interface and asked to comment on it (Nielsen and Molich, 1990). Heuristic evaluation was conducted by eight people, comprising the thesis author, two research colleagues from the author’s research group, a mental health researcher from a separate research group, a software developer who also met study inclusion criteria, two PPI volunteers and one PhD supervisor specialising in technology design and evaluation. Testing took place between August and October 2019 and involved each tester having the RADAR-base App installed onto their smartphone and responding to questionnaires for a consecutive four-day period. The four-day period was chosen as this is the length of time per month participants were asked to respond to ESM questionnaires.

The issues identified by heuristic evaluation and the resulting refinements are shown in Table 6.6.

Table 6.6 Heuristic evaluation test

Issues identified	**Refinement made**
Notifications did not occur in order to prompt some testers to respond to questionnaires.	This was due to the university firewall. Approval was granted by university ICT services for the App to send notifications. Once this was done, the notifications were sent successfully to all testers.
The correct sequence of the ESM questions did not appear. When the participants answered ‘no’ to being around people at the time of the notification, they were subsequently asked if they liked being around those people.	This was fixed by App developers so that only relevant questions were asked depending on previous responses.
Each questionnaire was available for response for longer than the allocated 15 minutes.	This was addressed by App developers so that questionnaires were available to testers for only 15 minutes each.
For some participants when the App was downloaded onto their phone, they had a permanently displayed message from the app saying “sending missed questionnaire logs”	This was fixed by App developers.
Notifications appeared on tester’s smartphones at the correct times however no sound occurred alerting testers to the notification.	A change was made to tester’s phone settings to enable sounds for the RADAR-base app. This was a separate

Only vibrate function and a visual notification occurred.	setting from general phone sounds.
Testers asked for the reset button to be removed in order to prevent participants accidentally resetting the app.	This was removed by App developers
When testers clicked on the notification a ‘pop up’ within the app appeared saying this was “blocked”. Testers asked for this to be removed, or for ‘softer’ language to be used.	The word “blocked” was replaced by “unavailable”.

Back-end checking involves evaluating whether the data entered in the app is stored correctly in the database used for data storage (Hamilton, 2022). This was particularly important with the ESM questions as they were asked frequently, so it was important to ensure that the answers given to questions by each participant were stored correctly in the database, e.g., ensuring the answers and the questions matched up. Backend testing involved four of the initial testers writing their answers to each ESM question down along with the time of the response. These records were then checked at the end of the four-day testing period by the thesis author to ensure the answers in the backend database matched the answers written down by testers.

The back-end check showed 100% accuracy for questionnaire responses and timing of each response when the manually recorded responses were compared to data stored in the back-end database.

Recruitment

Participants were recruited over a period of seven months. Recruitment took place using three different routes:

1. Service users who had given consent to be contacted for research purposes to the Clinical Research Network (CRN) East Midlands and

who met eligibility criteria for Unfold were invited to participate by a letter through the post with the PIS enclosed.

2. An initial approach to service users was made by Nottinghamshire Healthcare NHS Foundation Trust (NHFT) staff who were issued with study leaflets to distribute and posters to display on Trust noticeboards. Once an individual gave permission to be contacted, the signposting clinician informed the researcher and passed on the potential participant details.
3. Posters and leaflets were placed in NHFT premises such as waiting rooms and noticeboards in corridors. If a potential participant saw a poster and was interested in participating, they could contact the researcher directly by phone or email.

Irrespective of the recruitment route, when a potential participant expressed an interest in taking part, the thesis author contacted them by phone. During the phone call the researcher introduced herself and described the Unfold study including a brief description of the aims and the procedures involved. Then the researcher went through the eligibility criteria with the participant to check their eligibility to take part. If the potential participant did not meet the criteria, they were thanked for their time and their interest in the study and the call was ended. If they met the eligibility criteria, they were given the opportunity to ask questions about any aspect of the study and what participation would involve. If they were still interested in taking part, the researcher sent them a PIS (if they did not already have one) either by email or by post depending on their preference.

After the potential participant had been given at least 24 hours to read the PIS (Appendix 1), the researcher contacted them again by phone. They were given the opportunity to ask further questions. Participants were encouraged to take as much time as they wished to carefully consider the contents of the PIS and were encouraged to consult with confidants if wanted about their participation in the study. If they wished to take further time to consider, they were asked to contact the researcher when they were ready, using contact information provided on the PIS. If they decided that they would like to take part and did not have further questions, the researcher arranged to an in-person meeting at a time and available NHFT premises that was convenient.

The participant was welcomed to the building and shown into a pre-booked room. The participant was given a further opportunity to ask questions. The researcher described procedures for the study. Participants were informed that participation was voluntary, that non-participation did not influence their clinical care, and that they were free to withdraw from the study at any point without providing reasons. Informed consent was provided via a printed Informed Consent Form (ICF) (Appendix 1). Participants were asked to tick the relevant boxed and sign to indicate consent to participate. Participation in the study did not go ahead unless written consent was provided.

In order to ensure her safety whilst interviewing people with experience of psychosis alone, a number of safety considerations were made. Firstly, interviews took place in NHFT community spaces familiar to the thesis author. These were controlled spaces with signing in/out and booked rooms. Secondly as an NHFT employee on NFHT premises, the thesis author was trained in and adhered to the Trust’s lone working policy which detailed procedures for keeping safe whilst lone working and also what to do in the event of an emergency whilst working alone with vulnerable people. Thirdly, debriefing after each interview was available through supervision and through researcher peer support. During supervision the researcher reflected with her supervisors on the difference in roles between working clinically with people with psychosis and working with people with psychosis in a research context and the differing role expectations.

Data collection procedures for Unfold are summarised in Table 6.7.

Table 6.7 Data collection procedures

Meeting	Measures completed	Additional procedures
1 (baseline)	SEPRS Flourishing scale SIM-tool (SIM-1)	Training in using RADAR-base, installation of RADAR-base App onto participant smartphone, passive and active monitoring begin
2 (three months)	SEPRS Flourishing scale SIM-tool (SIM-2)	
3 (nine months ESM)	SEPRS Flourishing scale SIM-tool (SIM-3)	RADAR-base App uninstalled from participant smartphone, passive and active monitoring end Semi-structured interview (10 participants)

After informed consent had been obtained, participants were asked to fill out paper copies of the demographic questionnaire, the SEPRS and the Flourishing scale. Help completing the measures was provided by the researcher if required. SIM-tool was then administered as described in Section 6.5.

When the SIM-tool was completed, participants were offered a short break, and then provided with wifi details for the building and asked to connect their phone. They were provided with a training session on the use of RADAR-base App. The purpose of the app was clearly explained by the researcher. Participants were given an opportunity to complete the questionnaire using a training version of the RADAR-base app installed on the researcher’s phone and to ask any questions about the App or the questionnaire. RADAR-base was then installed and onto their phone and ESM notifications began.

At the end of meeting 1 the participant was reminded that there were contact details on the PIS and that the participant could contact the researcher if they had any issue with the app or further questions relating to any aspect of the study. After meeting 1, and each future meeting with the researcher, each participant was provided with £20 cash in compensation for their time and effort. Reasonable travel costs were also paid to participants after each meeting.

After meeting 1, the participant was allocated a Unique Identifier (UID) which the researcher used to label all completed questionnaires. The participant’s name and UID were added to a master linking document held on a secure server at the University of Nottingham. This was only accessible to the researcher and the chief investigator. The printed ICF was scanned and placed onto a secure server at the University of Nottingham. The paper copy was retained in the Study Master File and stored securely. Informed consent was recorded in the service user's clinical notes via their referring clinical team who were sent a copy of the signed consent form. Participants received a copy of the consent form, and a copy was also kept in the site file. Completed questionnaires from all meetings were scanned and saved onto a secure cloud-based server at the University of Nottingham. Paper copies were stored in a locked drawer in the researcher’s office, to which only she had a key. Paper copies of questionnaires were stored in the locked drawer until the end of the study when they were scanned and saved onto the secure server at the University of Nottingham. Paper copies were then destroyed.

The systematic review in Chapter 4 showed that researcher-initiated contact with participants increases data completeness in ESM.

Therefore, one month after the initial meeting, participants received a phone call from the researcher to provide any additional support as required.

Two and a half months after meeting 1, the researcher contacted the participant by phone to arrange a mutually convenient time and place for in-person meeting 2. In the meeting, the researcher re-administered SEPRS, Flourishing Scale and SIM-tool. Participants were given £20 cash by the researcher for their time and effort and travel expenses were reimbursed.

Five and a half months after meeting 1, the researcher contacted the participant again to arrange meeting 3. Again, the researcher re-administered SEPRS, Flourishing Scale and SIM-tool. After the measures had been completed, the researcher supported the participant to uninstall the RADAR-base app from their smartphone. The first 10 participants were offered an interview, and the other 40 participants were provided with £20 cash for their time and effort as well as reasonable travel expenses, thanked for their participation and informed about mechanisms for accessing study results. They were then informed that their participation in the study was complete.

The first ten participants enrolled into the study took part in a semi-structured interview after a short break. These interviews were used to address aim 2.1 (Change processes). The topic guides covered two topics:

> Topic guide 1: experiences of social identity change over the previous 9 months
>
> Topic guide 2: experiences about using the RADAR-base app to answer questionnaires.

The aims and purpose of the interview were described to the participant and a brief description was given on of the interview structure. There was opportunity for the participant to ask any questions. Audio recording of the interview was described to the participant. Before the interview commenced, the researcher turned on the recorder and read out the UID so that it was recorded.

At the end of the interview, the researcher stopped the recording and checked on the participants wellbeing. They were given an opportunity to debrief about their experience of the interview. They were then provided with £20 cash for their time and effort as well as reasonable travel expenses, thanked for their participation and about mechanisms for accessing study results before being informed that their participation in the study was complete.

6.8 Ethical aspects of the research

All participants were provided with a participant information sheet at the recruitment phase. Participants were encouraged to ask any questions. Informed consent was requested, and participants completed a consent form prior to participation.

Ethical aspects specifically relating to Unfold included participant burden and participant distress.

Participant burden

As discussed in chapter 4 (systematic review), participants find ESM burdensome due to the frequency of the sampling. Four features of the study were designed to minimise burden:

1. The active data collection phase was carried out in 4 day periods once per month rather than continuously throughout the data collection period
2. Questionnaires were designed to be completed as quickly as possible by participants
3. Training was provided to ensure participants understood how to operate the App prior to beginning data collection
4. In order to allow participants time without being asked to respond to questionnaires, participants were only prompted to answer questionnaires via the App between the hours of 9am and 9pm

Participant distress

To support the interview meetings, a distress protocol was developed in discussion with PhD supervisors. If, for any reason a participant became distressed at any time during any of the data collection meetings, they were given the opportunity to take a break or to conclude the meeting as preferred. They were given the option to pause the recording if this occurred during the interview. When participation concluded, participants were given the opportunity to debrief with the researcher to check on their wellbeing and reflect upon their experience. Participants who appeared to be experiencing significant distress or unwellness at the time of recruitment or at any point during their participation in the study were excluded or underwent a re-assessment of suitability for participation at that time. If necessary, participants were encouraged to seek support from their care team if within office hours or contact the Crisis Resolution Home Treatment Team if outside of office hours.

If risk indication was sufficient that confidentiality needed to be breached, and if the participant did not have adequate plans in place to enable them to deal with distress, then their clinical team / crisis service was contacted. Participants were given as much control as possible of the situation and decisions made by negotiation with the researcher. After the meeting the primary supervisor was informed as soon as possible, and the care team were contacted (with participant agreement if possible) to ensure they were aware that the participant had been distressed.

6.10 Data management

In accordance with the sponsor’s data management policy, a Data Protection Impact Assessment (DPIA) was carried out for the Unfold study. The DPIA was designed to identify risks that arose from the processing of personal data and to minimise the risks as much as possible. The DPIA was used to ensure the study complied with General Data Protection Regulation (GDPR) legislation which governs the way in which personal data is used, processed, and stored. The

DPIA was completed in collaboration with App developers working on the RADAR-base platform and data management specialists at NHFT. The GDPR principles that were identified by the DPIA as relevant to Unfold and the actions taken to adhere to them are summarised in table 6.8

Table 6.8 GDPR principles and action taken to ensure adherence

GDPR principle	**Action taken**
GDPR Principle 1: Personal data shall be processed lawfully, fairly and in a transparent manner	Participants were informed in the PIS: • how their personal data was collected and recorded • that they were able to withdraw from the study at any time • that If they withdrew consent their data was anonymised and not withdrawn from the study. • data processing was necessary for the performance of a mental health study which is a task carried out in the public interest
GDPR Principle2 Personal data are collected for specified, explicit and legitimate purposes (purpose limitation)	• All collected data was to be used specifically for the Unfold study

GDPR Principle 3: Personal data shall be adequate, relevant and limited to what is necessary (data minimisation)	• Sufficient data was collected to complete the aims of the study • In order to ensure that only the minimum amount of data required was collected, a study protocol detailing all data required and collected was written and approved by the study sponsor and HRA. • The data processing was designed to achieve the study aims and there was not another way to achieve them.
GDPR Principle 4: Personal data will be accurate and where necessary kept up to date (accuracy)	A feasibility study was carried out with a small number of test participants in order to ensure accuracy of the personal data
GDPR Principle 5: Personal data is kept in a form which permits identification for no longer than necessary.	• Appropriate retention periods for the personal data were identified • Data will be retained only in pseudonymised form. • Data will be pseudonymised using an identification log in the trial master file. This will be carried out by the thesis author.
GDPR Principle 6: Personal data are processed in a manner that ensures appropriate security	• The thesis author maintained logs of all system accesses, including data processing operations performed. • The RADAR-base App incorporates username and password controlled access to data. The Chief Investigator delegated access rights through the delegation of duties log.

	- All staff had Good Clinical Practice and health-related Information Governance training. This was logged in the training log. - RADAR-base app - regularly backed up to secure archive, from where it could be restored. - Nottingham research server - regularly backed up to secure archive, from where it could be restored. - Automated validation of data entered into RADAR-base app by participants

6.11 Data analysis

6.11.1 Aim 1

To address objective 1.1 (Data collection), Interview data were analysed using Reflexive Thematic Analysis (RTA). RTA is explained in detail in section 6.11.2.

6.11.2 Aim 2

To address objective 2 (Identity), qualitative and quantitative data were analysed separately and then integrated. Objective 2.1 (change processes) was met by integrating qualitative interview data relating to topic guide 1 (experiences of social identity change over the previous 9 months) with quantitative change scores from SIM-tool.

In a convergent mixed methods design, the researcher first analyses the qualitative and quantitative data separately before merging the two data sets (Creswell and Plano Clark, 2018). For Unfold it was important to analyse the qualitative and qualitative components of social identity change so that the two different ‘layers’ of knowledge regarding social identity change could then be merged.

Qualitative analysis

Interviews were analysed using thematic analysis. Thematic analysis was chosen because it offers a flexible approach to analysing data (Braun and Clarke, 2006). The flexibility offered by thematic analysis is appropriate for mixed methods studies (Creswell and Plano Clark, 2018). Interview recordings were transcribed by the thesis author. The thesis author then pseudonymised all transcripts by re-listening to all the interviews and editing transcripts to ensure that all identifiable information was removed. To explore participant experiences using the RADAR-base app, reflexive thematic analysis was used. Reflexive thematic analysis is a type of thematic analysis which is a data driven approach. It is an iterative approach, allowing the thesis author to begin with the motivations and factors identified by participants (Braun et al., 2019) .

The six phases of reflexive thematic analysis identified by Terry et al (2017) were followed.

1. Familiarisation

Familiarisation involves the researcher closely reading and familiarising themselves with the data. The transcripts are closely read, and notes made about what the researcher found interesting, or any connections they noticed in order to 'get to know' the data. Notes were made about individual transcripts and synthesised about the data set as a whole.

2. Generating codes

Codes are defined as meaningful labels attached to specific segments of the data set. Once identified, they are labelled with succinct words or phrases to capture the code meaning. Coding was done thoroughly and systematically using the software NVIVO. This phase resulted in a compiled list of codes.

3. Theme development

Initial codes are developed into potential themes. A theme represented a pattern of meaning or response identified across the dataset. Themes were developed through the use of thematic maps (Braun and Clarke, 2013). These were then discussed and reviewed with the supervisory team. Data was then gathered relevant to each potential theme from the codes.

4. Reviewing themes

Themes were reviewed to ensure they fit with corresponding coded extracts. A thematic SIM of the analysis was generated.

5. Defining themes

Defining and naming themes: Ongoing continuing analysis takes place to name and refine themes and the overall analysis. At this stage there is continuing clarification, definition, and naming of each theme. Theme development was carried out using thematic maps (Braun and Clarke, 2013). A thematic map can be used as a tool in thematic analysis which allows exploration and refinement of themes, subthemes, and overarching themes.

6. Writing up

The final analysis involves writing up the ‘story of the analysis. Definitions are provided for each theme in order to confirm each themes has a central organising concept. Quotations will be selected that provide illustrative examples. Quotations are selected from across the data set.

Quantitative analysis

Two SIM-tool metrics were considered: total number of groups and group positivity. The significance of differences over time were to be explored using inferential statistics. The scores of the two metrics in SIM-1, SIM-2 and SIM-3 were first tested for normal distribution using a histogram. If distribution was found to be normally distributed, differences were tested for significance using a paired samples T-test. If found not to be normally distributed, a non-parametric Wilcoxon signed-rank test on median scores was used.

Integration

Qualitative interview data was then integrated with the changed SIM scores. Integration is the defining feature of mixed methods research (Plano Clark, 2019). It describes the interaction between the qualitative and quantitative data components (O’Cathain et al., 2010). It distinguishes mixed methods studies from independent single method studies (O'Cathain et al., 2007). Integration occurs when quantitative and qualitative data is merged in such a way as to be mutually informative, resulting in findings that are greater than the sum of the individual components (Woolley, 2009). The result of integration is qualitative and quantitative data that is interdependent in order to address the research question (Guetterman et al., 2015). When integration is carried out effectively, it can create a more credible study findings than would have been achieved by combining the results of the two separate studies together (Fetters and Freshwater, 2015).

Integration is difficult to carry out effectively (Yin, 2006). In mixed methods studies, it is often carried out in a way that is limited (Bryman, 2007), or the two data sets are not integrated at all (O'Cathain et al., 2007). There are a lack of examples in the literature (Woolley, 2009), a lack of well-defined techniques to choose from (Johnson et al., 2019) and evidence is lacking on how to carry it out effectively (Guetterman et al., 2015). Novel approaches are therefore often required (Haynes-Brown and Fetters, 2021). When integration is not carried out, the knowledge generated from a mixed methods study is equivalent to that of sperate qualitative and a quantitative studies (O’Cathain et al., 2010).

Data integration methods need to be selected in relation to the intent of the integration (Fetters, 2020b). A pragmatist epistemological stance highlights the importance of considering the two data types in relation to their similarities in order to understand different ‘layers’ of social identity change (Feilzer, 2010). As Unfold has a convergent design, the intent of integration is to develop results that are comprehensive, confirmed and expand understanding (Creswell and Plano Clark, 2018). The intent of integration is to expand understanding of the role of social identity change processes in recovery from psychosis.

Two integration methods have been identified that will produce results that are comprehensive, confirmed and expand understanding of social identity in recovery from psychosis:

1. Narrative discussion
2. Joint display

Narrative discussion

Using a narrative discussion involves organising the quantitative results side by side within a paragraph of text and discussing them in terms of how the results are similar or different (Creswell and Plano Clark, 2018). The primary product from this integration strategy is an interpretative paragraph (Plano Clark et al., 2010).

Qualitative and quantitative findings are woven together when discussing each theme or concept (Fetters et al., 2013). A popular approach is to present quantitative findings on a specific topic, followed by quotes on the same topic and a comment on how the two results disconfirm or complement each other. (Creswell and Plano Clark, 2018). This approach enables the reader to make a direct comparison between the two results and to determine whether or not they are in agreement (Plano Clark et al., 2010).

Joint displays

Joint displays are tables, matrices, or figures that explicitly relate quantitative and qualitative information (Plano Clark, 2019). Data is brought together through visual means in order to allow new insights to emerge (Fetters et al., 2013). Joint displays provide a comprehensive understanding of the data (Haynes-Brown and Fetters, 2021) and encourage researchers to progress from considering findings relating to each method to considering themes across the data set (O’Cathain et al., 2010). The most common form of joint display used in mixed methods integration is a table (Creswell and Plano Clark, 2018). A well-designed joint display can be used to represent:

1. Juxtaposed data or findings of qualitative and quantitative data links
2. Areas of commonality across the qualitative and quantitative data that can be expressed as constructs or domains
3. Interpretation about the meaning of the two types of results when considered together (Fetters, 2020a).

A joint display will be used for integrating qualitative and quantitative data in Unfold. The visual display of both sets of data could allow for data to be compared more easily than in a narrative format. A joint display may allow for finding places where two data sets do not converge, which other integration techniques do not easily identify. (O’Cathain et al., 2010). Another reason for the decision to use a joint display are that it is recommended for use in concurrent mixed methods designs where joint displays can group quantitative data by qualitative themes or give side by side comparisons of qualitative and quantitative data (Guetterman et al., 2015).

The joint display table chosen was an adapted version of a table developed for use with a convergent mixed methods design (Moseholm et al., 2017).

The original table was used first. A blank joint display table was created with four columns. These were:

- Social identity theory domain
- Quantitative results
- Qualitative findings
- Mixed methods meta inferences

It was felt that the results required interpretation to allow for meaningful integration. Therefore, an interpretation column was added for quantitative results and also for qualitative findings:

- Social identity theory domain
- Quantitative results
- Interpretation
- Qualitative findings
- Interpretation
- Mixed methods comparison

The table organises the data by key topics which are listed in the left hand column. Qualitative and quantitative results are then displayed side by side in the middle columns. Meta inferences describe the mixed methods comparisons which are made in the right hand column. Comparisons can either result in discordance, conformation or expansion. Discordance describes the qualitative and quantitative data disagreeing with each other or being inconsistent or contradictory. Conformation described each type of data reinforcing the findings from the other. Expansion described the qualitative and quantitative findings expanding insights.

This particular joint display table was chosen as it had only four columns and the left to right design of the columns made it straightforward to populate and to interpret. The table allowed data to be grouped by social identity domains down the left column. This allowed different layers of those domains to be accessed by each type of data, in line with a pragmatist epistemology (Feilzer, 2010). The mixed methods comparison column allowed considerations to be made about how the data compared. Whilst populating the table, the researcher was required to work back and forth between the different data sets, with the mixed methods inferences serving as a point of connection (Teddlie and Tashakkori, 2012). This allowed for meta inferences to be created with the use of abductive reasoning associated with a pragmatist standpoint (Morgan, 2007).

Objective 2.2 (Identity and wellbeing)

Quantitative analysis

Hypothesis 1: Increase in social contact with members of social groups over time precedes increased sense of eudaimonic wellbeing. In order to test hypothesis 1, ESM data and Flourishing scale scores were to be used. A mixed effects model was developed. This allows for multi-level modelling of the data allowing for both within-patient and individual variation, in order to detect any differences of ESM wellbeing scores between participants who did and participants who did not report increase in social contact. The social contact variable was lagged in order to pick up on past social contact and whether this relates to increases in wellbeing.

Hypothesis 2 was tested by analysing SIM-tool data regarding groups maintained from SIM-1 to SIM-3 and Flourishing scale scores.

Two aspects of group maintenance were included in the analysis:

- Number of maintained groups
- Number of maintained positive groups

To measure the number of maintained groups and level of eudaimonic wellbeing, the number of SIM-1 groups maintained at SIM-3 (nine months later) was assessed for each participant. Participants were then partitioned into two groups: groups of high and low maintained groups partitioned at the midpoint. A paired-sample T-test was used to detect differences in Flourishing Scale score between the two groups.

The following was then identified for each participant between SIM-1 and SIM-3:

- Number of maintained positive groups

Participants were then partitioned into two groups: high maintained positive groups or low maintained positive groups (partitioned at the midpoint). A paired-sample T-test was used to detect differences in Flourishing Scale score between the two groups.

Chapter 7: Unfold 1 Results

This chapter describes the findings from the Unfold1 study. Unfold 1 was paused soon after starting due to the onset of the COVID-19 pandemic and associated social distancing restrictions. Ongoing restrictions meant that Unfold 1 could not be re-opened. The results of the Unfold 1 study up to the point where the study was closed are presented in Section 7.1. The reasons why the study design was no longer feasible, the implications of Unfold 1 for the remainder of the thesis, and the modifications needed in order for the study to be re-designed as Unfold 2 are presented in Section 7.2.

7.1 Unfold 1 results

Unfold 1 opened on October 31, 2019 and was paused due to the COVID-19 pandemic on March 19 2020. At the time of pausing, 13 participants had been recruited, and their clinical and sociodemographic characteristics are shown in Tables 7.1 and 7.2.

Table 7.1 Sociodemographic characteristics of participants (n=13)

Characteristic	**Category**	**n (%)**
Age (years)	18-24	4
	25-34	3
	35-44	3
	45-54	3
Gender	Female	9
	Male	4
Ethnicity	White	5
	Black	4
	Asian	1
	Other	3
Education	No qualification	1
	GCSE’s or equivalent	5

	A-Levels/ AS-levels/ NVQ or equivalent	5
	Degree level qualification	1
	Higher degree level qualification	1
Relationship status	Single / not in a relationship	10
	Married	1
	Other relationship	2
Employment	Full time paid employment	1
	Part time (<20 hours per week) paid employment	2
	Full time or part time study	1
	Volunteer	2
	Unable to work for health reasons	6
	None of the above	1
Housing	Own flat/house	3
	Private rental (flat/house)	3
	Communal establishment	1
	Social housing	5
	With family	1

The clinical characteristics of participants are shown in Table 7.2.

Table 7.2 Clinical characteristics of participants (n=13)

Age first diagnosed with mental health condition (years)		N (%)
	18-24	9 (69.2)
	25-34	3 (23.1)
	35-44	1 (7.7)
Years using mental health services		
	1-9	7 (53.9)
	10-19	4 (30.8)
	20-29	0 (0)
	30-39	2 (15.4)
Profession of primary clinician		
	CPN	6 (46.2)
	Psychiatrist	4 (30.8)
	Occupational Therapist	2 (15.4)
	None	1 (7.7)
Main treatment		
	Talking therapy	5 (38.5)
	Medication	11 (84.6)
	Peer support	1 (7.7)
	Recovery college	1 (7.7)
Taking psychotropic medication?		
	Yes	5 (38.5)
	No	7 (53.9)
Ever a mental health in-patient?		
	Yes	7 (53.9)
	No	6 (46.2)

Ever detained under the Mental Health Act?		
	Yes	3 (23.1)
	No	10 (80.0)
How would you describe yourself at the moment?		
	Recovered	2 (15.4)
	Living well	4 (30.8)
	Making progress	4 (30.8)
	Surviving day to day	2 (15.4)

Characteristics of smartphone use by participants are shown in Table 7.3.

Table 7.3 Participant smartphone use (n=13)

Smartphone use		
Type of smartphone owned		
	Samsung	6 (46.2)
	Huawei	1 (7.7)
	Sony	1 (7.7)
	Motorola	1 (7.7)
	iPhone (borrowed)	1 (7.7)
	Participant unaware	1 (7.7)
Smartphone plan	Pay monthly contact	9 (69.2)
	Other	4 (30.8)
Regular use of messaging services?		
	Yes	12 (92.3)
	No	1 (7.7)

The mean flourishing scale score was 33.5 (SD 9.0), the range was 14-43. The mean SEPRS score was 620.1 (SD 330.5), the range was 200-910.

SIM-1 data are summarised in Table 7.4.

Table 7.4 Social Identity Mapping round 1 (SIM-1) findings (n=13)

#	Total groups	High contact groups	Low contact groups	Positive groups	Negative groups	Important groups	Unimportant groups	Group links	Compatible groups	Incompatible groups	Group tenure Mean	Similar groups	Dissimilar groups
01	12	6	1	10	0	10	0	12	5	4	32	8	3
I’02	8	7	0	6	0	7	0	4	4	0	15	7	3
03	6	0	6	4	0	3	1	5	1	1	11	6	1
04	8	1	7	5	1	3	5	14	8	5	11	4	4
05	4	1	1	0	1	0	0	5	1	2	9	0	2
06	3	2	1	2	0	1	0	3	3	0	14	0	0
07	5	3	2	2	1	2	1	8	4	1	7	1	5
08	9	2	7	9	0	1	1	16	14	1	8	3	6
09	6	1	3	1	3	2	4	16	5	0	8	0	3
10	6	5	1	3	1	5	1	11	8	2	13	5	0
11	6	1	4	3	0	4	0	18	3	1	6	4	2
12	8	3	4	3	5	3	5	21	5	6	21	3	2
13	3	3	0	3	0	3	0	3	1	1	20	0	0

ESM data completeness is summarised in Table 7.5

Table 7.5 Data completeness n=13

#	Questionnaire prompts received n	Data completeness %	Time in study (months)	% ESM questionnaire completion		
				Month 1	**Month 2**	**Month 3**
01	157	10.1	1	10.1	0	0
02	152	4.6	1	4.6	0	0
03	195	53.5	3	19.1	17.1	17.1
04	154	50.0	3	15.6	16.9	16.9
05	156	28.2	3	16.7	7.1	4.5
06	114	30.7	2	21	9.6	0
07	114	7.0	1	7	0	0
08	114	22.8	2	22.8	0	0
09	112	6.3	1	6.3	0	0
10	112	0	0	0	0	0
11	13	53	1	53	0	0
12	0	0	0	0	0	0
13	35	32.9	1	53	0	0

One participant did not respond to any questionnaires. A total of 314 of a possible 1428 (22%) ESM questionnaires were completed. One participant was recruited in the first month of the study, 4 in the second, 3 in the third and 5 in the 4th month before the study closed. The mean completion rate was 27.1%. The first participant was enrolled into the study on 21/11/1019 and the final participant enrolled on 28/2/2020. No participants responded to any questionnaires after 28 February 2020.

Passive data collection

No changes to participant’s phonebook contacts were identified by the RADAR-base App during the data collection period for any participant.

Qualitative interviews

No qualitative interviews were carried out, because the qualitative interviews were due to take place after the quantitative phase of the study had been completed.

7.2 Enforced closure of the Unfold 1 study

In March 2020 the UK was placed under national lockdown (Johnson, 2020) as a result of the emerging coronavirus pandemic (WHO, 2020). From the onset of the lockdown, social distancing measures were introduced in order to limit social contact and to slow the spread of the virus. These restrictions included a ban on people leaving their homes for non-essential purposes and on socialising between households. The use of technology, rather than meeting in person, was encouraged to communicate, and working from home was required for everyone except for essential workers (UK Government, 2020) . At the time of the UK’s national lockdown, social distancing measures were passed into UK law (Public Health England, 2020).

At the beginning of lockdown, the sponsor of the Unfold 1 study - Nottinghamshire Healthcare NHS Foundation Trust (NHFT) - paused all research activity, including Unfold 1. When Unfold 1 was paused, the study was at the recruitment stage. Recruitment was scheduled to continue for another three months, and face-to-face follow-up meetings due to continue for another 11 months. There were 13 participants enrolled in the study at the time it was paused. The RADAR-base app had been installed onto the smartphones of all 13 participants.

According to guidance from the National Institute of Health Research (NIHR) published in May 2020, paused studies were permitted to restart provided studies met certain preconditions.

Preconditions for restarting were:

- Viability consideration: Only research that is still viable should restart.
- Safety consideration: Research should only restart when safe to do so.
- Capacity consideration : The restart and the commencement of new studies should be appropriate with capacity and readiness in local health services and the NIHR (NIHR, 2020)

In addition, a fourth precondition was identified in relation to Unfold 1: The consideration of social restrictions, meaning that the scientific knowledge generated by the study needed to be valid in the context of the pandemic and associated social distancing restrictions.

The possibility of re-opening Unfold 1 was considered in relation to these four conditions.

Consideration 1: Viability
One practical reason that indicated Unfold 1 was no longer a viable study related to the study timeline. In order to address the study aims and objectives, Unfold 1 had a longitudinal design (Bolger and Laurenceau, 2013a). The combined recruitment and data collection period was planned to last for 19 months. Once enrolled, participants were followed up after 3 months and then again at 9 months. Because the study had been paused after 4.5 months of recruitment 3-month follow-up had not taken place with any participants. When NHFT allowed studies to reopen, it was not possible to follow-up with the previously enrolled participants. The implication was that recruitment would have to re-start.

NHFT begun restarting sponsored studies in September 2020. At this time, the first UK lockdown had ended but social distancing measures were still in place. Almost a year of data collection time had been lost, including the initial 4 months prior to lockdown. The PhD was due to end in March 2022. If the study had reopened immediately in September 2020, the data collection period would have continued until after the time the PhD was due to finish. This meant that the recruitment and data collection period would no longer fit into the PhD timescale if the study restarted with the same design.

Consideration 2: Safety

Another precondition set out by NIHR for restarting paused studies was that they must only start when safe to do so, and must mitigate exposure of Covid-19 to researchers and participants (NIHR, 2020). From the onset of social distancing measures, particular advice was given to those with ‘underlying health conditions’ who were advised to observe stricter social distancing measures (UK Government, 2020). The Unfold 1 study population is people diagnosed with psychosis. This population are more likely to have multiple comorbidities including cardiovascular and respiratory disease (Chang et al., 2010). These comorbidities have been shown to greatly increase risk of serious complications from Covid-19 (Zheng et al., 2020). Unfold 1 consent and follow-up meetings had been conducted face-to-face between the researcher and participants. This had required participants to travel to meet the researcher at a Trust location. The heightened level of risk to this population indicated ethical implications of continuing to recruit and collect data using face-to-face approaches.

It was advised to work from home and to work remotely where possible (Johnson, 2020). A number of the data collection procedures for Unfold 1 would have been challenging to carry out remotely. Installation of the Radar-base app onto participants’ smartphones involved scanning a QR code to enrol each participant into the study. Enrolling the 13 participants previously had demonstrated that participants often requested help with this, which necessitated physical proximity between the researcher and the participant. This was also the case for the training session, where participants were taught how to use the app. Participants had often requested help and the researcher and participant were required to view the smartphone screen together in order to assist them.

A photo was taken of each completed social identity map (SIM). This was then uploaded to a secure server. This would need to be taken by each participant if the researcher was not physically present. This would not only have added to participant burden but risk the SIM data not being uploaded if not completed correctly.

Consideration 3: Capacity

Research capacity within the NHS was also a factor affecting viability of the study. Prior to lockdown, the Clinical Research Network (CRN) supported the study. The CRN is designed to support the public and health and care organisations to participate in research (NIHR, 2021b). Unfold 1 had received CRN support with recruitment, including advertising the study and providing clinical contacts within the Trust. The NIHR published guidelines for research priorities during the pandemic prioritising urgent public health studies. They requested for staff and other resources to be deployed to studies deemed urgent (NIHR, 2020). Unfold 1 was not deemed by NHFT to be an urgent study. This resulted in the CRN lacking the capacity to support recruitment for Unfold 1. CRN support was necessary for successful recruitment from NHS services. For this reason, the recruitment setting may need to be changed.

Consideration 4: Social restrictions

The impact of the pandemic on the generation of scientific knowledge through health research has been observed (Sohrabi et al., 2021). It is likely that social distancing measures will have a direct impact on social identity. Social identity is an individual’s knowledge that they belong to certain social groups, coupled with the emotional and value significance they experience from group membership (Tajfel, 1978b). Unfold 1 aims to investigate social identity change in recovery, which is challenged as a construct due to the impact of social distancing. Social contact and integration can be seen as a precursor to group identification (Sani et al., 2012). Changes in social identity therefore may be attributable to restrictions, rather than indicating anything about recovery from psychosis.

In prospective studies the phenomenon of interest needs to be dynamic in order for changes to be observed (Schumacher et al., 2021). Social identity change is a dynamic process as a person builds new social identities (Cruwys et al., 2013), loses social group memberships (Haslam et al., 2021) and uses their identity network as a platform on which to join other groups (Jetten and Pachana, 2012). Measuring social identity change prospectively would no longer generate valid data

Implications of NIHR guidance on reopening the Unfold 1 study are summarised in Table 7.7

Table 7.6 Implications of NIHR considerations for reopening the Unfold 1 study during the pandemic

Consideration	Impact on Unfold 1
Viability	Unfold 1 study no longer fits onto PhD timescale
Safety	Requirement to minimise risk of COVID-19 exposure to researchers and participants
Capacity	Support with recruitment and advertising no longer available
Social restrictions	Effects of social restrictions on social identity change mean the study would no longer produce valid results

7.3 Modifications to study design

Modification 1: Needs to be a viable study within PhD parameters. In order to be a viable PhD study, the Unfold 1 study timeline needed to be shortened to ensure it fits into the allowed timeframe. The requirement to shorten the timescale has implications for the design of the study. Longitudinal studies collect data at multiple time points, meaning they require more time than other designs (Schumacher et al., 2021). In Unfold 1, participants were enrolled for nine months, during which data was collected at three timepoints. This timeline was selected based on previous research as it was anticipated that social identity change processes were expected to be observed (Haslam et al., 2008).

It was considered unlikely a change would be seen in a study that is less time than this, so a longitudinal study will not be possible to measure social identity change.

Modification required: The requirement for a shorter study length mean that a longitudinal study is no longer possible to measure social identity changes.

Modification 2: Minimise risk of COVID-19 exposure to researchers and participants

In order to reopen studies, the risk of COVID-19 exposure needed to be mitigated for researchers and participants (NIHR, 2020). This had particular implications for advertising and data collection which had taken place during face-to-face meetings.

Advertising had been carried out by presentations by the thesis author and the CRN in clinical team meetings. It also involved displaying promotional materials in clinical areas or relying on clinicians to pass on promotional material during clinical meetings. After the onset of the pandemic, clinical team meetings took place online, and face-to-face meetings between clinicians and service users were reduced.

Data collection procedures for Unfold 1 involved three face-to-face meetings between researcher and participant. Each meeting required the participant to leave their home and visit Trust premises. This may involve using a taxi or public transport which may make it difficult to ensure social distancing.

Social identity mapping and app installation required face to face contact and would be difficult to implement effectively with social distancing in place. The face-to-face interview required up to an hour of additional face to face contact. Face-to-face data collection methods required modification in order to adhere to social distancing guidance and ensure the safety of participants and researchers.

Many studies restarted after lockdown has involved electronic data collection (Kunz et al., 2020). In order to eliminate the need for face-to-face contact, Unfold 2 took place online.

Modification required: advertising, recruitment, and data collection to take place online.

Modification 3: Setting and recruitment strategy

Changes to the study setting were necessary to ensure recruitment targets could be reached without support from the CRN. Successful recruitment for Unfold 1 had been reliant on CRN relationships within mental health services and their knowledge of the services. Without CRN recruitment support, it was necessary to make changes to the study setting to ensure that eligible participants could be recruited without the need for specialist knowledge of mental health services. For this reason, the setting was required to change to non-NHS settings in England. The decision to carry out the study online can enable this.

Changes to recruitment were necessary to accommodate the change in setting. An online study means that recruitment material will need to be digitalised and meetings with relevant groups for advertising would need to take place over videocall. A new strategy could rely on the participant directly contacting the researcher if they view promotional material and would like to take part or to find out more information. Pre-screening will need to be carried by the researcher after the potential participant makes contact.

Implication for Unfold 2: The study setting will be changed to outside of NHS services.

Modification 4: Needs to generate valid data

In order to generate valid data, the study design needed to be appropriate for measuring social identity change. Because of the pandemic, the study design was required to change to a design that did not measure social identity change at time points that occurred after enrolment in the study. In a retrospective design the study takes place after the event that is being observed (Euser et al., 2009). This means that a retrospective design was not affected by social distancing restrictions. A retrospective design will be used in Unfold 2.

Implication for Unfold 2: a retrospective design will be used in Unfold 2 Modifications required to the design of Unfold 1 are summarised in Table 7.8.

Table 7.7 Modifications required to Unfold 1

Consideration	Modifications required
Viability	Shorter study timescale required
Safety	Need to remove face-to-face contact between participants and researchers
Capacity	Change to study setting outside of NHS
Social restrictions	Change to retrospective design

Findings from Unfold 1 that can inform design of Unfold 2

Some conclusions could be drawn from the available data about the suitability of the study design and procedures for when the study reopened. Unfold 1 used three types of measures: standardised patient-rated outcome measures, SIM-tool and an ESM measure. Each will be considered.

The two standardised patient-rated outcome measures were suitable for use. Neither the SEPRS nor the Flourishing Scale had any missing data, and participants did not identify any issues or appear to the observing researcher to have any challenges in self-rating the measures. Whilst too few participants completed the measures to allow inferential statistics, the scores ranged from 200 to 910 (possible range 0 to 1500) for the SEPRS and from 14 to 43 (possible range 0 to 49 for the Flourishing Scale, indicating that the measures capture differences between participants.

Implication for Unfold 2: SEPRS and Flourishing Scale will be used in Unfold 2

The SIM-tool successfully enabled multiple social identity constructs to be captured for each participant. It was not possible to tell if the SIM could be used to measure social identity change in recovery from psychosis, as the study was closed before the second data collection point occurred for any participants. However, data for each participant appeared from researcher observation and support for SIM completion to represent a full subjective picture of the participant’s social identity at the time of completion. The SIM-tool procedures were generally very well accepted by participants who reported anecdotally to the researcher that they enjoyed the experience of creating a SIM. A number of participants took a photograph of their SIM after they had completed it, for personal interest. Some aspects of the analysis of SIM-tool were challenging. Due to the number of social identity constructs captured, it was time intensive to analyse, e.g., the Group similarity variable was measured by how close each post-it was to other post-its, which required measuring equipment to assess.

Since Unfold 1 was designed, an online version of the SIM-tool was developed. The Online social identity mapping tool (OSIM) allows participants to map their social identity using an online programme, rather than using paper and post-it notes (Bentley et al., 2020). This can be done via a link sent to participants via email, alleviating the need for face-to-face contact.

Implication for Unfold 2: OSIM will be used in Unfold 2.

ESM measures

The results show that completion of ESM questionnaires decreased for every month participants were enrolled in the study. After three months of ESM data collection, none of the participants responded to any ESM prompts. This is in line with the systematic review findings in Chapter 4, where greater data collection burden was consistently associated with reduced data completeness. In order to measure prospective changes to social identity, data collection is required for a number of months (Haslam et al., 2008). ESM does not appear to be an appropriate method for measuring social identity change over a number of months.

Implication for Unfold 2: ESM will not be used in Unfold 2.

Design of Unfold 2

Unfold will be redesigned and reopened as in line with NIHR guidance to enable the study to be carried out during the pandemic. Design modifications based on the results of the Unfold 1 study and modifications required due to social distancing restrictions are summarised below.

Modifications required

- A longitudinal study will no longer be used to measure social identity changes
- Advertising, recruitment, and data collection to take place online
- The study setting will be changed to outside of NHS services
- A retrospective deign will be used
- SEPRS and Flourishing Scale will be used
- OSIM will be used
- ESM will not be used

Chapter 8: Unfold 2 Methods

This chapter describes the methods used in the Unfold 2 study, A rationale is presented in Section 8.1 for the use of stage models as a framework for understanding identity change. The aims of the Unfold 2 study are then presented in Section 8.2, and the methods including amendments described in chapter 7 are described in Section 8.3.

8.1 Rationale

Due to the COVID-19 pandemic and associated restrictions, a prospective observational study was no longer possible to generate inductive knowledge. Therefore, as part of the adaption of the Unfold design, stage models were used as an existing framework for understanding identity change in recovery from psychosis.

8.1.1 Stage models

Stage models of behaviour change assume that changing behaviour requires a sequence of changes in psychological practices and factors as individuals come to adopt new behaviours (Sniehotta and Aunger, 2010). These changes can be conceptualised as distinct stages an individual passes through on the way to behaviour change (Davidson et al., 2010). Stages can be defined as a set of categorically different, ordered states, which are similar internally in terms of cognitive, emotional and behavioural features, but psychologically different from each other (Sniehotta and Aunger, 2010).

Stage models have four defining features (Weinstein et al., 1998):

1. Stage definitions

Individuals are assigned to a distinctive and exhaustive set of stages in accordance with behavioural/emotional/cognitive qualities.

2. Sequence of stages

Individuals pass through each stage sequentially on the way to adoption of new intentional behaviours. Regression to previous stages is possible.

3. Common stage-specific barriers exist

Barriers to progressing to the next stage are those things which need to be achieved to make progress from the current to the next stage.

4. Different barriers between different stages

People at different stages face different barriers, need to master different tasks, or differ regarding their mindset, and therefore benefit from different interventions to support behaviour change. The variables that differentiate between people in stages 1 and 2 are not the same variables that differentiate between people in stages 2 and 3 (Weinstein et al., 1998).

Transtheoretical model of change

Generic stage models have been proposed. The Transtheoretical model of change (TTM) is the dominant stage model in health psychology and health promotion (Sutton, 2015). The model emerged to describe behaviour change in addiction recovery (Prochaska and DiClemente, 1983), and has been applied to many other populations. The TTM separates behaviour into five stages described in terms of a person’s past behaviour and plans for future action (Prochaska et al., 1993). Stages consist of pre-contemplation, contemplation, preparation, action and maintenance, as described in Table 8.1.

Table 8.1 Transtheoretical model of change

Stage	Definition
Pre-contemplation	Refers to the period prior to behavioural change. The individual has not yet begun to think about and is not yet considering change.
Contemplation	The individual begins to consider the possibility of change and to evaluate the pros and cons associated with such efforts.
Preparation	The individual is seriously thinking about change behaviour, and begins planning to make changes to which they are truly committed
Action	The individual makes specific changes to end unhealthy behaviours and/or increase behaviours that enhance health
Maintenance	The individual works to sustain the positive behavioural change in the long term

Health related change occurs in a series of steps, through which people pass as they make progress by altering behaviour patterns (Davidson et al., 2010). TTM has been applied in a variety of areas including physical inactivity at work (Planchard et al., 2018), nutrition (de Melo Ribeiro et al., 2020) and academic performance (Moreira et al., 2020). Stages of change have been found to be relevant across many health related changes (Davidson et al., 2010).

Stage models in mental health recovery

Recovery-specific stage models have been proposed. A synthesis of recovery narratives identified five stages (Andresen et al., 2003). The model segments the overall process of recovery into stages, through which a person progresses from being overwhelmed by mental illness to taking on an increasingly active role in managing, understanding and overcoming the impact of mental illness (Davidson et al., 2010). Andresen's model has been shown to be valid and maps onto the TTC (Leamy et al., 2011). Each stage is described in Table 8.2.

Table 8.2 Andresen's five-stage model of recovery

Stage	Description
Moratorium	Characterised by denial, hopelessness, identity confusion, and withdrawal
Awareness	First signs of hope of a better life, and that recovery is possible. This can be an internal event, or it can be sparked by a clinician, significant other or a role model. Awareness of a possible self, other than that of "sick" person
Preparation	In which the individual begins working on recovery taking stock of the intact self, and of one's values, strengths and weaknesses. It involves learning about mental illness and services available, recovery skills, becoming involved in groups, and connecting with peers.
Rebuilding	Rebuilding through working on a positive identity, setting and working on goals, and regaining meaning in life;
Growth	Growth which involves living a full and meaningful life and looking forward to the future

Critique of stage models

Some limitations of stage models have been identified. One limitation is that in order for them to be meaningful, the stages and the corresponding barriers must be identified accurately (Weinstein et al., 1998). The type of help and support that promotes recovery will differ depending on the stage the person is at (Slade et al., 2008). The mechanisms for transitioning between the stages in the five-stage model are unclear (Davidson et al., 2010). If mechanisms cannot be identified accurately then this could undermine the applicability of the model (Weinstein et al., 1998).

Another criticism is that the model assumes the primary driver for change is the person themselves. Many factors involved in a person's recovery are outside of the person's control (Davidson et al., 2010). Looking at the course of a person's recovery without considering context is inadequate, and more consideration of the person within their environment should be given (Strauss et al., 1985). More generally, individualistic models of recovery have been criticised for implying that the responsibility of recovery lies entirely with individuals who need to modify their beliefs, thoughts, and feelings (Price-Robertson, 2017). When considering a person's recovery, consideration should be given to interdependence with friends and family as well as independence (Slade et al., 2008).

Stage models have been criticised for assuming that behaviour change is a linear process. Recovery has been shown to occur in a nonlinear fashion (Wood and Alsawy, 2018). It has been said that stage models need to more accurately reflect the non-linear nature of recovery (Davidson et al., 2010). Even though a feature of stage models is that an individual can return to previous stages (Weinstein et al., 1998), most stage models of recovery imply linearity, leading them to be read as various stages building on each other in a particular order (Davidson et al., 2010). It is questionable whether linear models are capable of capturing the processes that motivate decisions to engage in health behaviours (McGuire, 1973). Recovery is unique to each individual

(Leamy et al., 2011) and a model needs to be able to describe heterogeneity of outcomes (Strauss et al., 1985).

Despite criticism of stage models, identification of well-defined stages of change may be useful in strengthening understanding of recovery processes (Davidson et al., 2010). Change models could be particularly useful for Unfold, which seeks to understand specific processes of recovery and identity change over time. The five-stage model could be used as a framework to understand the context in which identity change in recovery occurs. Using the model to understand identity change in recovery may help to explain some of the barriers between stages.

The five-stage model of recovery and identity change

The five-stage model will be used as a predefined framework to investigate identity change. One of the variables that differentiate individuals between stages of recovery is positive sense of identity. Social identity change processes are evident between each stage. At the Moratorium stage, identity is defined by the psychiatric patient role (Andresen et al., 2003). The all-encompassing illness identity may reflect a person lacking in additional social groups in which to invest (Sani, 2008). This causes illness identity to become central to a person’s view of themselves (Ng et al., 2018).

Connecting with peers and becoming involved in groups is a feature of the preparation stage. This may illustrate that as an individual enters this stage they have begun to categorise themselves into additional social groups rather than being a member solely of an illness identity group (Turner et al., 1987). One of the mechanisms of peer support in severe mental illness is social support (Watson, 2017). Benefits associated with social support, including increased wellbeing, are underpinned by shared social identity (Praharso et al., 2017).

Elements of the growth stage closely resemble psychological wellbeing (PWB) (Andresen et al., 2003). The implications are that as a person progresses through each stage their level of wellbeing will increase. The wellbeing increase may result from increased psychological resources as a result of gaining additional social identities (Haslam et al., 2021).

Potential social identity related barriers between each of the 5 stages are described in Table 8.3.

Table 8.3 Potential barriers related to social identity between each of the 5 stages

Stage transition	**Task for the individual**	**Enabling contextual influences**
Moratorium to Awareness	Begin to believe in the possibility of gaining other social identities separate from all engulfing ‘mental patient’ identity	Awareness of / exposure to a sufficiently positive alternative social identity to create some hope that change is possible
Awareness to Preparation	Starts to become involved in other groups and connecting with people who have shared social identities	Opportunity to experience alternative social identities, such as recovery related groups
Preparation to Rebuilding	Build positive social identity groups and finding meaningful group-based connections	Opportunity to develop new skills allowing entry to new social identity groups, and context affording opportunities for new skills and identity development
Rebuilding to Growth	Maintain a positive social identity network providing support, meaning and purpose	Opportunity to maintain positive social identity network

Positive social identity is implicated in movement between stages of recovery. Identity change processes are barriers between stages of recovery. If a person is unable to follow the identity gain pathway or the identity maintenance pathway by gaining or maintaining social groups as part of their recovery, then they may not progress through the stages. This will have a negative effect on a person's wellbeing, as they will not benefit from the resources afforded by social group identification (Greenaway et al., 2016). They may also be affected by negative self-concept as a result of occupying a low status group (Ellemers et al., 1993).

8.2 Aims

8.2.1 Research aim

To characterise the processes involved in developing an identity as a 'person in recovery' for people with experience of psychosis who are in the Rebuilding and Growth recovery stages.

8.2.2 Research objectives

1. To explore the role of social identity change processes in recovery from psychosis (Change processes)

2. To investigate the relationship between social identity change, wellbeing and recovery (Relationships)

3. To develop a model of social identity change in recovery from psychosis (Change theory)

8.3 Methods

Design

Unfold 2 is a retrospective mixed methods study with a convergent design. In a retrospective design the study takes place after the event that is being observed (Euser et al., 2009). Participants were asked to recall events from a time prior to enrolment in the study. The retrospective design adheres to the principle of viability (NIHR, 2020), as the retrospective design does not require the longer timescale of a prospective study.

A disadvantage of the retrospective design is that data may be subject to recall bias, as the study relies on participant memories of past events (Solhan et al., 2009). Recall bias is an error due to differences in completeness or accuracy of recall (Spencer et al., 2017) . A strategy used to reduce recall bias is careful selection of research questions. Aided recall has been used in design of survey questions to reduce biases. It involves using cues as part of the question to jog participant memories (Kosicki, 2011). For this reason, the five-stage model will be used as a framework for characterising change. The stages will be used to inform questions and provide cues to aid participant recall, in order to reduce recall bias.

Chapter 5 outlined the definition of mixed methods research and identified how mixed methods research can be used to provide a more complex understanding of a phenomenon that would otherwise not have been accessible by using one approach (Creswell & Plano Clark, 2011; Morse & Niehaus, 2009). A mixed methods approach will also be used in Unfold 2. Social identity research has shown that a person’s identity is defined by the number of groups they belong to (Brook et al., 2008), as well as the quality of the connection they have to these groups (Ellemers and Jetten, 2013). Collection of only quantitative data could provide a general understanding of a person’s social identity change in terms of the number of social identity groups and how this may change between two timepoints. Collection of only qualitative data could provide knowledge of participants experiences of this change. Yet, collecting only one type of data will not allow for knowledge to be gained which will provide a full understanding of social identity change. Knowledge of group quality as well as group quantity will be sought in order to achieve complete and corroborated results (Creswell and Plano Clark, 2018). By engaging in both forms of data collection, knowledge can be obtained about social identity change in recovery from psychosis that would not be accessible through collection of only one type of data (Shannon-Baker, 2015).

The study had two distinct interactive phases:

1. Quantitative data was collected about social groups

2. Semi-structured interviews were conducted about experiences of social identity change and recovery

The qualitative and quantitative phases of the study occurred in parallel, ending at approximately the same time (Teddlie and Tashakkori, 2009 p.120). In a retrospective longitudinal mixed methods study, qualitative data are collected once, at the end of a quantitative longitudinal study to elicit participants' reflections on what has transpired (Schumacher et al., 2021). Collection of quantitative data from a participant will be followed by semi-structured interviews to expand on and to inform interpretation of the quantitative results and to examine participants’ recollections of the issue that was measured quantitatively (Van Ness et al., 2011).

Convergent mixed methods designs were described in detail in Section 6.2. A convergent design has been chosen for Unfold 2 as the design allows researchers to interpret the meanings of quantitative and qualitative results in order to generate new hypotheses (Van Ness et al., 2011). The study will be exploratory, allowing better understanding of social identity change in recovery. Results from Unfold 2 are intended to generate hypotheses for future research.

Participants

Inclusion Criteria

- Aged 18 or over
- Have experienced psychosis (formally diagnosed or self-defined)
- Are competent in English
- Can use a computer or smartphone and have an email address
- Able to give informed consent for participation
- At either the Rebuilding or Growth stage of recovery as measured by the Single Item Stages of Recovery (SISR).

Exclusion criteria

- Currently experiencing a significant period of unwellness or mental health difficulties.
- Currently having an in-patient admission or under the care of crisis services.
- At the Moratorium, Awareness or Preparation stage of recovery as measured by the Single Item Stages of Recovery (SISR).

People who have had self-defined experiences of psychosis were included. They do not have to have met diagnostic criteria for psychosis at the time of or prior to recruitment. This is due to the decision to recruit from outside of mental health services. People may be eligible to participate who are not currently under mental health services, who have been discharged or have ever used services. Due to the retrospective design, the decision was made not to include an upper age limit.

Participants were required to be at either the Rebuilding or the Growth stage of recovery, as measured by the Self-Identified Stages of Recovery Measure (SISR). This is so that identity change processes could be identified between the Moratorium stage of recovery and the time of data collection.

Sample size

The study aimed to recruit a total of 50 participants. This number was chosen because, although the design of the study had changed from Unfold 1, the study was still exploratory and therefore a power calculation was not appropriate. NIHR guidance for feasibility studies was drawn upon, which recommends a sample size of 40-50 participants (NIHR, 2019).

The qualitative sample size was not pre-specified for Unfold 2 as it was not known how many interviews would be required for central organising concepts to be identified in the data. Therefore, interviews took place until the thesis author and supervisor team agreed that the themes were coherent and were each organised around central organising concepts (Braun and Clarke, 2015). (Please refer to section 6.3 ‘Sample size’ for full discussion of power calculations and central organising concepts).

8.5 Setting

The study setting was non-NHS services in England. Recruiting from outside of NHS services was intended to increase the chances of meeting the recruitment target as advertising and study promotion could target relevant groups directly without requiring a clinical gatekeeper. Recruiting from outside NHS services also meant that the study did not breach the capacity principle, by relying on NHS services that were already at capacity for supporting research due to the pandemic (NIHR, 2020).

8.6 Measures

Self-identified stage of recovery (SISR)

SISR is a brief measure based on the stage model of recovery (Andresen et al., 2003). SISR is designed to assess recovery stage. It consists of 5 statements, each representing one of the stages of recovery as they are described in Andresen’s stage model. For example, statement 1 is ‘I don’t think people can recover from mental illness. I feel that my life is out of my control, and there is nothing I can do to help myself', reflecting the Moratorium stage. Participants choose one of the five statements which best represents their current experience.

The SISR has shown moderate correlation with the Stages of Recovery Instrument (Andresen et al., 2006), a longer measure based on the Andresen's model stage model of recovery. The SISR has been shown to correlate with the Recovery Assessment Scale, which is rated by the individual ($r = 0.45$, $p < 0.05$) and with the Health of the Nation Outcome Scales ($r = -0.39$, $p < 0.05$), which is rated by clinicians.

SISR was chosen for use in Unfold as a very brief measure is required to ensure that people interested in participation meet the eligibility criteria of being at the Rebuilding or Growth stages of recovery. To ensure that ineligible people's time is not wasted, a measure which is brief and quick to administer was required.

Short Warwick–Edinburgh Mental Wellbeing Scale (SWEMWBS)

The SWEMWBS is a shortened version of the Warwick and Edinburgh Mental Wellbeing Scale (WEMWBS), a scale developed to capture a broad understanding of wellbeing, including emotional, cognitive and psychological dimensions (Tennant et al., 2007). The SWEMWBS was developed using a Rasch measurement model which resulted in an 8-item scale after 7 items were removed in order to improve the overall fit of the data into the model (Stewart-Brown et al., 2009). The SWEMWBS consists of 8 items and asks participants how they had felt over the previous four weeks in relation to seven items used to measure aspects of wellbeing, including feeling optimistic and feeling useful. Responses are rated on a 5-point scale from 1 (none of the time) to 5 (all of the time). Final scores can range from 7 (low wellbeing) to 35. SWEMWBS has been shown to have a high level of internal consistency (Cronbach's alpha: 0.89), with scores correlating positively with other wellbeing measures and with negative moderate correlations with depression and anxiety measures. SWEMWBS has been validated for use in a population in Singapore with schizophrenia, depression and anxiety spectrum disorders (Vaingankar et al., 2017). The mean (SD) SWEMWBS score in the sample was 21.1 (5.3) and ranged from 7 to 35. The study demonstrates adequate validity and reliability of the SWEMWBS in a population with schizophrenia, depression and anxiety spectrum disorders.

SWEMWBS was chosen for use in Unfold 2 due to the broad conception of wellbeing.

Flourishing Scale

The Flourishing Scale is an 8-item scale measuring social–psychological prosperity. It was described in Section 6.5

The Self-Efficacy for Personal Recovery Scale (SEPRS)

The Self-Efficacy for Personal Recovery Scale (SEPRS) is a 14-item self-report scale measuring an individual’s autonomy and responsibility in defining and directing their own recovery. It was described in Section 6.5.2.

Online Social Identity Mapping Tool (OSIM)

The Online Social Identity Mapping Tool (OSIM-tool) allows participants to map their social identity online. The tool enables participants to record different aspects of their social identity in the form of an online social identity map (OSIM). Aspects of social identity captured by OSIM include quantity of social relationships, total number of groups and number of high contact groups and quality of group memberships, and numbers of supportive, compatible and positive groups. How the groups relate to each other are also captured within each map, including levels of group compatibility and similarity between groups.

OSIM has been used to investigate changes to social identity over time. Two studies have used online creation of a social identity map for a previous point in time (OSIM-1) and for now (SIM-2). One used OSIM to investigate identity change after becoming a mother (Bentley et al., 2020). The study recruited women who had given birth in the last 5 years. They were asked to think back to 12 months before the birth of their most recent child and to create a map of their social group memberships at that time. Once complete, they were then asked to create an additional map representing their social group memberships at the present day.

Another study used OSIM to investigate adjustment to retirement. A sample of 193 retirees were asked to create a map of their social group memberships as they are in the present-day (post retirement) (Bentley et al., 2020). After this, they were asked to think back to 12 months before their retirement and create a map of their social group memberships as they were at that time (Bentley et al., 2020).

The OSIM has been shown to have good level of user acceptability, with no participants across 4 different studies reporting any difficulties in using the measure. OSIM has a high level of internal consistency with most OSIM variables significantly correlated. Convergent validity was assessed by comparing OSIM results with a social group listing task.

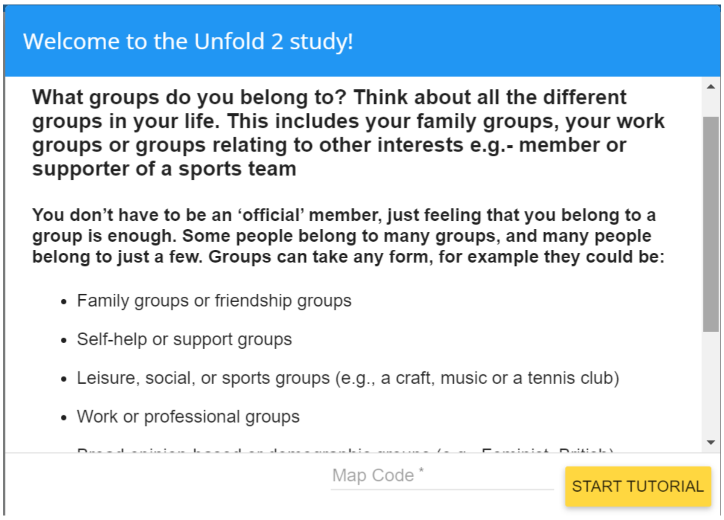
OSIM variables were found to have significant positive correlations with corresponding OSIM scores.

There are no published papers validating OSIM for use with people who have experienced psychosis and so it is not possible to report any norms for the OSIM measure with this population. OSIM has been used with a population of ex-prisoners to measure group identification and wellbeing (Kyprianides et al., 2018). In this study, participants belonged to a mean number of 4.31 social identity groups. Other social identity measures are designed to assess only one social identity process at a time such as identification or multiple group membership and so data from other scales measuring social identity are not comparable.

The OSIM features Likert scales to measure how participants experience different social identity constructs. One criticism of Likert scales is that they assume an equal distance between scores. E.g. that an increase between 0-1 for group supportiveness is considered by participants to be the same amount of increase that occurs between scores 4 and 5 (Bishop and Herron, 2015). Concepts such as supportiveness are complex and reducing this complexity in order to measure social identity constructs could led to measurement error (Polit and Yang, 2016). Measurement error is refers to the discrepancy between the observed scores obtained from a OSIM and the true scores that it is designed to measure. This may be a particular issue with OSIM in which each Likert scale has only 5 response options. Measurement error may affect the validity of the OSIM scale.

After clicking the link to open the OSIM tool, participants are presented with an opening screen informing them about social identity groups and providing examples. The opening screen is shown in Figure 8.1.

Figure 8.1 OSIM Unfold 2 opening screen



Welcome to the Unfold 2 study!

What groups do you belong to? Think about all the different groups in your life. This includes your family groups, your work groups or groups relating to other interests e.g.- member or supporter of a sports team

You don't have to be an 'official' member, just feeling that you belong to a group is enough. Some people belong to many groups, and many people belong to just a few. Groups can take any form, for example they could be:

- Family groups or friendship groups
- Self-help or support groups
- Leisure, social, or sports groups (e.g., a craft, music or a tennis club)
- Work or professional groups
- Broad opinion-based or demographic groups (e.g., Feminist, British)

Participants entered a code which consisted of a Unique identifying number allocated to them by the researcher, plus 'A' for the present day map and 'B' for the map from earlier on in their recovery (e.g. 001A). They were then presented with a two-minute interactive video tutorial. The tutorial provided instructions on how to build a social identity map and concluded with an invitation for participants to create their own map.

Map creation takes place in the following order:

1. Identifying and labelling social identity groups

2. Rating the importance of each group

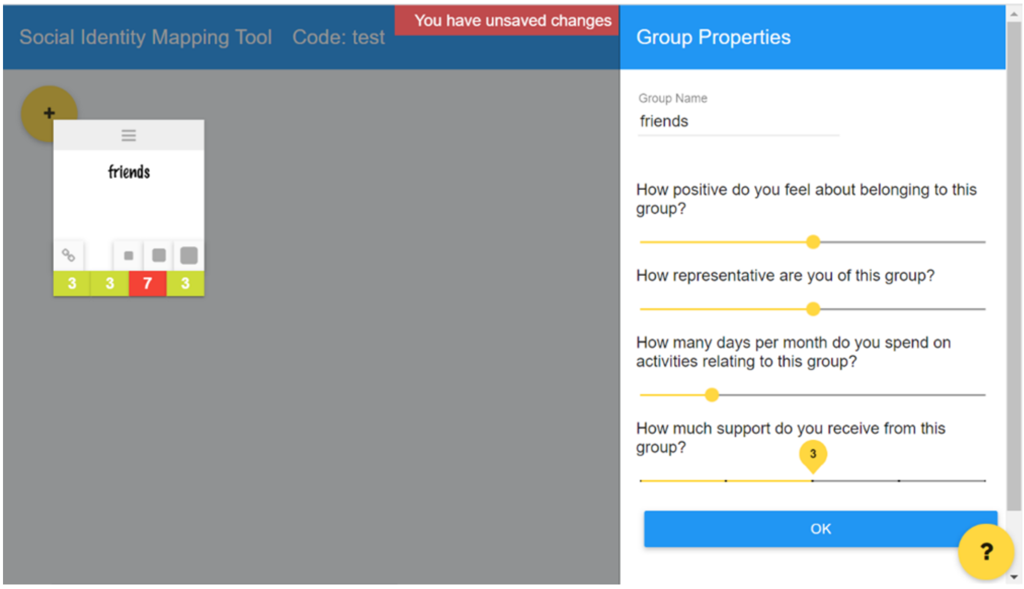
3. Answering questions about the following social identity concepts for each group: positivity, contact, prototypicality and supportiveness

5. Positioning groups in relation to each other

6. Rating the compatibility between each group.

Figure 8.2 shows part of the OSIM map creation process. The boxes each represent a different social identity. The box in the diagram represents a social identity group that the participants has labelled ‘friends’. The scoring panel is on the right -hand side and the participant assigns scores to each social identity group construct using the scales. The numbers at the bottom of each box are scores assigned to the different social identity constructs, comprising (reading from left to right) positivity, contact, prototypicality and supportiveness.

Figure 8.2 OSIM map creation process



Group Name
friends

How positive do you feel about belonging to this group?

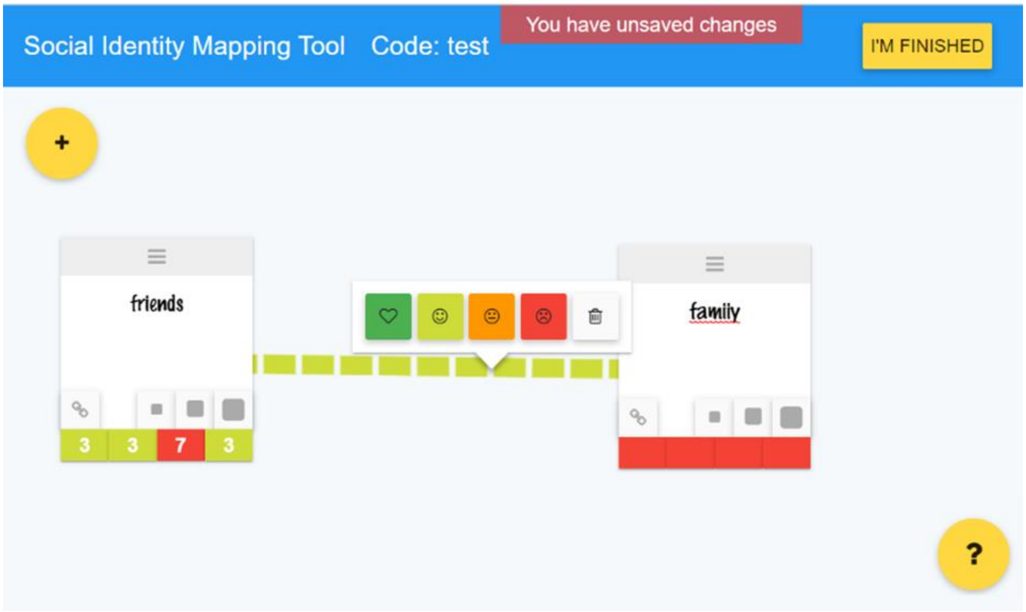
How representative are you of this group?

How many days per month do you spend on activities relating to this group?

How much support do you receive from this group?
3

Figure 8.3 shows how participants are able to link their groups together to represent compatibility.

Figure 8.3 Using the OSIM to select the level of compatibility between groups



The colours represent the scores for different social identity constructs related to that identity e.g., group positivity. The lines represent group compatibility. The green lines represent very compatible groups, orange represent medium compatibility between groups and red, low compatibility.

An illustrative example of a completed OSIM is shown in Figure 8.4.

Figure 8.4 Illustrative example of a completed OSIM

The completed OSIM in figure 8.4 shows the different social identities linked by the lines representing compatibility. The OSIM automatically generates a colour for each score at in the bottom of each box. Red represents a low score, orange a medium score and green indicates a high score in that social identity domain.

Table 8.4 describes the social identity constructs measures by OSIM.

Table 8.4 Social identity concepts measured by OSIM

Social identity concept	**OSIM Measurement**
Group quantity	Total number of groups each participant includes on each map
Group importance	Measured by the size of each group on the map. Three available sizes large (very important), medium size (medium importance, small (less important).
Group similarity	How close together each group is on the map. The closer groups are placed together on the map, the more compatible they are.
Group contact	How many days per month do you spend on activities relating to this group? (1-30)
Perceived Positivity	How positive do you feel about belonging to this group? (1 not very positive-5 extremely positive)
Prototypicality	How representative are you of this group? (1 not very represenentative-5 extremely representative)

Supportiveness	How much support do you receive from this group? (1 not very much support-5 a lot of support)
Group compatibility	Proportion of compatible groups on the OSIM out of the total number of groups

The OSIM has been chosen for Unfold 2 as it is the online version of the SIM-Tool used in Unfold 1. The Unfold 1 study demonstrated the appropriateness of the SIM-Tool for allowing data collection on multiple facets of a person's social identity which are in line with social identity theory (Cruwys et al., 2016). The data collected by using the OSIM will allow the aims of Unfold 2 to be met. The OSIM allows social identity data to be collected from participants online, which adheres to the principle of safety by minimising contact between researchers and participants (NIHR, 2020).

8.7 Procedures

8.7.1 Patient and public involvement

A PPI group with lived experience was used for the which consisted of 5 people who had experience of psychosis. Due to the pandemic, members of the group met individually with the researcher via Microsoft Teams and collaborated by email. The group were actively involved in the design of the study. The most significant contribution of the PPI group was the testing of the data collection process, including use of the OSIM platform and Microsoft Teams simultaneously. Testing involved group members taking the place of a participant and creating two OSIMs via Teams with the researcher. This enabled both platforms (Teams and OSIM) to be tested and for the researcher to familiarise herself with the processes. It also tested processes for accessing, downloading and saving of data from the OSIM platform by the researcher.

Significant contributions of the PPI group included:

- Co-creating the wording of the OSIM opening page to ensure definitions were clear and relevant
- Commenting on the wording of the PIS and consent form to ensure they were clear
- Contributing to specific design decisions e.g., informing the decision to carry out the ‘present day’ OSIM with participants before the retrospective OSIM

8.7.2 Recruitment

Seven approaches to recruitment were used:

- Advertising on social media, including dissemination of poster/poster information to groups focused on mental health / wellbeing or focusing on psychosis or recovery.
- Targeted advertising to mental health / psychosis / wellbeing organisations / blogs / charities / forums /podcast
- Advertising through Institute of Mental Health networks including PPI groups and targeted emails to staff
- Advertising through University of Nottingham networks including student union and wellbeing service
- Through newsletters, including the Institute of Mental Health newsletter, University of Nottingham School of Medicine and School of Health Sciences news and research bulletins or other online publications
- Advertising on participant recruitment service https://www.callforparticipants.com/
- Information on the study website https://www.researchintorecovery.com/unfold

Advertising took the form of a poster containing key information and contact details.

The advertising poster is shown in appendix 11. Using the poster led to successful recruitment of the target number of participants in 4 months and so the poster design was thought to be an effective recruitment material.

All advertising routes indicated that if a person was interested in taking part in the study, they should contact the researcher using included contact details.

Prior to the study opening for recruitment, data collection procedures were tested by the Patient and Public Involvement (PPI) group, who have had specific PPI training and are experienced in evaluating research studies. Study questionnaires were tested to ensure the links worked correctly and questionnaires were checked for any errors. The OSIM was tested to ensure wording for the introductory screen and other text were clear and acceptable.

When a potential participant expressed an interest in the research, the researcher spoke with them via phone or email to carry out a pre-screen to ensure that the person was eligible to take part. This was done via a discussion with reference to the inclusion criteria, including completion of SISR. If they did not meet eligibility criteria, they were thanked for their interest in the study and informed that they were not eligible. Participants were also asked when they would be free for a meeting via videocall using Microsoft Teams. Teams was chosen as a platform because it does not require the participant to log in, thus reducing participant burden. It is also approved for use by the University of Nottingham due to its compliance with General Data Protection Regulation (GDPR) guidance.

If a person met the criteria, they were emailed a PIS and link to the online consent form (Appendix 7). They were requested to tick the boxes of the consent form, stating they had read the available study information, understood, and gave consent to creating an online social identity map and that they may be asked to participate in an interview. They were also asked to consent to participating in an interview and to type their name at the bottom in place of a signature. Participation did not go ahead unless consent was provided. The email also contained an invite link to a meeting on Microsoft Teams.

After a participant gave consent, they were allocated a Unique Identifier (UID). To ease participant burden, the participant was not required to remember this number. When consent had been obtained, the researcher added the participant UID to the demographic questionnaire, Flourishing Scale, SWEWBS and SEPRS (Appendices, 2, 3 and 5) before the participant was sent an email containing links to these measures. Participants were informed that they could either complete the questionnaires before the scheduled Teams call or if they did not fill them out prior to the call they could fill them out at the beginning of the meeting. The email also included a link to access the scheduled Teams meeting and a link to access the SIM-tool.

If the participants did not accept the Teams meeting request up to 24 hours before the scheduled meeting, they were contacted by email or phone to ask if this time was still convenient or to reschedule. When a participant clicked on the links to the questionnaires, they were redirected to JISC Online Surveys where they could complete the questionnaires.

At the arranged appointment time, the participant could access the Teams meeting via the link. The researcher gave the participant the chance to ask any further questions and ensured that the participant understood the procedures and still consented to take part. Participants were given the opportunity to fill out the questionnaires if they had not done this previously. Participants were asked to share their screen via Teams by using the “share content” button. They were then asked to create OSIMs by clicking on the link sent to their email address. When they clicked on the link, they were prompted to type in their UID provided verbally by the researcher. Participants were asked to enter their UID plus the letter ‘A’ before completing the tutorial and an OSIM for when they were early on in their recovery.

Participants were asked to complete OSIMs for two points in their life: a point when they were very early in their recovery journey (Previous OSIM) and currently (Current OSIM). Participants were supported to identify a time they were very early in their recovery journey by discussion with the researcher, who used a selection of prompts from the SISR, including:

- “I didn’t think I could recover from mental illness”
- “I felt like my life was out of control”
- “There was nothing I they could do to help Myself”
- “I had just recently realised that people can recover from serious mental illness”
- “I was just starting to think it may be possible to help myself”

OSIM creation was carried out in the following order:

(a) identifying and naming groups

(b) deciding on the importance of each group

(c) answering questions about each group (e.g., how positive one feels about the group

(d) positioning the groups so that similar groups are closer together; and

(e) rating the compatibility of pairs of groups.

The researcher was available via video call to offer support to the participant whilst they create their OSIMs.

After the two OSIMs were created, some participants were invited to participate in a semi structured interview. If the participant was not selected for interview, they were thanked for their participation, informed of study timelines and how to access resulting publications, and their participation in Unfold ended at this point.

Participants who were selected for interview were offered a short break before the interview commenced. After the break, the researcher gave them an opportunity to ask further questions. The researcher then checked that they consented to recording the interview and ask permission to record verbally before the recording started. When the recording started the researcher read out the UID before the interview started.

Semi-structured interviews were conducted by the thesis author. The interview topic guide was developed by the thesis author and based on SIT constructs. It included prompts to clarify previous experiences of social identity change. Participants were encouraged to use their two OSIMs as prompts during the interview in order to find out about experiences between the time they were at the Moratorium stage of recovery (Previous OSIM) and the stage of recovery they are in at the present time (Current OSIM). Participants were asked if they would like to have their OSIMs available to them on the screen. If they requested this the researcher made these available by loading the two OSIMs and sharing their screen. At the end of the interview the researcher informed the participant that the recording had stopped. She checked that the participant was not emotionally distressed and offered them an opportunity to debrief before ending the call.

Participants were paid £20 in compensation for their time and effort. They were asked to fill out a claim form with their bank account details and this was paid directly into their bank account. In the event that a participant did not have a bank account, £20 cash was sent to them through a ‘signed for’ delivery.

8.8 Research Ethics Committee (REC) approval

A separate ethical application was made for Unfold 2. REC approval was obtained from the University of Nottingham Faculty of Medicine and Health Sciences Research Ethics Committee (FMHS 251-0521). All participants gave consent to participate and for their data to be anonymised and used in publications.

8.9 Ethical aspects of the research

All participants were provided with a participant information sheet at the recruitment phase (Appendix 6). Participants were encouraged to ask any questions. Informed consent was requested, and participants completed a consent form prior to participation (included in Appendix7).

At the consent stage, mental capacity was considered by the thesis author. The Mental Capacity Act (MCA) states that mental capacity must be assumed unless there are grounds to believe otherwise (Mental Capacity Act code of practice, 2014). This may be relevant to people with experience of psychosis as a formal test of a person’s mental capacity requires consideration of any impairment in the mind or brain (such as psychosis) meaning they are unable to make a decision.

As the MCA guidance encourages presumption of capacity it would have been inappropriate to assess potential participants for capacity at this stage. The decision to exclude those experiencing a significant period of unwellness or mental health difficulties or currently having an in-patient admission or under the care of crisis services served to mitigate the chance of this occurring.

As a clinician experienced in working with this population, it is likely that the thesis author could have identified any potential capacity issues. Should this have occurred she would have paused any recruitment procedures and sought advice from her supervisory team.

In addition to the ethical considerations discussed for Unfold 1 in Section 6.8, ethical aspects specifically relating to Unfold 2 included participant distress and online data collection methods.

Participant distress

The study required participants to think back to, and to describe a time when they were at a very early stage in their recovery. This is something which may have caused distress for some participants. There was also a possibility that participants may have found discussing their social groups difficult in the context of social distancing restrictions relating to the COVID-19 pandemic distressing. Therefore a distress protocol was developed through discussion with PhD supervisors.

Participants who appeared to be experiencing significant distress or unwellness at the time of recruitment or at any point prior to or during their participation in the study were excluded or underwent a re-assessment of suitability for participation at that time. If, for any reason a participant became distressed during at any time during video call, they were given the opportunity to take a break or to conclude the interview as preferred. They were given the option to pause the recording if this occurred during the interview. When participation concluded, participants were given the opportunity to debrief with the researcher to check on their wellbeing and reflect upon their experience. If necessary, participants were encouraged to seek support from trusted family or friends and were made aware of national support services. National mental health support services were also documented on the PIS. If participants continued to experience distress, they were encouraged to contact a source of support as soon as possible such as a trusted family member or friend, and if necessary, their GP.

Online data collection methods

Data collection took place online via email and videocall. Participants were encouraged to go somewhere quiet if possible as they were discussing potentially sensitive personal information and may not wish to be overheard.

Participants were informed when video recording began and ended. They were informed that they could ask for the recording to stop or to be paused at any time. They were reminded of this at the beginning of the videocall and on the PIS. At the beginning of the call, the researcher checked they were aware of the privacy settings such as switching from video to audio if they wished and blurring their background for additional privacy. Participants were encouraged to use Microsoft Teams which is GDPR compliant and approved for use in research by the University of Nottingham.

8.10 Data management

A detailed data management plan was created for the study. The plan was created in collaboration with data management specialists at the University of Nottingham. The plan included a detailed description of the data that was collected and the ethical and privacy issues relating to participant data, data curation and details of data storage and security. All data was stored in a password protected file on a secure cloud-based server at the University of Nottingham. Participants were provided with information about how their data was stored and used on the PIS.

8.11 Analysis

To analyse qualitative data for objective 1 (change processes) Reflexive Thematic analysis was used. This approach is described in detail in, Section 6.11.

Although the six stages of thematic analysis were adhered to as described, there were some differences in the methods for Unfold 2 compared to the thematic analysis methods planned for Unfold 1.

Due to the interviews taking place online, the interviews were transcribed using the Microsoft Teams automatic transcription function. The thesis author then corrected and pseudonymised all transcripts by listening to all the interviews and ensuring that all identifiable information was removed.

NVivo (version 12) was used to organise the data. Theme development was carried out using thematic maps (Braun and Clarke, 2013). Visual aids have been recommended for use in thematic analysis (Terry et al., 2017). A thematic map can be used as a tool in thematic analysis which allows exploration and refinement of themes, subthemes, and overarching themes.

At stage 3 (theme development), an initial thematic map was generated by the thesis author (Braun and Clarke, 2013). At this stage the thesis author was beginning to consider the relationships between the codes, themes and levels of themes and the thesis author therefore produced an initial thematic map.

In stages 4 (Reviewing) and 5 (Defining themes). adjustments were made to candidate themes represented in the initial thematic map. The thesis author used additional thematic maps to check that the candidate themes captured the meaning of data she had previously coded. She checked that for each candidate theme all the data extracts related to the central organising concept of the theme.

At this stage, the thesis author also discussed the candidate themes with members of the supervisory team and also with two other mental health researcher colleagues.

To meet Objective 2 (Relationships), three OSIM metrics were considered: total number of groups, group positivity and group supportiveness. Differences were explored using inferential statistics. The distribution of OSIM scores for differences between total number of groups, group positivity and group supportiveness were not normally distributed. Therefore within-participant differences in OSIM ratings between the Moratorium stage of recovery and the Rebuilding / Growth stages of recovery were investigated using a non-parametric Wilcoxon signed-rank test on median scores.

The correlations between changes in each of the three OSIM scores and the three standardised measures were investigated using the Spearman's rank correlation coefficient, as the measures scores were found not to be normally distributed.

To test the three hypotheses relating to the SIMIC model, correlations were calculated using the Spearman's rank correlation coefficient. Hypothesis 1 stated that multiple group memberships before life change will be associated with enhanced health and wellbeing after life change. To test this hypothesis, a correlation was calculated between total groups in Previous OSIM and Flourishing scale scores.

Hypothesis 2 stated that the extent to which people belong to multiple groups will increase the likelihood of maintaining pre-existing groups to support social identity continuity. This was calculated using a correlation between total number of groups in Previous OSIM and total number of groups participants maintained between Previous OSIM and Current OSIM.

Hypothesis 3 stated that the extent to which people belong to multiple groups will increase the likelihood of joining new groups to support social identity gain. This was tested by calculating the correlation between total number of groups in Previous OSIM and the difference in total number of groups between Previous OSIM and Current OSIM.

8.11.3 Objective 3 (Change theory)

The third objective was to develop a theory of social identity change in recovery from psychosis. This aim was addressed by integrating the qualitative and quantitative data analysed for objectives 1 and 2. This was done using a joint display table. This method was described in Section 6.11.

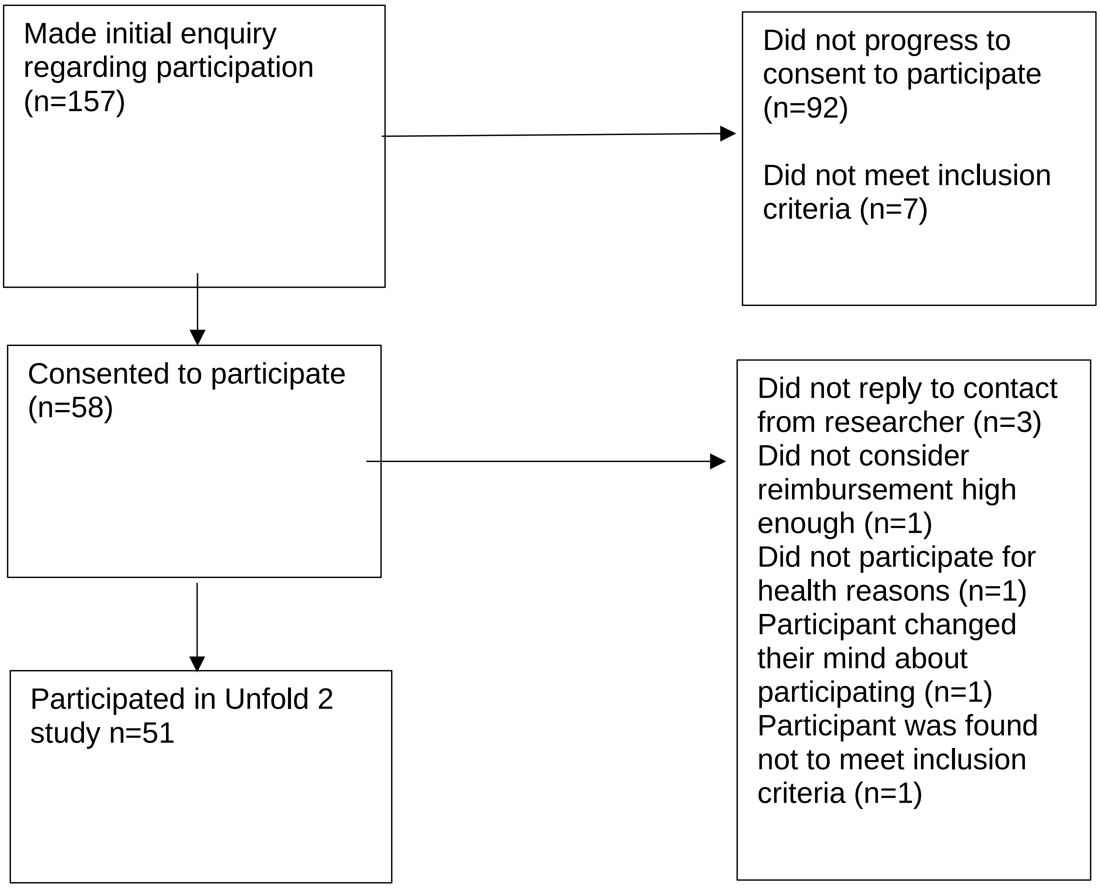
Chapter 9 Unfold 2; Qualitative findings and discussion

Chapter 9 presents participant demographic information (9.1). This is followed by the qualitative findings and integrated discussion. Section 9.2 is a reflexive look at the findings, followed by a critical appraisal of the methodological strengths and limitations of this analysis in section 9.3.

9.1 Participants

A total of 51 participants were recruited. The recruitment process is shown in Figure 9.1.

Figure 9.1 Unfold 2 Recruitment process



Recruitment routes for participants comprised Facebook (n=18), Unfold 2 study website (n=11) and community mental health groups (n=22).

A total of 36 interviews were conducted. Two interviews were carried out by phone, with the researcher taking notes. This was due to one participant's computer not loading Microsoft Teams and one participant who became stressed about not being able to work Teams and was therefore offered an alternative. Participant demographics are described in Table 9.1.

Table 9.1 Participant demographics (n=51)

Participant demographics		**n (%)**
Age	18-20	3 (6)
	20-29	10 (20)
	30-39	14(28)
	40-49	12 (24)
	50-59	7 (14)
	60-69	1 (2)
	70-79	3 (6)
Gender	Female	33 (66)
	Male	17 (34)
Ethnicity	White	39 (78)
	Black	4 (8)
	Asian	3 (6)
	Mixed/Multiple ethnic groups	4 (8)
Education	No qualifications	0
	GCSE's or equivalent	5 (10)
	A-Levels/ AS- levels/ NVQ or equivalent	13 (26)
	Degree level qualification	23 (46)
	Higher degree level qualification	14 (4)
	Other	2 (4)

Relationship status	Single / not in a relationship	26 (52)
	Married	9 (18)
	Widowed	2 (4)
	Prefer not to say	1 (2)
Employment	Full time paid employment	13 (26)
	Part time (<20 hours pw) paid employment	11 (22)
	Full time or part time study	8 (16)
	Volunteer	5 (10)
	Unable to work for health reasons	9 (18)
	None of the above	4 (8)
Housing	Own flat/house	18 (36)
	Private rental (flat/house)	11 (22)
	Communal establishment	1 (2)
	Social housing	15 (30)
	Other	5 (10)
How would you describe yourself at the moment?	Recovered	6 (12)
	Living well	24 (48)
	Making progress	24 (48)
	Surviving day to day	4 (8)
Received formal diagnosis	Yes	46 (92)
	No	3 (6)
	Prefer not to say	1 (2)

Demographic information from one participant was not collected due to a technical issue with their participant characterisation form, which did not save correctly on the Jisc online survey platform. Three attempts were made to save the information, and then efforts were abandoned as it was too burdensome for the participant to ask them to try again. Additionally, one participant chose not to provide their age.

The SERPS was not completed by one participant as they reported that they found the questions too difficult to answer as they were orientated towards the future.

The mean Flourishing Scale score was 36.29 (SD 6.93), mean SEPRS score was 71.20 (SD14.68) and mean SWEMWBS score was 24.82 (SD4.04).

9.2 Objective 1 (Change processes)

Objective 1 was to explore the role of social identity change processes in recovery from psychosis. This aim was addressed through the qualitative arm of the study. Interviews were conducted with 36 participants.

Of the 36 participants interviewed, 8 framed their psychosis experiences specifically as an illness, defining an illness social identity group as relating to their symptoms or diagnosis e.g. “Psychotic”, “Depressed”, “Schizoaffective”. 21 participants described their psychosis social identity in relation to services they were accessing e.g., “Mental health service user”, “Patient” or simply, “Hospital”. This was surprising as these participants were recruited outside of mental health services, and so might have been expected to have an understanding of their experiences that was less framed by a clinical perspective. The fact that the majority of participants did conceptualise their psychosis as an illness or service user identity may point to the dominance of the clinical model in wider society.

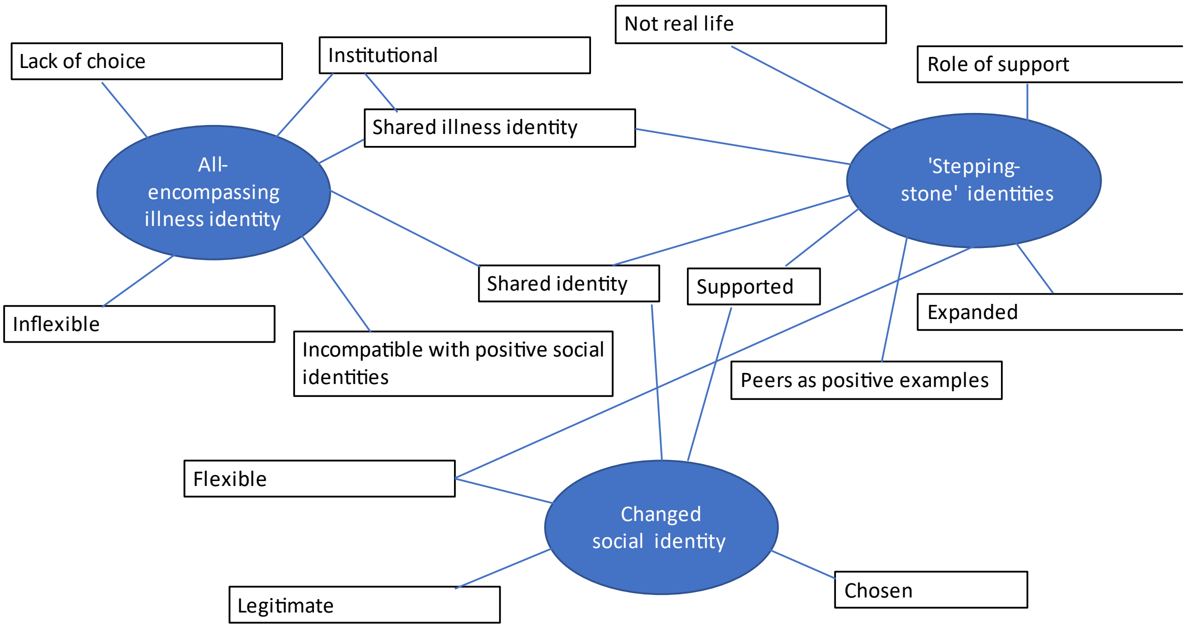
Some people with psychosis-like experiences conceptualise their experiences as wholly or partially positive (Hearing Voices Network, 2023). There were no descriptions of positive experiences or aspects of a psychosis related identity at the moratorium stage of recovery. A small number of participants did not describe any social identity relating to their illness at the Rebuilding/Growth stages of recovery. The majority of participants did describe positive aspects of their illness identity at these later stages of recovery however, such as giving and receiving support from other illness identity group members. Positive groups relating to illness identity were groups providing support to other group members such as “mental health advocate” and “service user representative”.

In general, participants described their psychosis experiences as proceeding linearly from an ‘illness identity’ which eradicated any former positive social identities, through a period of the illness identity receding as participants sought to come to terms with and accept their illness. Eventually, more positive social identity groups were incorporated as participants sought to regain a sense of positive social identity and the illness identity largely receded. This was generally described as a linear progression however this may have been described in this way due to the use of the stage model to inform the interview topic guide.

The findings are presented below as follows: first the process of analysis is outlined using three thematic maps. This is followed by a summary of how participants described characteristics of the ‘positive’ and ‘negative’ social groups to which they belonged. Finally, three themes are presented from the data.

Figure 9.2 shows the first stage of thematic analysis illustrated by a thematic map.

Figure 9.2 Initial thematic map

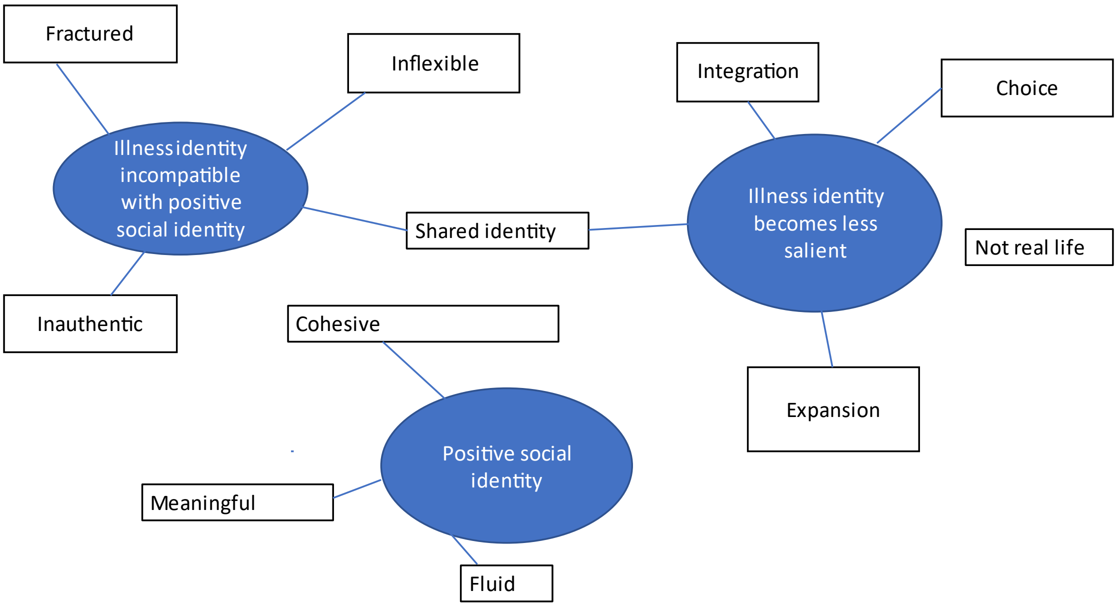


The initial thematic map shows that three broad areas of data were identified as preliminary themes: ‘All-encompassing illness identity’, ‘Stepping-stone identities’ and ‘Changed social identity’. The white rectangles represent preliminary sub-themes. The lines between each rectangle represent potential relationships between themes and sub-themes. The lines between subthemes indicate that they are linked; at this initial stage, themes and subthemes were not yet distinct from each other. At this early stage in the analysis, a key thing that participants discussed was the importance of support they received from those who shared an illness identity.

At this stage of the analysis, core concepts uniting the data into themes had not yet been developed, and further analysis was needed to identify the central organising concepts which would mark themes as truly distinct from each other.

Figure 9.3 shows the second stage of the analysis – the developed thematic map.

Figure 9.3 Developed thematic map



At this stage, potential themes were becoming more refined and moving away from the semantic-level (descriptive) coding. More latent (interpretive) themes are beginning to emerge, for example “Illness identity becomes less salient” has emerged from more semantic descriptions such as “changed”, “flexible” and “chosen”. The potential sub-theme ‘illness identity incompatible with positive social identity’ became a potential theme because after further analysis, it emerged as more important to participants than the researcher originally perceived. The ‘stepping-stone identity’ potential theme has been refined to ‘illness identity becomes less salient’. Shared illness identity was still a potential sub-theme, but it was linked to two separate themes indicating that the central organising concept for each theme is not yet distinct. The three overarching themes were identified at this stage, and the central organising concepts had been identified for each theme. The process of refining sub-themes was ongoing.

The final thematic map is shown in Figure 9.4.

Figure 9.4 Final thematic map

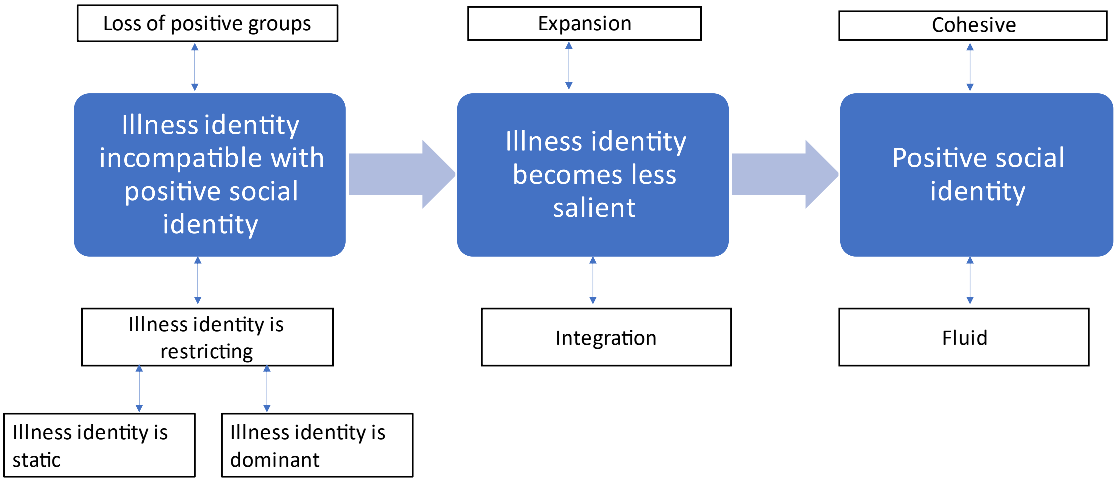


Figure 9.4 shows the final thematic map illustrating the finalised themes and sub-themes. The diagram with the addition of horizontal arrows was used to illustrate the temporal relationship between the themes. The thesis author found this made the analysis easier. The three overarching themes are connected with thick arrows in order to illustrate the change over time in social identity. The final themes are unchanged from the previous thematic map, however the sub-themes have become more refined and distinct and sub-themes are related to separate themes, indicating the central organising concept for each theme is present and distinct for each theme.

A description of how participants described positive and negative groups is given next, to provide some context for the themes found.

Characteristics of positive groups

Characteristics of positive social identity groups were that they were perceived as accommodating, adaptable, supportive and purposely selected. Some examples of positive groups in from the data were “church”, “friendship group” and “family”.

Participants described members of their positive groups as being accepting of their psychosis social identity and psychosis symptoms, as well as being generally accepting of all group members, regardless of whether they had experienced psychosis or not. Participants felt that this acceptance from the group allowed them to feel comfortable and to feel they could be their ‘authentic’ selves in a way they did not feel able to do easily in groups they experienced as negative. They felt they did not have to hide their diagnosis or psychosis symptoms and were appreciated for their other identities aside from their mental illness.

Participants described how positive groups were adaptable, and the role of specific identity groups often changed as group members adapted their relationship to the person in order to meet their needs. This often occurred with the onset of illness symptoms, where participants’ needs changed and they required different forms of support. Participants often varied in their levels of social contact with members of their positive groups. However, these groups remained important aspects of their social identity:

> *In the beginning I lost a lot of friends. No one understood and I lost a lot of friends and I feel like I lost my relationship with my mom as well because she instantly became my carer and stepped up. There was no one else, it was just her. (#12)*

Here, participant #12 describes how prior to recovery, her mum’s role changed to being her carer. Her mum was the only other member of her ‘family’ social identity group. In her interview, she describes how she moved back in with her mum after her discharge from hospital. Prior to her hospital admission she had been living almost independently in supported accommodation, only requiring a small amount of support. She described her mum’s adaptability and being accommodating towards her as being an important factor in her recovery.

One of the main features of positive groups was that participants described them as providing social support. Social support refers to acts in which individuals and groups provide resources to others (Haslam et al., 2012). Resources provided to participants included the offer of psychological “moral support” and friendship, practical support and assuming caring responsibilities when participants became unwell.

Many participants described how their positive social identity groups were purposefully selected and chosen. This was either through social identity gain, where new groups were joined, or by purposefully leaving some social identity groups, leaving their positive groups remaining and resulting in a changed social identity. Some described positive groups that they did not join by choice but they were automatically members such as their family group, which they became a member of by birth.

“*I suppose family. Like I mentioned moral support and felt that connection. So I was able to have the connection with them. So I was able to discuss how I was feeling and so I'm able to, they gave me good advice on how to move forward”* (10)

Participant 10 described his family as a positive group, the shared social identity allowed him to feel a ‘connection’ with them.

Another feature of positive social identity groups was that they were selected and joined by choice. Participant 24 described the process of selecting and choosing her groups:

> *I think they've (the social identity groups) become a lot more refined. I'm not friends with as many people, but the people who I use as my support network. It's a quality over quantity basically ….I felt like it might have happened anyway, but I just realized that I could probably be happier if I wasn't trying to please all of these people come and sort of focus on myself and my recovery. So it was me that refined the groups opposed to it happening naturally” (24).*

She describes a process of refinement of her groups. This was described as a conscious process. She purposely selected groups which provide her with social support, allowing her to prioritise her recovery.

Characteristics of negative groups

Negative groups were described by participants as discriminatory, unsupportive and not joined by choice. Examples of negative groups are “prisoner”, “not a mum” and “widow”.

> *“Initially what upset me was the whole ‘you're going to hell’ thing.. But then with mental health on top when you're being told something like that, you believe it, especially when from the trusted person like a vicar, and then you start spiralling in your head and it gets to a very dark place. So in the end I had to stop attending church regularly and starting frequenting other places like Spiritualist churches. It's a little bit more laid back, it's still about praising God… And it's no eternal damnation”* (#11)*.*

Participant 11 describes how the church was a negative social identity for him. He wanted to join due to his Christian beliefs but was discriminated against by members of the church due to two of his other social identities: being gay and also for having a mental illness. Due to this discrimination he eventually left to t spiritualist church which felt more compatible with his other social identities.

Another feature of negative groups was the lack of social support or other resources provided by group members. Participants did not report receiving social support or any other resources from negative groups. In contrast participants reported how they discriminated against and felt judged and ostracised by negative group members.

> *“Wider family is a bit more problematic in that I don't have a very good relationship with my dad and my step mum . They’ve never really understood. Yeah, when we do talk it's yeah I ‘are you still taking your meds’ kind of thing.. I don't think I want to talk about it because they don't want to know whether they had a factor in the circumstances that led to all of so Uhm? But yeah, that's been more problematic over. Over time”* #22*.*

For participant #22 their wider family became a negative group. His family were unable to provide social support as they preferred not to discuss his illness identity out of fear would blame them for the onset of his illness.

Participants did not describe becoming members of negative groups by choice. An example of this is the illness identity, which was joined unintentionally by participants due to the onset of illness symptoms, admission to hospital or by receiving a diagnosis of psychosis or a related condition. Other negative social identity groups discussed by participants were ‘homeless’, a group joined by the loss of a fixed address, or ‘prisoner’, joined by someone being detained in prison.

> *“So over the years, so my groups have changed. So in the present day, like I used to have contact with my parents, I cut those out of my life. So I don't identify as a daughter or. I'm not part of that wider family anymore by my choice, so that's been part of my recovery. It's been a really positive thing” (#26)*

For some participants, membership of the same group was both positive and negative at different times. For example, being in a specific friendship group was described by one participant as *“Building [them] up” but also “letting [them] down”(*#20) at different times. Participants attributed this to a lack of understanding of some groups when members had not experienced psychosis, or stigma.

Theme 1: Illness identity is incompatible with positive social identity.

The first overarching theme describes participants’ social identities prior to positive identity change. Participants described their illness identity group as incompatible with positive social identity groups. SIT describes compatibility as referring to the inter-relationships between social identity groups (Bentley et al., 2020). It describes the fit between the identity network any new social identity (Iyer et al., 2009).This resulted in social identities that were more contracted than desired, with a limited number of positive social identity groups. Participants attributed incompatibility to social identity groups becoming lost and illness identity being restricting. These are discussed as subthemes below.

1.1: Positive social identity groups become lost

This sub-theme is characterised by the loss of previously held positive social identity groups such as employment, leisure or hobby related groups or friendship groups. Due to the loss of these social identity groups, illness identity was described as becoming more prominent. Participants described finding it difficult or impossible to relate meaningfully to previously held positive social identities:

> *For about two years it was an extremely lonely and imprisoned feeling time. [My social identity] was sort of.. disintegrating. (#36).*

Participant 36 had formerly been living with his wife and children and working as an architect in a company he co-owned. He described in his interview how the onset of psychosis symptoms preceded his marriage breaking down and the loss of the friends he had shared with his ex-wife. These events led to the sense of imprisonment described above which was possibly heightened by the fact that they were now a single parent with little access to support from friends or family.

Participants described the loss of groups and the contracting of their social identity. In SIT, loss of social identity occurs when a person either loses or intentionally lets go of a social identity group (Haslam et al., 2021). Intentional and unintentional loss of social identity groups are both apparent in this analysis:

> *I lost myself. I lost... my sense of humour, lost my interest in music. A lot of interest in comedy lost and I lost a lot of personal things and also …I was really scared about engaging in those things. (#29)*

For this participant 29, loss of social identity groups was described as involuntary and something he became fearful of engaging with for fear of becoming more unwell.

> *I was very shut down at the time and the thoughts and things that you're having are kind of like, all of what you are so therefore*

> *you're kind of quite focused on that… so I was very shut down to that world other friends (#20)*

This participant described how the psychosis symptoms they were experiencing were all encompassing and had become almost synonymous with her sense of self. This resulted in her attention being taken away or ‘shut down’ from their other social identity groups, making engagement with these feel impossible. For some, loss of positive groups was described as a mechanism they employed to help them to cope with their illness symptoms. Participant 11 described how he perceived the isolation to have been something that he had choice over and he was active in promoting this, choosing to ‘isolate himself’ rather than isolation experienced as a result of something beyond his control:

> *I closed myself off completely for about 3 years. I never left my flat, I never did anything. I had very little communication with people. I completely isolated myself (#11)*

Participants found the resulting social identity to feel inauthentic and not in line with their ‘true’ sense of self. This inauthenticity caused them to feel uncomfortable with their own identity. This participant found it hard to recognise herself following the loss of so many social identity groups:

I came to a point where I felt segregated from my family my beliefs, who I basically am, from myself, and you get to point where you confused. You don't know whether it's you. (#8)

Loss of previously held social identity groups after the onset of psychosis is something found frequently in wider literature. A systematic review on understanding identity changes in people experiencing psychosis found that identity change in psychosis is usually discussed in terms of loss (Conneely et al., 2021). Psychotic disorders are often described as bringing about identity loss (Gergel and Iacoponi, 2017) and has been described as disorders of disturbance of the self which disrupts in an individual’s self-hood or self-experience (Sass and Parnas, 2003). In this analysis, a sense of disruption following loss of group memberships is evident, where participants feel unable to engage with their true or authentic self.

Loss of social groups has implications for health and wellbeing. Social identity groups offer protection against reduction in wellbeing associated with life changes (Jetten et al., 2009). Being able to maintain existing group memberships is key to protecting wellbeing. According to SIMIC, one of the ways in which protection occurs is via the social identity continuity pathway, which enables group maintenance. Participants reported loss of social groups meaning that group maintenance was not possible and they were unable to receive protection against reduced health and wellbeing (Haslam et al., 2021).

The loss of social identity groups at the onset of psychosis illustrates how participants found it difficult to maintain pre-existing groups. This is consistent with another qualitative study about how psychosis influences social identity processes (Hogg et al., 2022), this study found that the onset of psychosis makes maintaining social identity groups challenging, which results in social identity group loss. Participants in Hogg's study attributed this to the impact that psychosis had on their social functioning, including inducing shame and stigma, suspiciousness or mistrust of others, hearing voices and paranoia. This is supported by this analysis and impact on social functioning is discussed more in section 1.2.

1.2: Illness identity is restricting

The second sub-theme relates to the nature of the illness social identity group. Participants described how they felt unable to engage meaningfully with social identity groups they aspired to join such as university or other educational groups, employment groups or family related groups such as parent due to the presence of their illness identity. Identifying with an illness identity group prevented participants from engaging meaningfully with other desired social identities. This was an almost universal experience among participants. Participants described how their illness identity prevented them from acquiring or maintaining desirable social identity groups. The illness identity was perceived as too restrictive to allow other social identities to exist easily alongside it. Participants described how they did not feel they had the option to re-gain positive identity groups and found it impossible or challenging to belong to positive groups whilst they were a member of an illness identity group. This was due to the dominance of the illness identity group and their social identity feeling static.

> *“Well, I suppose now that I'm not in a mental hospital ... I suppose I'm a bit more closer to my family because I get to see them more and I feel closest to my friends because I wasn't like allowed internet or anything there so I couldn't particularly communicate with them. You know my friends in the big wide world if you know what I mean”* (005)

For this participant, restriction related to the limitations placed upon her after being detained in hospital. The limitations on what was permitted on the hospital ward made it impossible for her to communicate with her other groups such as her online gaming community.

> *“I think they may see me as odd or bizarre,or they may find that what I'm saying is too challenging and then come down on me hard, you know, and I don't want to be put in a position where I'm making myself vulnerable to these people*” (#13).

For this participant, it was the fear that his mental health symptoms would make him stand out that he would seem unusual to other group members that made him reluctant to join other groups. He described later on in the interview how he had experienced discrimination due to his psychosis experiences before and this had made him nervous about the reactions of people who were members of other groups. This has resulted in him not wanting to join so as not to make himself seem “vulnerable” to other group members.

1.2.1 Illness identity is dominant

At this stage, some participants described how their entire social identity comprised of the illness group, and this identity became all they would use to describe and to define themselves. They were unable to see a difference between themselves and their illness identity:

> *When I went through the psychosis and the episodes and then I got eventually got a diagnosis when I was 16. I got the diagnosis, it kind of became me who I was that whole. 'I am a service user', this is my life now, I have got no hope. (#12)*

For participant 12, it was receiving a diagnosis that triggered the dominance of her illness identity. On receiving her diagnosis, the 'service user' identity became dominant. She perceives this identity as permanent which leaves her feeling hopeless.

> *"I couldn't see the difference between me and illness. I did feel like my life was very dominated by it and even when I wasn't in the hospital or under the CMHT it did feel like a huge part of my life was just that". (#14)*

Participant 14 also felt that even when not accessing services, her service user identity was still extremely prominent to an extent that her service user identity had begun to define her.

Membership of an illness identity group is often something imposed on individuals in a 'top down' manner by health professionals or by processes such as compulsory hospital admissions (Hogg et al., 2022). This process is described by participants 12 and 14. A diagnostic label and entry into mental health services has inadvertently categorised them into a social identity group associated with a particular diagnosis. The illness identity group is assigned therefore by a comparison of predetermined in/out group memberships, e.g. doctor versus patient, psychotic versus not psychotic. (Postmes et al., 2005). This is known as 'top down categorisation'.

> *"Mental illness and mental ill health impacts severely on your social life. On how people view you, this is another reason why I don't. I don't join many groups [that are] not to do with mental health. Because I've learned from hard experience"* (#13)

The dominance of the illness identity group made the prospect of joining new groups or maintaining existing ones feel difficult or impossible. Participant 13 described how he didn’t feel able to join any groups that were not related to mental health due to having experienced stigma in the past from other groups.

> *“When I had the condition it was obviously some could not stick with somebody that condition, for some it was, it was like a burden to them. You cannot have a relationship with them. They think you won’t recover. It was a burden to them. Yeah, for them it's like only reversible conditions”* (#15)

Participant 5 describes their illness identity group as a “burden” for others who believed they would never recover. They describe how it is the perceived permanence of the illness identity which makes it a burden for others. He feels it would have been perceived as less of a burden if his illness was considered reversable.

> *“When you've got mental health problems, your life is dominated by the mental health stuff. It's very hard to actually try and develop friendships beyond that because anyone who's not in that kind of area of mental health... you feel like, what can I talk to them about, that’s not mental health stuff? It's quite hard to find something that's common ground that isn't to do with mental health”. (#21)*

> *“I had a lot of guilt with social interactions before, I felt that I didn’t have anything to offer, the crisis was defining me and defined those relationships as well”. (#1)*

Participants 21 and 1 were reluctant to interact with people from non-mental health groups as they felt they had nothing to offer to other group members. Participant 1 was a young woman who had previously worked in an advertising job. Prior to becoming unwell, she described how she had an active social life that was largely connected to her work colleagues. After she had developed psychosis symptoms, she had to give up her job and she subsequently lost her friendships and her social life. The “guilt” she described relates to her feeling that she didn’t have any other social identities to draw on during conversations and she was worried that all people would perceive her as was someone who had suffered a mental health crisis.

The literature terms dominance of the illness identity group ‘identity engulfment’. (Lally, 1989). Identity engulfment happens when a person’s self-concept becomes increasingly organised around a particular role or identity (Lally, 1989). Instead of becoming part of a person, the identity engulfs a person until it overtakes their entire self (Estroff, 1989). This process is described by participants in this analysis. In social identity literature people often report serious mental illness as self-defining (Cruwys and Gunaseelan, 2016) and in those who experience psychosis, a person can become defined exclusively by an illness identity and the illness identity becomes central (Konsztowicz and Lepage, 2019). This is supported by this analysis where the illness identity is described as central and at the Moratorium stage of recovery.

1.2.2 Social identity is static

For some participants, the restricting nature of the illness identity group made the possibility of joining other groups seem remote and previously held positive identities seemed difficult or impossible to engage with.

> *So in terms of my Christianity.. when I was quite unwell or before we came unwell, I was quite into my faith and was in my Catholic church … I stopped all that. … I did lose a bit of faith like ‘Oh well you know. I've got this now. I've got this condition. (#18)*

For participant 18 their Christianity group which they had previously belonged to felt less easy to be a member due to the presence of the illness identity. In her interview, she goes on to describe how she felt that the stigma around mental illness is prominent within in the church community. For others, their identity as an ill person meant that certain desired positive identities, such as ‘parent’ or ‘graduate’ no longer seemed possible:

> *If you asked me do you want to be a mum I’d have said yes, [if you had asked] ‘are you going to be a mum?’: [I’d have said] ‘no’…. I wouldn't want to give them this illness or what happens if the trauma I've received I do to them?. (#27)*
>
> *I was really reconciling myself to the future of not doing anything with my life and not having opportunity to finish your degree or continue with pursuing stuff. (#29)*

This static form of social identity described by participants is in contrast with the literature which describes social identity as fluid, variable (Ethier and Deaux, 1994), context specific and changeable depending on environment (Bentley et al., 2020). In this analysis, the illness identity felt too restrictive to allow other social identity groups to exist easily alongside it. Social identity was prevented from changing due to the dominance of the illness identity group. One reason for this might have been that participants were presenting their identity as static or fixed in the context of an interview which they knew was focused on psychosis. Therefore, they may have focused on this identity to the exclusion of other social identity groups.

The restricting nature of the illness identity made the possibility of joining other groups seem remote. Even groups where participants had been a member previously seemed inaccessible. Social mobility between groups is based on the assumption that society is flexible and permeable (Tajfel et al., 1979). Permeable group boundaries are what allow people to move from one group to another (Ellemers et al., 1990). When the boundaries between mental health and mental ill health are permeable it is possible for a person to leave a mental illness group via recovery (Cruwys and Gunaseelan, 2016). The static nature of the illness identity in this analysis implies a lack of permeability of illness identity group boundaries at the moratorium stage of recovery. When boundaries are perceived as impermeable there is no alternative and group membership cannot be changed.

Theme 2: illness identity becomes less salient

The second theme describes the change processes experienced by participants as they recovered from psychosis. Participants described how their illness identity became less salient as they recovered and gained other, positive social identity groups. This happened through integration of illness identity and expansion of positive groups, these are discussed as subthemes below.

2.1: Integration of illness identity into a positive social identity

This process often began using a shared social identity as a mechanism for integration. In the early stages of recovery, participants joined groups where they shared an illness identity with other group members. The impetus for joining these groups was often loneliness and isolation which motivated participants to begin interacting with others. Participants described a desire to meet peers who would understand and offer non-judgemental support.

“I knew that I was isolated. I knew I'd have to retrain to go back into work at some point. So basically I just started an evening class” (#42),

These groups were either specifically related to psychosis social identity e.g. a pottery group for mental health service users, or a group that was unrelated to psychosis such as a local church. In the psychosis related groups, a psychosis identity was shared with all members. In the groups unrelated to psychosis, a psychosis identity was shared with some group members. Shared psychosis social identity became something which participants could use as a ‘stepping-stone’ to join other positive groups:

> *I’ve remained a member of the peer support group. Other groups have emerged from that. I’ve needed to find common ground with peers for my recovery. The peer group made me actually engage in recovery and be less passive. I was drawn into recovery by the peer group. You still try to engage, even if not well. (#17)*

> *With the mental health groups, I have been building the foundation to be social again. (#1)*

‘Stepping-stone’ groups were often perceived as temporary or transitory. Participants described how it was through shared identity and the acceptance and social support provided through these groups that allowed them to gain confidence and to feel accepted until they felt ready and able to expand their social identity.

Participants described how they benefited from the social support provided by these groups:

> *They have helped me a lot because actually they showed me how to belong. Emotionally, socially I was prepared 'cause I knew they could support me. I have people who are caring and can support me. (#6)*
>
> *That group experience gave me more confidence to face the outside world better. So it's more like a stepping stone and not a jump. To the real world...It wasn't a bad group to be a part of, but it wasn't what I actually wanted to do. I went to it. But it was just a stepping-stone to being able to do what I wanted to do” (#37)*

During this time, participants described an increase in their wellbeing which they felt was due to new group memberships. This increase in wellbeing was expressed as an increase in confidence following acceptance from others, feeling more engaged with the people around them and also feeling inspired and empowered due to witnessing the successes of other group members:

> *“I think [groups] helped me to feel calmer and happier. And I think that feel that I'm more socially active now than I was before” (#23)*
>
> *“Restoring a bit of self-confidence a bit of self-esteem, more meaningful activity to do day by day and meeting some new colleagues* (#22)

> *“I need to feel like it's achievable I need to be able to identify with that person…So seeing that guy at the hospital volunteering with mental health problems Made me sort of go. ‘Oh, I can do that’” (#18)*

The increase in social support participants experienced from the ‘stepping-stone’ groups may indicate that participants were beginning to categorise into these groups. Accessing supportive environments in recovery is dependent on the person’s relationship with these environments (Sommer et al., 2021). Social identification has been shown to influence the degree to which social support is perceived as beneficial (Haslam et al., 2004). The dynamics of support are always defined by identity-based relationships (Haslam et al., 2012). One of the critical factors defining relationships is the degree to which the groups or individuals concerned perceive each other to share a social identity (Turner et al., 1987). It is only when a person identifies with a group, and when the group is internalised in a way that contributes to his or her sense of self, that the group is likely to provide benefits (Cruwys et al., 2014). The social support experienced by participants from members of ‘stepping-stone’ groups is likely therefore underpinned by a sense of shared social identity, indicating participants are categorising into groups beyond their illness identity group. An example of this is in participant 24’s description of how the social support he gained from the peer group was based on a shared understanding of their illness experiences and is distinct from the support he received from other groups without this shared experience.

“I basically got very different types of support from the different people I confided in. The people that could potentially understand if they'd been through it themselves we'd sit and have a conversation and share our experiences, whereas. other people who didn't understand they were still supportive. And you know, we just do normal stuff…. It was nice having both rather than ‘you can either have someone who you just talked to death about it with and someone who doesn't really

understand but will, take you out for lunch and make sure you're OK" (#24)

Social support from those sharing a 'stepping-stone' group facilitated transition into new social identity groups. This may have occurred through bottom-up categorisation (Postmes et al., 2005). Bottom up categorisation occurs when intragroup discussion and interaction creates a sense of group identity. Identity can develop inductively in small groups via positive social interactions. Critical to recovery is the sense of a positive shared identity (Cruwys et al., 2014). The data suggests that bottom-up categorisation may have occurred through 'stepping-stone' groups and that the social support participants experienced from other members of these groups created a sense of belonging within new groups.

2.2: Expansion beyond illness identity

This is the process of acquiring new social identities or re-establishing identities that had been lost. Through this process social identity is broadened beyond illness identity. The mechanism through which expansion occurred was choice. Participants described feeling that they had acquired the freedom to join social identity groups of their own choosing. They no longer felt restricted by illness identity and therefore had the opportunity to join positive social identity groups. Participants did not in general give details of what changed in their lives which meant they were able to experience choices, instead they used phrases such as 'I managed to get back on track' without specifying how.

> *I then [went] to university. I managed to get back on track and then finished my degree and then moved to London on a Masters and then started working (#27)*
>
> *When I starting to work. I had friends, friends working in the workplace as well. That's how I built up (#28)*

These participants describe the groups they began to join in order to expand their social identities.

> *I was starting to feel that whoever I am I can cope and I need to start reconnecting with wider life. (#36)*

> *Expanding my awareness of what is possible and what I can do as a person and that there is more to life.. I've picked those people, who are aware of mental health stuff and how it affects me, and therefore I'm able to use them as a safe point to try out new things with them. Even when your mental health gets worse, you still have that like knowledge that those things are there again to kind of come back to. Even if you lose all interest because you're depressed. You can kind of still think well. That there that's there in the background. (#21)*

These participants describe their feelings preceding expansion of their social identities. One described feeling that they needed to reconnect with other groups as they were now at a stage in their recovery where they could cope with the demands of doing this. Another described her awareness of what groups it was possible to join.

Participants described a process of growing their positive social identity and also of “refinement”, whereby they became members of groups they found particularly meaningful.

> *I think [the groups] have become a lot more refined. I'm not friends with as many people, but the people who I use as my support network. It's a quality over quantity basically. So there's just a lot more, they're just nicer people really (#24)*

> *I think the groups that I've reconnected with and started to rebuild those relationships with. They've definitely got more of an understanding of my mental health situation and how difficult it was. Before I never really spoke about it. I was just kind of put a front on. Uh. So there's definitely, I think the connection is now more genuine just because I'm being more open about things and more, just more real, I suppose. (#40)*

SIMIC highlights the importance of developing new social identity group memberships via a social identity gain pathway (Jetten et al., 2009). The group processes specified in SIMIC highlight two key pathways through which health and well-being can be protected in the event of life change: the social identity continuity pathway (enabling group maintenance) and the social identity gain pathway (enabling new group acquisition). Social identity gain can be the basis for self-redefinition after a life transition (Haslam et al., 2021). In this analysis participant's social identity expanded to consist of more groups, allowing for redefinition to take place. The shared illness identity groups gained by participants were perceived by participants as temporary or transitional. Participants used the shared group membership as a 'stepping-stone' to gain confidence to join new groups or to eventually feel able to branch out into additional groups unrelated to illness identity. These 'stepping-stone' identities illustrate how the boundaries of social identity groups were beginning to be perceived as permeable and joining other groups had become a realistic possibility. Participants were aware of gaining groups that felt compatible with their illness identity group.

Theme 3: Positive social identity

In the final theme, participants described their social identities after transition into someone with a wider set of social identities. Social identity was described as more positive and varied than it had been previously. For some participants, this was a process which took place over more than 50 years. For others, this happened in less than a year.

Illness identity generally remained a part of the participants' social identity but became less restricting and more compatible with positive groups. Additional positive social identity groups had been joined. Participants described a positive impact on wellbeing. Two sub-themes were identified: social identity is cohesive, and social identity is fluid. Participants described their social identity cohesive and their illness identity group as fluid.

3.1: Social identity is cohesive

This sub-theme relates to social identity in its entirety. Participants described how, after identity change, their social identity groups fit together and felt compatible and positively linked:

> *[The groups] are all positive, quite a few of them in their separate bubbles from each other, some of them are interlinked... that's my main sort of network, interlinked groups. (#36)*

Participant 36, describes her social identity as consisting of groups which are ‘interlinked’ with each other. This contrast from participants descriptions of their social identity at the Moratorium stage which was felt retracted with groups not existing easily alongside each other.

> *Now the groups that I've got, are very focused on my recovery. So the gym so doing physical exercises about my mental health and my physical health is improving as well. (#26)*

> *I'm incredibly involved in left wing politics and I've got a really active social life. My relationship is fantastic and yeah, generally I'm incredibly happy. (#35)*

For both these participants, it no longer felt difficult or challenging to belong to multiple groups. This was described as having a positive effect on wellbeing.

> *I think in previous jobs I have not disclosed because it's been too fresh. I think being the right job and right setting has helped me to be accepting of in how you can use it for positive as opposed to it being a negative which a lot [of] people have that view with people mental conditions. (#18)*

Of the most striking things about cohesive social identities are that participants generally described still belonging to a social identity group, however this group no longer restricts someone from joining other social identities which can exist easily alongside it. Participant 18 begun a job as a peer support worker in mental health services. She describes how she is able to use her experiences of having psychosis as a positive thing in helping others. She goes on to say that this is in contrast with the negative way that mental illness is generally viewed by others.

SIT defines gaining membership of high status groups to be the predominant way of establishing a positive identity (Ellemers et al., 1990). A group with high status is one that is positively distinguished from other groups (Ellemers et al., 1992). Unfold 2 participants described belonging to a range of social identity groups that were perceived as positive. These groups included, mum, student, employee gamer, and mental health advocate.

3.2 Illness identity becomes fluid

This sub-theme describes the nature of the illness identity group after identity change. For most participants, illness identity group is still present at the Rebuilding/Growth stage of recovery but its salience changes depending on the other social identity groups and context. Participants described their social identity as no longer restricted by the presence of the illness identity. Illness identity is perceived as flexible and context dependent. Participants described acceptance of the illness identity, with corresponding good and bad days.

> *There's ‘mental health service user’ because I will always be one. But it's right next to ‘mental health advocate’ and ends the stigma because I no longer stigmatise myself. (#12)*

For participant 12, who earlier described how she considered her service user identity to be permanent, the identity was still present, but this identity group sits alongside that of ‘mental health advocate’ which has grown from her service service user identity. She describes how, for her, this marks the end of her service user identity being stigmatised.

> *[The illness] is a part of my life rather than the whole of my life. At times that can wax and wane. Some identities can be quite transient and the mental health stuff can be bigger at some*

> *points and smaller [at] other points. My life has been less dominated by mental health stuff (#21)*

For participant 21, her life has become ‘less dominated’ by her mental health identity group. Depending on social context her illness identity can ‘wax and wane’, meaning her illness identity group is changeable and context specific as sosicl ideneitites are commonly described in the literature(Bentley et al., 2020).

Participants also described their hope of acquiring additional meaningful groups in the future.

> *I’d hopefully to have like a partner, I’d like my Christianity, hopefully to be more strong. My beliefs.., back to how they were before I became ill. And having my network of being a black woman to be bigger as well so that I can connect to people like me… have as many as possible who I can relate to. (#18)*

> *I want my service user kind of group and label to kind of diminishing to less significant and being a partner and a parent and a worker.. I want those to be the biggest part. (#26)*

Social identity groups were perceived as compatible with each other, and it was possible and comfortable to be a member of each social identity, (including the illness identity group) simultaneously. When describing their social identity after identity change, participants did not often describe an absence of the illness identity group, rather a change in how they viewed being a group member and a change in how illness identity group membership related to their wider social identity. The illness identity group was still present but rather than being stigmatising and inflexible, it was perceived as fluid and changeable depending on social context or environment. This finding supports the idea that recovery should not be viewed as a simplistic transition from a poor health state to good health (Jatta et al., 2022).

One participant who did not describe their illness identity becoming fluid was a woman who had experienced only one episode of psychosis.

This occurred 20 years prior to the interview, and she attributed this episode to substance and alcohol misuse. She chose not to disclose the episode to anyone at the time or to seek any formal clinical support. She no longer considered herself a member of an illness identity group in the present day. Here she describes how the her illness identity group has disappeared from her social identity:

> *"It just started becoming less and less prominent until it wasn't a thing anymore. And yeah, it's gone completely"* (#35).

One reason for this may be the fact that she didn't receive any formal clinical support or formal diagnosis. This analysis has shown how it is often the participant's relationship with mental health services that influence how they define and describe their illness identity. Without any relationship with these services, she has not been categorised into a patient or service user role via top-down categorisation as described by other participants (Hogg et al., 2022). She was the only participant in the study who described experiencing drug and alcohol induced psychosis. Another possibility therefore, is that she related to her illness identity differently to other participants due to this experience.

> *"That to me is how psychosis felt, [it] was my own brain sabotaging me. So I thought. Well fundamentally I'm not going to the doctor, I'm not taking medicines for this. I'm going to try and ride it out and beat it myself and to me it seemed to be a case of trying to like myself again and to build back myself, respect" (#35).*

Here she describes her reluctance to get any clinical support, instead choosing to try to recover outside of services. For most participants however, recovery did not signify the loss of the illness identity group, rather a change in the way they related to it.

Transition into a positive social identity supports research suggesting that recovery is a process of moving from a negative identity state, to a positive state of psychological wellbeing (Dell et al., 2021). This analysis describes some of the processes involved in this change. For most participants, social identity change in recovery from psychosis was not a process of leaving of an illness identity or service user group. Identity change was a shift from seeing illness identity group membership as a negative thing, to seeing it as an acceptable group membership that could become a part of a wider social identity. Positive groups of a person's own choosing were joined via shared social identity and the illness identity group could exist comfortably alongside them. This is described by Participant 09 who describes how she has purposefully built a positive social identity and is now able to define herself and her social identity groups rather than have her social identity defined by others through diagnostic labels or mental health service use.

> *"[Illness identity] is not so much part of my identity, but that's because of the changes I've made in my life, and the support I've received in order to do that. It's not the focus. It's not like' you are [name], you are a schizophrenic' It's , 'you have schizoaffective disorder or you have a mood disorder or whatever'. I get to say what I am instead of other people telling me what I am. And that's the difference".* (#9)

9.3 Reflexivity

Reflexivity is the process of reflecting critically on the self as a researcher (Denzin & Lincoln, 2010). Reflexivity refers to how the researchers' own views and opinions may impact upon research. The researcher's own positions and interests may influence research across all stages of the research process. By identifying the positions held by the researcher, it is possible to understand this influence (Parahoo, 2006). In RTA, it is crucial for the researcher to reflect on their own preconceptions and assumptions as they may influence identification of themes (Braun et al., 2019).

In order to understand her own positionality, the researcher used a reflexivity tool which takes the form of a social identity map (Jacobson and Mustafa, 2019). The tool enables researchers to understand and express how the different aspects of their own social identity impact on their own research. The Reflexive Social Identity Map is intended to be used as a flexible tool to guide researchers to be reflexive and to reflect on their social identity. Researchers being reflexive about their own social identities, particularly in comparison to the social position of participants, allows researchers to remain aware of their own effect on the research process and outcomes. Reflexivity was considered particularly relevant to this study as particular social identities can be ‘activated’ in certain situations. This is called identity salience. Salience of a group membership is its psychological significance in a given environment (Oakes, 1987). Therefore, the researcher’s salient social identity may have had an impact on the salient social identities of participants which may in turn have affected the findings. The researcher makes some reflections below.

As discussed in section 1.1.5 I am an Occupational Therapist who has worked with people who have experienced psychosis since qualifying. My work has been in community settings involving community integration and social inclusion. During this time, I worked with a number of extremely isolated individuals who were to mental health services and wider society defined by their psychosis social identity. I got to know a number of these clients and remember feeling that they had so much more to offer and where so much more than just a set of symptoms or a diagnosis. This was one aspect of my clinical work which motivate me to carry out this research.

My social identity as clinician may influence the way in which I interpret participants relationship to their psychosis identity. Despite working in services which were recovery orientated, I have found them to be influenced by the medical model which treats service users as either ‘ill’ or implies they are ‘cured’ by discharging them back to the care of their GP. This linear treatment path seems unlikely to be congruent with how clients experienced their illness and recovery. Also, I have found that services prioritise diagnostic labels which may not be the way in which participants relate to or define a psychosis social identity.

My clinical background may have influenced the way I've presented the data. Participants described a shift from one recovery stage to another, this finding may have emerged due to my former role as a clinician influencing how I've interpreted the data. One reason for this shift in recovery stages may be due to participants completing OSIM's for two distinct recovery stages prior to interview. This may have affected how they described their experiences if they were focused on these two specific stages and the time in between.

Another social identity I bring to the analysis is the identity of researcher. I felt this social identity particularly important to reflect upon. When participants were recruited to the study, they took on the role of participant as informed by my researcher identity. As Unfold was a study about psychosis, this may have meant that their psychosis social identity had become more salient during interviews and interactions with me, as a researcher. These social identities shaped my understanding of the interviews, for example heightening my awareness of psychosis-related social identities.

Since starting my PhD in 2018 I have experienced a period in my life of huge social identity changes. This has included the transition from clinician to student and the more recent transition to parent. Because of these changes I have been able to bring to the analysis an awareness of how these identity changes can unfold. For example, my experience of isolation during the pandemic as a new parent may have resulted in me being more sensitive to participants mentioning that they felt isolated. I also bring an understanding of how stressful these changes can be and of some of difficulties which can arise even after positive life transitions. Due to this understanding, I have been able to appreciate (albeit to a lesser degree) the difficulties an individual can face when managing incompatibility of social identity groups. My understanding may have also meant that I was more sensitive to the stressful aspect of identity change and so I noticed it more.

9.4 Critical appraisal of the methodological strengths and limitations of Unfold 2

Thematic Analysis is described by the authors as ontologically flexible. This means RTA can be used within a variety of ontological frameworks (Terry et al., 2017). Consistency and cohesion of an analysis can be promoted by making explicit and applying an epistemological position that underpins the study's empirical claims (Holloway & Todres, 2003). The authors of RTA Braun and Clarke (2019), suggest researchers should be explicit about their ontological position and to ensure that this is engaged with in a way that is transparent. A strength of this analysis is engagement with the pragmatist framework which is discussed in detail in Chapter 5. The pragmatist epistemology endorses a focus on practical effects as well as a contextual understanding of findings based on human experience. Pragmatism prioritises actions and endorses practical theories (Teddlie and Tashakkori, 2003) and focuses on producing knowledge that is "useful" (Feilzer, 2010, p6). Carrying out RTA within a pragmatist framework has resulted in themes which have real-world implications. For example, knowledge of a person's social identity expanding beyond that of a psychosis identity and knowledge about how social identity groups integrate into a person's social identity as they recover from psychosis could provide the basis for providing practical effects when applied to future clinical interventions. Future interventions could support the maintenance of existing social identity groups in order to prevent loss of positive social identity groups. Another target for intervention could be supporting the categorisation into positive social identity groups.

Pragmatism recognises the significance of context in the generation of new knowledge. RTA involves making sense and interpreting data within its specific context. The Pragmatist epistemology provides a framework for acknowledging the influence of context on themes. Pragmatism encourages researchers to consider the situational aspects that shape the emergence of themes. Social identity is inherently context specific, and change is therefore dependent on a person’s situation or environment. An example of how this shaped the analysis is the theme of illness identity being incompatible with positive social identity. This theme considers the wider social context that participants are situated and how they currently feel unable to engage with it.

Reflexive thematic analysis intends to capture underlying ideas, patterns, and assumptions across the dataset (Terry et al., 2017). An example of a poor analysis could see the analysis rely too heavily on domain summaries of the data, without identifying underlying themes that organise the analysis (Finlay, 2021). For this analysis, both semantic- level (descriptive) and latent (interpretive) approaches to coding and theme development were employed. Firstly, a semantic approach was taken, in order to remain close to participants’ verbatim interviews, with latent coding being employed in later stages (Terry et al., 2017). An example of this is the theme “Illness identity becomes less salient” which is a latent theme and emerged from more semantic descriptions of social identity groups such as “changed”, “flexible” and “chosen”. The development of themes is illustrated by thematic maps which demonstrate how the themes developed by moving beyond meanings expressed by participants, to underlying patterns in the data.

Another disadvantage of RTA is that it can be difficult to prove that an analysis is trustworthy and credible (Lincoln and Guba, 1985). Credibility in thematic analysis refers to the ‘fit’ between participant views and the researcher’s representation of them (Tobin & Begley, 2004). A number of techniques have been suggested to enhance credibility, including peer debriefing and triangulation (Nowell et al., 2017). Peer debriefing involves allowing research peers to provide an external check on the research process, which may increase credibility. This took place during the analysis whereby the researcher consulted with two qualitative researcher colleagues twice during the analysis. During the debriefing, thematic maps were discussed and checked in relation to the raw data. Findings were also discussed at length with the supervisory team. Although this was a strength of the analysis, using multiple analysts throughout the analysis process could have led to a more comprehensive interpretation of the data. Methodological triangulation involves researchers employing multiple research approaches or methods to answer the research question from different perspectives. This thesis used a mixed methods approach and discordant findings were acknowledged after qualitative findings were integrated with the quantitative results.

Chapter 10 Unfold 2: Quantitative results, integration and discussion

Chapter 10 presents the results from the quantitative arm of the study. The results are presented (10.1) followed by a discussion (10.2). The integration of the qualitative and quantitative data is then presented (10.3). A discussion of the integrated results follows (10.4).

10.1 Objective 2 (Relationships)

Aim 2 was to investigate the relationship between social identity change, wellbeing and recovery. Two OSIMs were created by each participant, one capturing their social identity at the previous Moratorium stage in their life (Previous OSIM) and the other at the current Rebuilding / Growth stage (Current OSIM). For each OSIM, three metrics were considered: total number of groups, group positivity and group supportiveness.

Total OSIM score is the number of social identity groups identified on each OSIM. Participants had a mean of 5.90 (SD 2.06) social identity groups in Previous OSIM and 6.92 (SD 3.40) in Current OSIM. The difference in total OSIM score was 1.20 indicating a larger number of social identity groups at the Rebuilding/Growth stage of recovery.

Group positivity refers to how positive participants felt about each social identity group they belonged to. This was scored between 1 (low) and 5 (high). Mean group positivity was 3.10 (SD 1.02) in Previous OSIM and 3.96 (SD 0.55) in Current current. The difference in mean group positivity between Previous OSIM and Current OSIM was 0.86, i.e. a difference in mean total groups between was 1.02. This indicates that participants felt more positive about their social identity groups at the Rebuilding/growth stage than they did at the Moratorium stage.

Group supportiveness is the level of social support participants reported receiving from each social identity group. This was scored between 1 (low) and 5 (high). Mean supportiveness was 3.10 (SD 0.96) in

Previous OSIM and 3.37 (SD 0.58) in Current OSIM. The difference in mean group supportiveness between the Moratorium stage and Rebuilding/Growth stage was 0.27. This indicates that participants felt that they received more social support from members of their social identity groups at the Rebuilding/growth stage than they did at the Moratorium stage.

The significance of differences was explored using inferential statistics. The distribution of OSIM scores for differences between total number of groups, group positivity and group supportiveness were not normally distributed. Therefore within-participant differences in OSIM ratings between the Moratorium stage of recovery and the Rebuilding / Growth stages of recovery were investigated using a non-parametric Wilcoxon signed-rank test on median scores, as shown in Table 9.3.

Table 10.1 Comparison of OSIM at Moratorium versus Rebuilding / Growth stages (n=51)

	Moratorium Median (IQR)	**Rebuilding / Growth Median (IQR)**	**p-value**	**Z score**
Total groups	5.0 (5.0-7.0)	6.0 (4.0-8.0)	0.012	1
Group positivity	3.20 (2.40-3.67)	4.00 (3.6-4.33)	0.001	0.80
Group supportiveness	3.00 (2.50-3.50)	3.33 (2.91-3.75)	0.018	0.33

There was a significant difference between Moratorium and Rebuilding / Growth stages in all of the total number of social identity groups, group positivity and group supportiveness.

The mean Flourishing Scale score was 36.3 (SD 6.9), mean SEPRS score was 71.2 (SD14.7) and mean SWEMWBS score was 24.8 (SD4.0). The mean Flourishing scale score was lower and the SEPRS higher than the normative data from other relevant populations described in Methods.

The three standardised measures – Flourishing Scale, SEPRS and SWEMWBS – were not normally distributed. The correlations between changes in each of the three OSIM scores and the three standardised measures were investigated using the Spearman's rank correlation coefficient, as shown in Table 9.4.

Table 10.2 Correlation between changes in OSIM scores and measures of wellbeing, flourishing and recovery

	Change in mean total groups Correlation coefficient (p)	**Change in mean group positivity Correlation coefficient (p)**	**Change in mean group supportiveness Correlation coefficient (p)**
Short Warwick Edinburgh Mental Wellbeing Scale (SWEMWBS)	0.121 (0.398)	0.187 (0.189)	0.081 (0.573)
Flourishing Scale	0.316 (0.023)	0.054 (0.708)	-0.101 (0.479)
Self-Efficacy for Personal Recovery Scale (SEPRS)	0.020 (0.890)	0.073 (0.616)	0.025 (0.861)

The results show that participants were more likely to report higher Flourishing scale scores if they had increased their number of social identity groups, although this was a small correlation (ρ=0.316, p=0.023) which would not be significant if Bonferroni adjustment were applied which would set statistical significance at p=0.017.

To test the three hypotheses relating to the SIMIC model, correlations were calculated using the Spearman's rank correlation coefficient.

Hypothesis 1 stated that multiple group memberships before life change will be associated with enhanced health and wellbeing after life change. To test this hypothesis, a correlation was calculated between total groups in Previous OSIM and Flourishing scale scores. The correlation coefficient was -0.79 (p=0.580) indicting that the hypothesis was not supported. A correlation between total groups in Previous OSIM and Short Warwick Edinburgh Mental Wellbeing Scale (SWEMWBS) scores was calculated. The correlation coefficient was 0.113 (p=0.430) indicating that the hypothesis was not supported.

Hypothesis 2 stated that the extent to which people belong to multiple social identity groups will increase the likelihood of maintaining pre-existing groups to support social identity continuity. This was calculated using a correlation between total groups in Previous OSIM and total number of groups participants maintained between Previous OSIM and Current OSIM. The correlation coefficient was 0.001 (p=0.997), indicating that the hypothesis was not supported.

Hypothesis 3 stated that the extent to which people belong to multiple groups will increase the likelihood of joining new groups to support social identity gain. This was tested by calculating the correlation between total number of groups in Previous OSIM and the difference in total number of groups between Previous OSIM and Current OSIM. The correlation coefficient was -0.199 (p=0.161) indicating that the hypothesis was not supported.

10.2 Discussion Objective 2: Relationships

Objective 2 was to investigate the relationships between social identity change, wellbeing and recovery. Two OSIMs were created by each participant, one capturing their social identity at the previous Moratorium stage in their life (previous OSIM) and the other at the current Rebuilding / Growth stage (Current OSIM). Three OSIM metrics were considered: total number of groups, group positivity and group supportiveness.

The results showed that participants were more likely to report higher scores on the Flourishing scale scores if they had increased their number of social identity groups. This is in line with social identity literature that posits social identity is the source of social psychological resources that are critical to health and well-being (Haslam et al., 2021). One explanation for Unfold participants having lower mean Flourishing scale scores than the closest available population of students with psychosis could be that the student population had the additional 'resources associated with belonging to their student identity.

There was no correlation between increase in social identity groups and wellbeing. A reason for this might be that the Flourishing scale is designed to assess aspects of social–psychological functioning, such as having supportive and rewarding relationships and contributing to the happiness of others (Diener et al., 2010). The resources provided by the social identity groups gained by participants may have provided an increase in social–psychological functioning. The SWMWBS is designed to capture a broader understanding of wellbeing (Stewart-Brown et al., 2009), which may not have been impacted by an increase in social identity groups. For future social identity research, a more appropriate wellbeing measure may be the Flourishing scale which assess aspects of social–psychological functioning relevant to social identity change processes.

SIMIC hypotheses were tested using the using the Spearman's rank correlation coefficient. Hypothesis 1- multiple group memberships before life change will be associated with enhanced health and wellbeing after life change, Hypothesis 2- the extent to which people belong to multiple groups will increase the likelihood of maintaining pre-existing groups to support social identity continuity and Hypothesis 3- the extent that people belong to multiple groups, will increase the likelihood of joining new groups to support social identity gain). None of the three hypotheses were supported. This may imply that the SIMIC model needs refinement when applied to stigmatised groups. When groups are unhealthy or stigmatised, group membership may give members more harm than benefits (Dingle et al., 2015). Nuances of the benefits associated with membership of a psychosis social identity group have been identified such as compartmentalisation of the illness identity depending on current mental state (Hogg et al., 2022). The SIMIC model may require modification to account for fluctuations in how people with an illness identity identify with their illness identity group.

10.3 Objective 3 (Change theory)

Objective 3 was to develop a theory of social identity change in recovery from psychosis. This aim was addressed by integrating the qualitative and quantitative data analysed for Objectives 1 and 2. The integrated data was then used to create a model of social identity change in recovery from psychosis.

Integration was carried out using a joint display table, shown in Table 10.1, The table organised the data by the social identity domains relevant to Unfold. These are listed in the left hand column. These were based on the social identity domains identified in Chapter 3. The key findings and interpretation are shown for the qualitative results in columns 2 and 3, and for the quantitative results in columns 4 and 5. Mixed methods comparisons were made in the right hand column. Comparison were categorised as discordance, confirmation or expansion. Discordance described the qualitative and quantitative data disagreeing with each other or being inconsistent or contradictory. Confirmation described each type of data reinforcing the findings from the other. Expansion described the qualitative and quantitative findings expanding insights.

Table 10.1 Integration of qualitative and quantitative data

Social identity theory domain	**Quantitative results**	**Interpretation**	**Qualitative findings**	**Interpretation**	**Mixed methods comparison**
Social identity gain	Increase in mean number of groups between Previous OSIM and Current OSIM (Z=1, p=0.012)	Participants had more social groups at the Rebuilding/Growth stage of recovery	Sub-theme 2.1 Integration Sub-theme 2.2 Expansion	The way in which participants number of groups increased was by integration of illness identity into the wider social identity and expansion of positive social identity groups	Expansion
Social identity group change: Group positivity	Increase in mean group positivity between Previous OSIM and Current OSIM: (Z=10.8, p=0.001)	Participants felt more positive about their social identity groups at the Rebuilding/growth stage than they did at the Moratorium stage	Theme 1.1: Positive social identity groups become lost	After positive social identity groups had become lost, participants described how their social identity changed into a	Expansion

			Theme 3- positive social identity	positive social identity consisting of positive social identity groups	
Social identity change: Group supportiveness	Increase in mean group supportiveness (Z=0.33 (p=0.018)	Participants felt that they received more social support from members of their social identity groups at the Rebuilding/growth stage than they did at the Moratorium stage	Sub-theme 2.1 Integration Sub-theme 2.2 Expansion	Participants reported receiving more social support from members of their social identity groups as their illness identity group was integrated into a positive social identity and their social identity groups expanded Social support from others sharing an illness identity was	Expansion

				a mechanism for integration and expansion	
Relationship between social identity change and wellbeing	No correlation between SWEMWBS scores and change in mean total groups: 0.121 (p=0.398), change in mean group positivity: 0.187 (p=0.189) and change in mean group supportiveness 0.081 (p=0.573)	Participants did not show higher levels of wellbeing if they had more total groups, higher levels of group positivity or higher levels of group supportiveness	Theme 1: Illness identity is incompatible with positive social identity Theme 3. Positive social identity	Prior to identity change, participants experienced reduced wellbeing due to their incompatible social identities. This was followed by increased levels of wellbeing as their social identity changed and became more positive	Discordance
Relationship between social	Small correlation (ρ=0.316, p=0.023) between	Participants were more likely to report higher Flourishing	Theme 1: Illness identity is	Prior to identity change, participants	Confirmation

identity change and wellbeing	Flourishing scale scores and change in number of mean total groups	scale scores if they had increased their number of social identity groups	incompatible with positive social identity Theme 3. Positive social identity	experienced reduced wellbeing due to their incompatible social identities. This was followed by increased levels of wellbeing as their social identity changed and became more positive	
Relationship between social identity change and recovery	No correlation between SEPRS scores and change in mean total groups: 0.020 (p=0.890), change in mean group positivity: 0.073 (p=0.616), or	Participants were not more likely to report higher levels of recovery if they showed an increase in mean number of total groups, mean group positivity and mean group supportiveness.	Theme 2: illness identity becomes less salient Theme 2.1: Integration of illness identity into a positive social identity	Participants described the process of integrating a negative illness identity into their social identity and expanding their social identity to	Discordance

	change in mean group supportiveness: 0.025 (p=0.861)		Theme 2.2: Expansion beyond illness identity	include positive identity groups. these processes are often described in recovery literature	
Social identity model of identity change	No correlation between total groups in Previous OSIM and Flourishing scale scores:0.79 (p= 0.580) No correlation between total groups in Previous OSIM and SWEMWBS scores: 0.113 (p= 0.430)	Participants were not more likely to have higher wellbeing scores if they belonged to more groups prior to identity change	No data collected	N/A	N/A

	Moderate correlation between total groups in Previous OSIM and total number of groups in current OSIM: (0.522 p=0.001)	Participants were more likely to maintain group memberships if they belonged to a larger number of groups at the Moratorium stage.	No data collected	N/A	N/A
	Correlation between total number of groups in Previous OSIM and the difference in total number of groups between Previous OSIM and Current OSIM: -0.199 (p=0.161)	The extent that people belong to multiple groups does not increase the likelihood of joining new groups	No data collected	N/A	N/A

The quantitative results show an increase in number of social identity groups, an increase in group positivity and an increase in group supportiveness between the Previous OSIM and Current OSIM. The qualitative results expand on these quantitative results. Knowledge regarding increase in number of social identity groups is expanded by providing an account of the processes that enabled participants to gain social identity groups. The qualitative results show that social identity gain took place through the illness identity group becoming integrated into a wider and more positive social identity and by social identity broadening through joining new groups or existing groups increasing in perceived importance.

Understanding of the processes involved in increasing group positivity is provided by the qualitative findings. At the Moratorium stage, participants described the loss of positive social identity groups. After joining new groups through integration and expansion participants described having a social identity that comprised of positively evaluated groups which had a positive impact on their wellbeing.

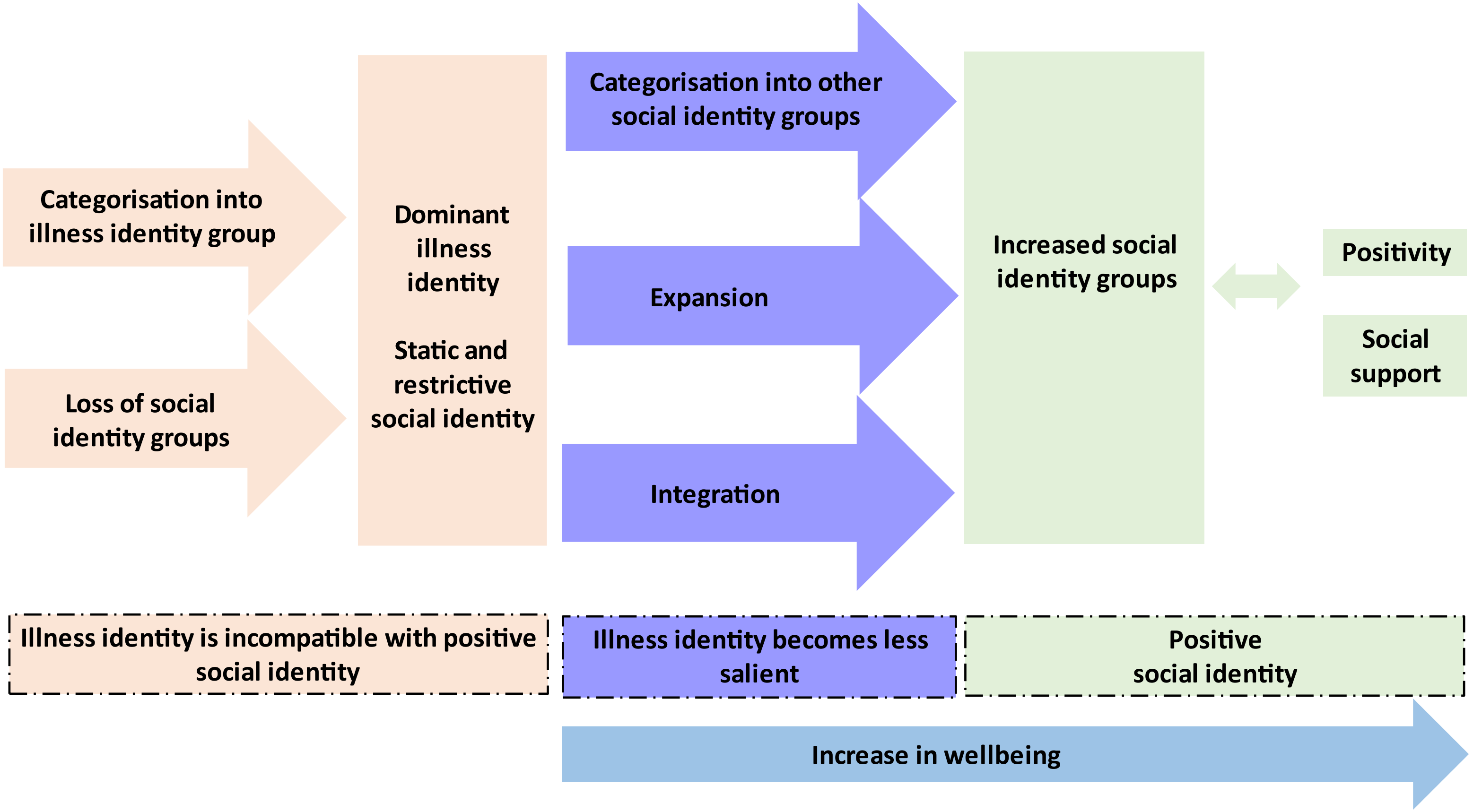
Knowledge about increases in group supportiveness was expanded by qualitative results which showed that as integration and expansion took place, social support increased, and new support networks began to emerge. Support was provided by those who shared an illness identity. This support contributed to participants increasing in confidence and eventually joining additional groups.

There was both discordance and expansion between qualitative and quantitative data regarding the relationship between social identity change and wellbeing. There was an increase in Flourishing scale scores between the Moratorium stage and the Rebuilding/Growth stage but no significant increase in SWEMWBS scores. The qualitative data showed that belonging to an illness identity group at the Moratorium stage had a negative effect on participants wellbeing, but when it became easier to be members of different social identity groups, there was a positive effect on wellbeing. This description of changes in level of wellbeing as social identity changed expands on the Flourishing scale data as it describes the processes involved in the increase in wellbeing. The qualitative data is discordant with SWEMWBS scores which did not change significantly.

There was discordance between the qualitative and quantitative data relating to the relationship between social identity change and recovery The SEPRS scores showed no significant change in recovery between the Moratorium stage and the Rebuilding/Growth stage. The qualitative data however showed that a positive social identity was gained through engaging with recovery based groups or groups that facilitated recovery and illness identity became less salient through expansion and integration. Development of a positive sense of identity occurred which has been defined as a key recovery process.

The findings from the integration of the qualitative and quantitative data were synthesised to create the Unfold Model. Only integrated data that showed expansion or confirmation were used to inform the model. The Unfold Model is shown in Figure 10.1.

Figure 10.1 Unfold Model of social identity change in recovery from psychosis



The Unfold Model illustrates social identity change in recovery from psychosis. The direction of change towards positive social identity is from left to right. The three different colours represent the different stages of identity change.

The left-hand pink section relates to social identity prior to the onset of recovery. Social identity change begins with self-categorisation into an illness identity group. Categorisation occurs simultaneously alongside a loss of positive social identity groups. The resulting social identity is static with a dominant and restrictive illness identity group. At this point, illness identity is incompatible with positive social identity and a reduction in level of wellbeing occurs.

The middle purple section describes how illness identity becomes less salient through expansion, integration and self-categorisation into other social identity groups. This results in an increase in wellbeing.

The right-hand green section describe how a positive social identity consists of increased social identity groups that are positive and provide social support. Wellbeing continues to increase in a sustainable way.

10.4 Discussion Objective 3: Change theory

Objective 3 was to develop a theory of social identity change in recovery from psychosis. This aim was addressed by integrating the qualitative and quantitative data analysed for Aims 1 and 2. The integrated data was then used to create a model of social identity change in recovery from psychosis.

The five-stage model of recovery was used as a predefined framework to investigate identity change. The Unfold Model illustrates social identity change processes between the Moratorium and Rebuilding/Growth stages of recovery. The Unfold Model identifies that one of the variables that differentiate individuals between the Moratorium and Rebuilding/Growth stages is positive social identity. The Unfold Model demonstrates that social identity change processes occur between recovery stages when positive social identity develops. This confirms that social identity change processes are barriers between recovery stages and development of a positive social identity is a requirement for recovery to occur. Participants gained positive social identity groups as they recovered. They were then able to progress through recovery stages.

The Unfold Model also builds on elements of the SIMIC model (Jetten et al., 2009). SIMIC was developed to explain the role that social identity processes play in adjustment to life change (Haslam et al., 2021). The Unfold study conceptualises recovery from psychosis as a life change. The Unfold Model provides more detail on the processes described in SIMIC. The SIMIC model outlines the wellbeing benefits of maintaining and gaining social identity groups after a life change. The Unfold Model extends this by describing the consequences of not maintaining multiple group memberships during life change. Participants were unable to maintain social identity groups at the onset of psychosis. They experienced loss of positive identity groups which resulted in illness identity becoming more prominent. The Unfold Model also describes the specific processes involved in gaining new groups: Expansion of social identity groups occurs as people categorise themselves into new social identity groups and they integrate their illness identity into an overall positive social identity.

As hypothesised by the SIMIC model, the Unfold Model shows an increase in wellbeing as illness identity becomes less salient and the number of social identity groups increases. Wellbeing homeostasis describes wellbeing being maintained within narrow margins, referred to as a ‘set point’. Highly unusual events can cause a person’s level of subjective wellbeing to change temporarily, but it will return to its previous level over time (Brickman et al., 1978). Subjective wellbeing of both lottery winners and paralyzed accident victims eventually return to previous levels (Brickman et al., 1978). The set point is maintained by psychological factors including personality traits and adaptation. Wellbeing may not therefore be a good indicator of improved social identity as indicated by the Unfold Model.

Chapter 11 Discussion and Conclusion of thesis

Chapter 11 presents a discussion of the overall thesis. The knowledge contributions are discussed in 11.1 in relation to the thesis aims and objectives. Thesis strengths and limitations are addressed in 11.2. Scientific and clinical implications of the findings are discussed in 11.3. Reflections on producing the thesis are discussed in 11.4, followed by conclusions.

11.1 Knowledge contributions of the thesis

The thesis makes five knowledge contributions:

1. The typology of design choices used in ESM studies and predictors of data completeness
2. Identification of experiences of social identity change in recovery relating to Illness identity being incompatible with positive social identity, illness identity becoming less salient and positive social identity.
3. Identification of total number of social identity groups, group positivity and group supportiveness as measurable aspects of social identity change in recovery from psychosis
4. Identification of the relationship between social identity change, wellbeing and recovery
5. The Unfold Model of Social Identity Change in Recovery from Psychosis

Unfold 1 had two aims:

1. (Methods): To assess digital data collection methods to evaluate prospective assessment of identity change.
2. (Identity): To characterise the processes involved in developing an identity as a ‘person in recovery’ with particular attention to social identity and sense of wellbeing.

Objective 1 was met by the systematic review of design decisions and data completeness for experience sampling methods used in psychosis (presented in Chapter 4). The resulting knowledge contribution is the typology of design choices used in ESM studies and predictors of data completeness. Aim 2 was unmet due to the onset of the COVID-19 pandemic and resulting study closure. This was addressed in Unfold 2.

Unfold 2 had an overarching aim: To characterise the processes involved in developing an identity as a ‘person in recovery’ for people with experience of psychosis who are in the Rebuilding and Growth recovery stages.

It also had 3 objectives. Each objective was met by a corresponding knowledge contribution outlined in Table 10.1.

Table 11.1 Research objectives and corresponding knowledge contributions

Research objective	Knowledge contribution
1. (Change processes) To explore the role of social identity change processes in recovery from psychosis.	Identification of experiences of social identity change in recovery relating to Illness identity being incompatible with positive social identity, illness identity becoming less salient and positive social identity. Identification of total number of social identity groups, group positivity and group supportiveness as measurable aspects of social identity change in recovery from psychosis
2. (Relationships) To investigate the relationship between social identity change, wellbeing and recovery	Identification of relationships between social identity change, wellbeing and recovery
3. (Change theory) To develop a theory of social identity change in recovery from psychosis	The Unfold Model of social identity change in psychosis

11.2 Strengths and limitations of the thesis

Unfold is the first mixed methods study to explore social identity change in people recovering from psychosis. The study expands the understanding of identity change from personal identity to focus on social identity. There are three major strengths to the thesis.

First, the use of social identity mapping (through use of SIM-tool and OSIM) to measure changes to multiple social identity domains simultaneously is a strength. Social identity is multifaceted and complex. The use of social identity maps allows a range of different social identity constructs to be captured. The completed maps offer a comprehensive understanding of a person's social identity. These social identity features may have been difficult to capture using a single psychometric scale.

Second, the study engaged with the philosophy of pragmatism. It has been asserted that qualitative and quantitative research have different paradigmatic assumptions and therefore cannot be combined (Greene, 2008, p.12). This issue has been resolved in this thesis by adopting the underpinning philosophy of pragmatism. Pragmatists believe that the world consists of an existential reality, consisting of different layers, some objective, some subjective, and some a mixture of the two (Feilzer, 2010). The Unfold study further engaged with the philosophy of pragmatism by developing a theory of social identity change in psychosis and adopting a convergent design which gave equal weight to qualitative and quantitative data.

Third, was the collaboration with a dedicated PPI group. Involving a PPI group in research has been shown to improve research quality, and ensure research is relevant to clinicians and service users (NIHR, 2021). The group consisted of five members, two with personal experience of psychosis. The group were consulted throughout the design and data collection of Unfold 1 and Unfold 2. The group provided feedback that informed the design of both studies, commented extensively on study materials and tested the RADAR-base app and the OSIM platform.

A major complication of the thesis has been the enforced closure of Unfold 1 due to the onset of the COVID-19 pandemic. The closure of the longitudinal study meant that the aims of Unfold 1 could not be met.

A strength of the thesis is that it after the enforced closer of Unfold 1, a new study was designed in accordance with National Institute of Health Research (NIHR) guidance for restarting a research study during the pandemic (NIHR, 2020). This included consideration of validity, NHS capacity and participant and researcher safety. Additionally, consideration was given to social restrictions and that the scientific knowledge generated by the study needed to be valid in the context of the pandemic. The resulting Unfold 2 study:

1. Was viable study within PhD parameters.
2. Minimised risk of COVID-19 exposure to researchers and participants
3. Recruited and ensured study participation took place online
4. Generated valid data

A further strength is that the thesis used mixed methods in order to explain the complex phenomenon of social identity. This would not have been possible using a single method. The qualitative and quantitative data were able to access different layers of social identity relating to different social identity domains. An example of this occurred when integrating data relating to social identity gain, in which the quantitative data was able to provide knowledge on whether a gain in social identity groups had occurred, and the qualitative data provided knowledge on how participants experienced this increase taking place. These two types of data have been integrated in order to explain social identity change more comprehensively.

A limitation was the restrictions placed on social contact during the data collection period for Unfold 2. Data collection took place during 2021 when the UK government was reducing social distancing restrictions. Although for most of the data collection period there were no legal restrictions, people in England reduced their level of social contact during this period (Gimma et al., 2022). Social contact has been shown to change group members attitudes to their social identity groups (Brown, 2000). Therefore, there are implications for generalisability of the study findings.

One specific limitation resulting from the pandemic restrictions was that the data collection was carried out online via video call. Due to the COVID-19 pandemic and associated social distancing restrictions, Semi-structured interviews were conducted using Microsoft Teams. It has been suggested that carrying out interviews with researchers and participants face to face is the “gold standard” (Novick, 2008, p.397.) for interviewing. Reasons for this include researchers are able to understand the context of the interviewee, and to create a personal connection with participants due to the physical proximity (Seitz, 2016) and to build a rapport with participants by picking up on body language and other non-verbal cues (Vogl, 2013). Another limitation to carrying out the study online is that the there was a risk of internet user population bias, with some potential participants not able to be involved due to digital exclusion. Although throughout the course of the pandemic, the general population has become more used to using the videocalls in their day to day lives (Self, 2021).

Another limitation was the risk of recall bias. Recall bias is an error due to differences in completeness or accuracy of recall (Spencer et al., 2017) . This is a risk in Unfold 2 due to the retrospective design. Risk of recall bias has been minimised by using the five-stage model as a framework to inform questions and provide cues to aid participant recall.

Another limitation of the study is the relatively small sample size (50 participants). A power calculation was not performed due to the exploratory nature of the study. A power calculation could have been used to calculate if either study was powered sufficiently to prevent failure to detect an important effect due to low sample size. This could also helped to avoid any ethical issues resulting from enrolling too many participants or too few as an underpowered study may not contribute to the evidence base (Halpern et al., 2002). A power calculation was not used because Unfold was an exploratory study aiming to explore how ESM methods could be used with people with psychosis. A power calculation may not be appropriate in exploratory studies as there is insufficient data on which to base calculations (Jones et al., 2003). Instead, to decide the sample size NIHR guidance for feasibility studies was drawn upon who recommend a sample size of 40-50 participants (NIHR,2019). This relatively small sample size may limit transferability of the study findings.

A sample size was not decided prior to recruitment to the qualitative arm of the study. A sample size was not pre-specified due to this not making ontological sense within a pragmatist paradigm. Instead, data collection finished when the thesis author and the supervisory team agreed central organising concepts had been reach. Thirty six interviews took place before coherent and meaningful patterns were identified within in the data, resulting in three themes. This relatively small sample size may limit the generalisability of the findings.

Throughout the thesis there are multiple inferential statistics carried out using relatively small sample sizes, including some with repeated testing. This is appropriate given the exploratory and hypothesis-generating focus of the research questions, but may limit the transferability of the thesis findings and indicates a need for future studies to investigate social identity change in recovery from psychosis, for example using a quantitative hypothesis-testing design with a larger sample size based on a formal power calculation.

11.3 Implications

Scientific implications

The typology fills a knowledge gap related to design decisions for ESM studies recruiting people with psychosis. The classification of design choices may provide knowledge for researchers designing future ESM studies. Identification of design decisions which predict data completeness could enable researchers to make informed design decisions in order to increase chances of collecting a more complete data set.

Recent literature suggests that research needs to focus on improving understanding of the processes involved in recovery (Hampson et al., 2019). There has been a lack of clarity or consensus about what identity change in people living with psychosis consists of (Conneely et al., 2021). The thesis contributes to knowledge through identifying experiences of social identity change in recovery, identification of total number of social identity groups, group positivity and group supportiveness as measurable aspects of social identity change in recovery from psychosis and Identification of relationships between social identity change, wellbeing and recovery and the Unfold Model of Social Identity Change in Recovery from Psychosis. The findings provide empirical evidence on recovery processes which is lacking (Cruwys et al., 2020). The thesis findings confirm research suggesting that recovery is a process of moving from a negative identity state, to a positive state of psychological wellbeing (Dell et al., 2021). By operationalising recovery as a process, rather than a transition from poor health to good health, a better understanding may be gained of the barriers to recovery and also how to ensure better health states can be maintained over time (Jatta et al., 2022)

The thesis expands understanding of recovery and wellbeing as social phenomenon by focusing on social identity change in recovery. Much of the recovery literature has focused on individualistic understandings of recovery (Wyder et al., 2022). A criticism of personal recovery is that it does not consider the social context in which the individual is situated (Onken et al., 2007). The thesis confirms findings suggesting that recovery processes unfold within a social and interpersonal context (Sommer et al., 2021). Research has found that recovery should be viewed as an interactional process between person and environment (Price-Robertson et al., 2017) and that critical to recovery is the sense of a positive shared identity (Cruwys et al., 2014). The thesis confirms these findings by identifying how recovery affects changes to social identity groups, which in turn, can affect a person's overall health and wellbeing.

Consideration of statistical significance throughout the thesis

The thesis identifies a number of statistically significant findings relating to changes in OSIM scores between the Moratorium and the Rebuilding/Growth stages of recovery. Statistical significance refers to the probability that observed differences or associations between variables are not due to chance (Chen et al., 2017).

By contrast, clinical significance refers to the practical or meaningful impact of a finding or an intervention in 'real-world' healthcare settings. It focuses on whether the observed association or effect has a meaningful impact on clinical practice or patient outcomes (Sharma, 2021).

The Reliable Change Index specifies the amount of change in score on a specific psychometric instrument for that change to be considered reliable, i.e., larger than that reasonably expected due to measurement error alone (Jacobson and Truax, 1991). Only if the change is reliable is it then meaningful to consider the change in scoring to be clinically significant. The Reliable Change Index for the OSIM tool is un-known. Future research will need to characterise this change metric, in order to judge whether the changes reported in this thesis are clinically significant.

Methodological challenges of the mixed methods approach

Mixed methods studies are complex, and a researcher can encounter a number of challenges when designing carrying out a mixed methods study (Dawadi et al., 2020). The thesis author experienced a number of challenges in the design and implementation of a mixed methods thesis. Firstly, a common concern related to concurrent mixed methods designs is that the qualitative and quantitative data may influence each other as it is collected at the same time. The thesis author found that this aspect of the design was beneficial. Participants first completed two

OSIM's mapping their social identity groups before some participants took part in an interview. A strength of this approach was that participants had already described their social identity groups and some chose to refer back to their OSIM throughout the interview. The thesis author found that this helped to orientate participants and to keep focus on their social identity groups during the interview. Social identity change may have been a more challenging concept to discuss without an OSIM to base discussions on and without prior consideration of social identity groups during completion of the OSIMs.

Secondly, a lack of guidance in relation to integration of qualitative and quantitative data made data integration challenging. Although descriptions of joint display tables were available and there were examples in the literature, the one which was ultimately used for this thesis was an adapted version of a table used by other researchers. This meant that although there was a detailed description of how to integrate data with the original table design, when additional column headings were added, there were no instructions or guidance on how to populate these.

A common issue in mixed methods studies is challenges in interpreting divergent findings. It has been described as a common misconception that divergent findings imply that a mixed methods study is low in quality (Zhou et al., 2022). Unfold 2 results included divergent findings relating to the relationship between social identity change and recovery and the relationship between social identity change and recovery. Divergent findings can be addressed by making suggestions for further research (Zhou et al., 2022). This has been addressed at the end of this section.

Clinical implications

Knowledge gained from the thesis could have a number of implications for clinical practice. The Unfold Model could identify targets for clinical intervention. The model describes the loss of positive social identity groups due to the presence of illness identity. Multiple group memberships are beneficial for health and wellbeing, therefore at the onset of psychosis, or when someone receives a diagnosis, intervention could support the maintenance of existing social identity groups. Another target for intervention could be supporting the categorisation into positive social identity groups. If someone describes their social identity as static due to the dominance of the illness identity, intervention could support them to expand their social identity beyond groups associated with illness.

The model also highlights the importance of interventions that encourage peer support. The process of an illness identity group becoming integrated into a wider and more positive social identity involves social support from peers. Peer support is something which is provided formally within mental health services (World Health Organization, 2021). The model could be used to assess when formal peer support may benefit an individual. Social identity groups in which participants shared an illness identity with other group members were perceived by participants as temporary or transitional. Participants used these groups to gain confidence to join other groups or to eventually feel able to branch out into other groups. If someone has successfully increased their social identity groups and the groups are providing social support and positivity, then peer support may then be less beneficial.

Knowledge of changes in social categorisation could be used to inform criteria for entry into mental health services. If a person does not categorise themselves as a service user or into a group relevant to requiring mental health support such as relevant diagnostic groups, this may have implications for the effectiveness of any intervention or support offered by the service. Therefore, relevant social categorisations may be considered on referral to consider the likelihood of interventions offered by the service being relevant or effective.

There are implications for the design of group interventions within mental health services. Unfold 2 demonstrated a change in whether individuals categorise themselves into positive social identity groups as they recover. This may influence effectiveness of group based interventions provided by mental health services. If a person is far enough along in their recovery that they identify with other, more positive social identity groups then they may benefit instead from support to join community groups separate from mental health services. This may facilitate the categorisation into other social identity groups, supporting them to move on from more negative or stigmatised groups.

The findings also have implications for clinical assessments. Information about a person's stage of recovery could be gained by knowledge of their social identity. If a person has high levels of group identification with groups they perceive as unrelated to their illness, then it is possible they may be at a later stage of their recovery than those who identify strongly with an illness identity group.

Future research

The findings from this thesis could be developed in 4 ways.

1. Future research relating to Unfold 1 may investigate whether the typology of design choices used in ESM studies improve the design and reporting of future ESM studies. The refinement of the typology into formal reporting guidelines would be one approach to improving reporting quality.

2. Researchers may also investigate whether knowledge of how to achieve higher levels of data completeness results in more complete data sets in ESM studies. A comparison could be nested within an ESM study, with different design features used in the same study to compare data completeness rates.

3. A future study could focus on investigating whether the Unfold Model can provide a theoretical basis for clinical intervention. The model identifies processes which may serve as targets for intervention. A future study may focus on testing interventions that prevent loss of

positive social identity groups when someone develops psychosis. Candidate components of such an intervention include the use of the OSIM-tool to assess a person’s social identity groups (Bentley et al., 2020). This could be followed by structured support accessing social contact with existing social identity groups identified by the OSIM-tool

4. Researchers may also test interventions which promote integration and expansion to support illness identity becoming less salient. When referred to mental health services, service users could be offered support to join peer-led groups for a finite period. During this time, they could benefit from the social support provided by those sharing the illness identity. This could be followed by support to build social identification beyond an illness identity. Service users could be supported to join other groups within the community, where they could cultivate supportive relationships with members of different groups.

11.4 Reflections on producing the thesis

The philosophical basis of this thesis is pragmatism. Pragmatism endorses the belief in human experience as a theoretical starting point for generation of knowledge. It is therefore appropriate to conclude with some reflections about my own personal experience of completing the PhD and the impact this may have had on the knowledge produced.

Throughout my PhD journey I have experienced two major social identity changes. First, my transition from Occupational Therapist to researcher, and second, gaining the social identity of parent. Both life transitions were challenging for different reasons, and I have found that some of the experiences of participants’ social identity changes mirror my own.

The identity change from clinician to researcher was one which I found challenging due to the values I maintained in my clinical work differing from those valued in academia. The values of Occupational Therapy are very strongly aligned with personal recovery and also my own, personal values such as equality, justice, wellbeing and self-care. I have found these values to be lacking in some academic environments which value productivity and output. I do not think that these values are inherently opposing and am certain that they can exist together in an environment valuing maximum productivity whilst also ensuring self-care wellbeing and diversity are encouraged, but this something I have come to understand is rare in academic environments.

In my opinion, it is essential that certain values are not viewed as relevant only to those being treated or researched. Experiences of recovery and related concepts (e.g., wellbeing, connection, compassionate spaces and approaches) should not be perceived as relating only to ‘others’ (i.e., those who have experienced mental ill health), but as necessary elements for the health of every individual located on the spectrum of human experience. These are values to maintain within any healthy, functioning work environment, especially those related to mental health and wellbeing. If this does not happen, I believe this may contribute to perpetuating stigma or ‘otherness’ in those who are being researched. I have therefore wondered throughout my time doing this PhD if standard academic practice is an appropriate method for generating knowledge in this field.

The social identity transition to motherhood has been challenging in the context of my working environment. One of the main things I have learned from this period in my life is that society is not as equal as I had believed. Since disclosing my pregnancy, I have been repeatedly stunned at the attitudes towards women and particularly mothers who work in academic jobs. I have experienced sexism on an institutional and interpersonal level. The result of these experiences means I have spent the latter 2/3 of my PhD attempting to integrate the low status social identity of mother alongside that of researcher and navigating the difficulties associated with belonging to incompatible social identity groups. What I experienced as a pregnant woman in an academic workplace will live with me for a long time. When I look back on my PhD journey, the sense of alienation I felt at this time is at the forefront of my mind. I have worked in adult mental health for ten years and believed I was aware of the challenges of navigating a stigmatised group. Now that I feel personally aware of the realities of this position, I have a renewed empathy for those living with any stigmatised identity. I have found the culture in which I have been working very far removed from the characteristics of recovery and social inclusion which have been the focus of my research. This has been confusing for me professionally, as an early career researcher, and personally difficult for me to reconcile.

A key thing I learned throughout the course of this PhD is that researcher's epistemological perspective defines what can be known, which influences the creation of knowledge. If human experience is a theoretical starting point for generation of knowledge, then in order to generate knowledge, it is important to engage with all forms of human experience. I feel that if the academic world continues to generate knowledge in a way that can discriminate and 'other' its workers and those who are being researched, then the lack of diversity will increase, ensuring that that only a very narrow range of experiences are starting points for new knowledge. I have questioned during this process how this can be an effective way of working, and ultimately whether it is possible to produce knowledge that is truly relevant to people living with psychosis using current academic practices.

During my social identity transition from clinician to researcher, I have been able to produce findings inspired by my clinical practice. The thesis findings regarding knowledge of how social identity groups can support recovery has been influenced directly by my clinical work and I am proud of this achievement.

11.5 Conclusion

This is the first mixed methods study to explore the processes involved in developing a social identity as a 'person in recovery'. This thesis makes five knowledge contributions: the typology of design choices used in ESM studies and predictors of data completeness; identification of experiences of social identity change in recovery relating to Illness identity being incompatible with positive social identity, illness identity becoming less salient and positive social identity; identification of total number of social identity groups, group positivity and group supportiveness as measurable aspects of social identity change in recovery from psychosis; identification of relationships between social identity change, wellbeing and recovery, the Unfold Model of Social Identity Change in Recovery from Psychosis. The findings meet the aims of the thesis and have provided new knowledge relating to how people who have experienced psychosis develop a social identity as a ‘person in recovery’. Future work could build on this by testing the Unfold Model as a basis for clinical intervention.

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Appendices

Appendix 1: Unfold 1 Information Sheet and consent form

V3.0 30th September 2019 IRAS reference: 263220

Research Study Title: UNFOLD: How does identity as a
person recovering from psychosis unfold over time?

Research Team:
Researcher: Emilia Deakin
Emilia.deakin@nottingham.ac.uk
Investigator: Prof Mike Slade, Dr Michael Craven and Prof Carol Coupland

Invitation for participation in a research activity

You are invited to take part in the UNFOLD study. The following information has been provided to help you understand the purpose of the research and what the research will involve. Please take your time in deciding whether to participate, and please get in touch with the researcher listed above if you have any questions.

What is the purpose of the UNFOLD study as a whole?

The purpose of UNFOLD is to understand how recovery unfolds over time. “Recovery” here refers to the process of learning to live as well as possible, either with or without mental health problems.

Why have I been invited to participate?

Participants are being recruited who have experience of psychosis, to help us understand how recovery unfolds over time and how this may result in identity change The study will also investigate the feasibility of collecting data using a smartphone. You must own and use a smartphone with an Android operating system in order to participate

Do I have to take part?

Participation in this research is entirely voluntary, and there will be no negative consequences for you (e.g. for your care) if you choose not to participate. You can discontinue participation at any time. If you do withdraw after enrolling in the study, any identifiable data that has been collected about you will be anonymised and will not be withdrawn. If you do choose to take part, you will need to sign a form indicating your consent for taking part in the research.

What will I be involved in if I agree to take part?

If you agree to take part, please contact the researcher, using the details provided at the top of this information sheet, to organise a venue and a time to meet.

At the first meeting you will be asked to fill out questionnaires with information about you, your wellbeing and your recovery. Next you will be asked to carry out an activity describing the social groups you belong to in the form of a picture or a ‘map’. You will be supported to download two Apps called RADAR-base from Google Play onto your phone, and will receive training on how to use the Apps to answer questionnaires about your wellbeing and how you feel about your social groups. You will be given a phone number so you can call the researcher about any issues you may be having with the Apps. You will be paid £20 plus reasonable travel expenses as a compensation for your time and effort.

Whilst the Apps are installed on your phone it will send you a questionnaire to fill out four days out of every month for 9 months. You will receive a message to your phone to fill this out ten times per day on those four days. It is a short questionnaire that will take you less than 2 minutes to complete each time.

Whilst the Apps are installed it will also collect data about the number of social contacts in your phone book at the end of every month, to see if this changes. This will be done automatically, without you having to do anything. No details or information about phone contacts will be collected and the app cannot distinguish between numbers stored for practical purposes e.g. a dentist or those used socially.

One month after the Apps are installed you will receive a phone call from the researcher to check you are not having problems with using the Apps. The phone call will give you an opportunity to share any issues you may be having with the Apps with the researcher so that these can be addressed.

Three months after the first meeting you will be contacted by the researcher to organise another time and venue to meet. At this meeting you will be asked to fill out the same questionnaires about your wellbeing and recovery. You will also be asked to amend your social ‘map’ with any changes that may have taken place since you first created it.

Nine months after the first meeting you will be contacted again by the researcher, to organise a second meeting. You will be asked to fill out the same questionnaires about your wellbeing and recovery. You will also be asked to amend your social ‘map’ with any changes that may have taken pace. At this point, you can uninstall the RADAR-base Apps from your phone. You will be paid £20 plus reasonable travel expenses as a compensation for your time and effort.

In addition, ten participants out of a total of 50 recruited to the study will also be asked to meet for an interview about their social contacts and the experience of taking part in this study. The meeting will last for about an hour.

What are the possible benefits of taking part?

The UNFOLD study will investigate how recovery from psychosis unfolds over time. The knowledge developed through this process will have an impact on future clinical practice. Making a contribution to this process, through taking part in the study might be perceived as a benefit, as might the experience of sharing information about your social relationships with a trained listener.

What are the possible disadvantages and risks of taking part?

For some participants, having their data collected by smartphone might cause distress.

Talking about their own experiences can also be distressing, and the distress that this causes could be perceived as a disadvantage of participation. You can stop at any time.

What happens after the study?

Your interview will be transcribed by the researcher or by an external transcriber with a confidentiality agreement in place. Any names of people and places in it will be replaced with fictional ones to protect your identity and the identity of others. The researcher will analyse both the smartphone data and the interview, and will produce analysis reports and publications which summarise what has been learnt. Quotations from you might be used in study publications, but any published data will be thoroughly anonymised, e.g. details will be changed to ensure that you cannot be identified through it.

What will happen if I withdraw from the study?

Your participation is entirely voluntary and you are free to withdraw at any time, without giving any reasons, and without your legal rights being affected. If you withdraw, then any identifiable information held about you will destroyed, including transcripts in which names have been changed. To withdraw, please contact the researcher listed above, providing your name, and stating that you wish to withdraw. To allow for withdrawal, we will keep a master file, linking your name to your data. Access will be strictly controlled by the chief investigator. If we are made aware that you no longer have capacity to consent to participate, for example due to mental health problems, then we will not contact you again and will make use of information we have already collected from you.

Will my taking part in this project be kept confidential?

All identifiable information collected through this study will be held confidentially, with access to third parties strictly prohibited. Digital data will be held on secure servers owned by the University of Nottingham, whilst physical data (such as signed consent forms) will be held in locked cabinets in the Institute of Mental Health. The social identity map and other questionnaires will be labelled with your participant unique identifier (UID) rather than your name. The map will be stored in a locked drawer at the Institute of Mental Health, and destroyed at the end of the UNFOLD study. Any personal data (e.g. interview recordings and signed consent forms) will be transferred securely from to the University by the researcher where they will then be stored in a locked drawer. Audio recordings will be transferred to an encrypted laptop prior to transportation. Our project sponsor (Nottinghamshire NHS Foundation Trust) may audit data, but only under terms of strict confidence, with disclosure to a third party strictly prohibited.

Please note that confidentiality may be breached if your interview suggests that you are at risk of harming yourself or others, or if it suggests that you or others have engaged in criminal activities that require notification (e.g. relating to protection of children). Decisions to breach confidentiality will be made in negotiation with you as far as possible, and in collaboration with the investigator.

In the event that your phone is hacked or stolen the risk to your personal data relating to the UNFOLD study is extremely low. No personal data relating to the study will be held on the phone or by the RADAR-base Applications. Phonebook data is anonymised and sent over a secure connection to a server at the University of Nottingham. Questionnaire responses are sent via secure connection to a university of Nottingham server as soon as they are completed. No further personal data will be stored on your phone for the purpose of the UNFOLD study.

When will my data be destroyed?

Smartphone data and digital recordings of your interview will be deleted after the UNFOLD study ends. Transcripts will be deleted at the end of the study and only destructively anonymised data will be retained, e.g. data where sufficient information is removed so that an individual cannot possibly be identified through it. The master file will be deleted by the end of the UNFOLD study.

What will happen to the results of the research project?

Findings will be disseminated through academic, practitioner, consumer and carer articles and presentations. If you would like to keep track of these, then details will be provided through the project website at http://www.researchintorecovery.com/UNFOLD. If we include any quotes from your interview in project publications, then they will be sufficiently anonymised that it will not be possible to identify you through them.

What should I do if I feel distressed?

If you feel distressed whilst taking part in UNFOLD research activities, please tell us, and we will offer to pause or conclude the process. If you continue to feel distressed after leaving, you might wish to speak to your mental health worker for support:

What if something is going wrong?

If you have any concern about the study, you should first speak to the researcher (details in Section 2 above). If you remain unhappy, and wish to formally complain, you should contact the Research and Innovation office at Nottinghamshire Healthcare NHS Foundation Trust, who are the sponsor for the study, by email to RandIenquiries@nottshc.nhs.uk or phoning 0115 9691300 extension 11903 or 11904. Alternatively, you can contact your local Patient Advice and Liaison Service by phoning 0115 993 4542

Who is organising and funding the research?

The research is funded by Nottingham Biomedical Research Council.

Who has reviewed the project?

All research in the NHS is reviewed by an independent Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by a research ethics committee. The project has also been reviewed by the Health Research Authority, and by the Research and Innovation Team at Nottingham Healthcare NHS Foundation Trust, who are sponsoring the project.

How will we use information about you?

We will need to use information from you for this research project. This information will include your contact details, age, gender, ethnicity, social roles, relationship status, employment, housing, clinical characteristics (including medication and current treatments) and smartphone use (including length of contract). People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.

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

You can find out more about how we use your information at www.hra.nhs.uk/information-about-patients/ or by asking the researcher detailed at the top of this form.

Study ID: UNFOLD. IRAS reference: 263220

Participant unique identifier (UID):

CONSENT FORM

Title of Project: UNFOLD: How does identity as a person recovering from psychosis unfold over time?

Name of Researcher: Emilia Deakin

Please initial boxes 1, 2, 3, 4 and 5

I confirm that I have read and understand the information sheet for the UNFOLD study dated 30th September 2019 version 3.0 I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. I understand that my data will be held by Nottingham University and the Nottingham Institute of Mental Health. I understand that my data will be accessed by the study team, and may be audited by Nottinghamshire NHS Foundation Trust. I give permission for these individuals to access this data.

I agree for my mental health team to be informed about my participation in the UNFOLD study [ ]

I agree that my data can be shared in anonymised form with other researchers. [ ]

I agree to being contacted about taking part in the additional in-depth interviews [ ]

I agree for interviews I participate in as part of the study to be audio recorded [ ]

I agree to take part in this research activity. [ ]

Participant UID	Date	Signature
Name of Person taking consent	Date	Signature

Appendix 2: Flourishing Scale

Below are 8 statements with which you may agree or disagree. Using the 1–7 scale below, indicate you agreement with each item by circling the statement you most agree with

Question	Score
I lead a purposeful and meaningful life. My social relationships are supportive and rewarding I am engaged and interested in my daily activities I actively contribute to the happiness and wellbeing of others I am competent and capable in the activities that are important to me I am a good person and live a good life I am optimistic about my future People respect me	1. Strongly disagree 2. Disagree 3. Slightly disagree 4. Mixed or neither agree nor disagree 5. Slightly agree 6. Agree 7. Strongly agree

Appendix 3 Self-Efficacy for Personal Recovery Scale

Question (please rate from 0 (not confident I can do this at all) to 100 (highly confident I can do this)
How confident are you that in the future you will be able to live a satisfying life alongside any mental health problems you may have?
How confident are you that you can do things to manage any future mental health difficulties?
How confident are you that in the future you will no longer experience mental health symptoms?
How confident are you that you can…
Form connections with others?
Maintain satisfying connections with people in my life?
Develop a view of myself beyond being a psychiatric patient Identity?
Be able to respond to stigma in a way which is effective for me?
Tell services my views on how to manage my mental health?
Actively manage my own mental health Empowerment?
Do satisfying and rewarding things in my life?
Use my experience of mental health problems in a way that benefits myself or others?
Make changes to better manage my health?
Maintain a healthy lifestyle?
Do things that can help reduce the effects of stress?
Do things that can help to cope with mental health symptoms?

Appendix 4: Self-identified stage of recovery

PART 1

People who are told they have a serious illness can feel differently about life with the illness at different times. Below are five statements describing how people may feel at times when living with a mental illness.

Please read **all five** statements (A-E) before answering the question that follows.

A.“I don’t think people can recover from mental illness. I feel that my life is out of my control, and there is nothing I can do to help myself”	☐
B. “I have just recently realised that people can recover from serious mental illness. I am just starting to think it may be possible for me to help myself.”	☐
C. “I am starting to learn how I can overcome the illness. I’ve decided I’m going to start getting on with my life.”	☐
D. “I can manage the illness reasonably well now. I am doing OK, and feel fairly positive about the future.”	☐
E. “I feel I am in control of my health and my life now. I am doing very well and the future looks bright.”	☐

Of the five statements above, which one would you say ***most closely*** describes how you have been feeling over the **past month** about life with the illness? Tick the box next to that statement.

PART 2

Below are four statements about how people can feel about aspects of their lives.

For the **past month**, how much would you agree with each statement?

Please circle the appropriate number.

1) I am confident that I will find ways to attain my goals in life.

Disagree Disagree Disagree Agree Agree Agree

2) I know who I am as a person, and what things in life are important to me.

3) The things I do in my life are meaningful and valuable.

4) I am completely responsible for my own life and wellbeing.

Appendix 5: Short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS)

Question	**Responses**
I’ve been feeling optimistic about the future I’ve been feeling useful I’ve been feeling relaxed I’ve been dealing with problems well I’ve been thinking clearly I’ve been feeling close to other people I’ve been able to make up my own mind about things	None of the time Rarely Some of the time Often All of the time

Appendix 6: Unfold 2 Participant information sheet

Study Title: UNFOLD: How does identity as a person recovering from psychosis unfold over time?

PARTICIPANT INFORMATION SHEET

Research Ethics Reference: FMHS 251-0521

Version 1.0 Date: 05.04.2021

We would like to invite you to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. One of our team will go through the information sheet with you and answer any questions you have. Please take time to read this carefully and discuss it with others if you wish. Ask us anything that is not clear.

What is the purpose of the research?
The purpose of UNFOLD is to understand how recovery unfolds over time. “Recovery” here refers to the process of learning to live as well as possible, either with or without mental health problems.

Why have I been invited to take part?
You have been invited to take part in this research because you are between the ages of 18 and 65 and have had experience of psychosis (diagnosed or self-defined). To help us understand how recovery unfolds over time and how this may result in identity change. You must score either 4 or 5 out of a possible 5 on a measure called Self-identified stage of recovery (SISR) in order to take part. The study takes place online and you must have access to a computer or smartphone and have an email address.

The exclusion / inclusion criteria are:

- People aged 18-65
- Who have experienced psychosis (diagnosed or self-defined)
- who are competent in English
- who can use a computer or smartphone and have an email address
- Participants do not need to have received any medical support for their mental health difficulties.
- Able to give informed consent for participation
- Must be at either the ‘rebuilding’ or ‘growth’ stage of recovery as measured by the Single Item Stages of Recovery Measure (SISR).

We will be recruiting up to 50 participants in this study.

Do I have to take part?

No. It is up to you to decide if you want to take part in this research. We will describe the study and go through this information sheet with you to answer any questions you may have. If you agree to participate, we will ask you to sign a consent form and will give you a copy to keep. However, you would still be free to withdraw from the study at any time, without giving a reason and without any negative consequences, by letting the research know. If you are a student at the University of Nottingham, there would be no disadvantages to your study or to you personally if you decide not to take part in this study, or if you decide to withdraw at any point.

What will happen to me if I take part?

A researcher will contact you to go over the information sheet, explain the procedures, and go through a pre-screening with you to check if it is safe and appropriate for you to participate. You will then be asked to arrange a time that is convenient for you to meet with a researcher via Microsoft Teams. All participation will be online with a researcher on a Teams call. At this meeting we will talk you through the study procedures and give you chance to ask any questions. If you agree to take part in the study, you will be asked to sign a consent form. This will be emailed to you so that you can sign electronically.

The study will involve filling out questionnaires about you and your wellbeing. These will be sent to your email address. Next you will be supported to carry out an online activity describing the social groups you belong to and have belonged to previously. This will be in the form of a 'map'. This will involve clicking on a link we send to you via email, which will direct you to a website. On the website you will be given instructions on how to create a map of your social groups. You will be asked to create 2 maps of your social groups, one based on your social groups at a previous time, and another which maps your social groups at the present time. This will take no more than one hour.

In addition, 30 participants out of a total 50 recruited to the study will be invited to take part in an interview about their social groups. This will take place after the two sosicl identity maps are created and will last about an hour.

After you will be paid £20 expenses as a compensation for your time and effort.

The research lasts for a total period of 6 months.

What is OSIM
The Online Social Identity Mapping Tool (OSIM) is used to gain a better understanding of a person's social groups. OSIM allows participants to create a map of their social identity groups (SIM) online. The tool enables each participant to record different aspects of their social groups and to map how they relate to one and other. These include quantity of social groups, perceived group quality and numbers of supportive and positive groups. The software is accessed through a link sent by researchers to participants email address. The software guides participants through the SIM creation process.

Are there any risks in taking part?

For some participants, remembering and discussing their social groups at a time they were unwell may cause distress. The distress that this causes could be perceived as a disadvantage of participation.

In order to reduce risk of distress you can stop or pause research activities at any time

Are there any benefits in taking part?

There will be no direct benefit to you from taking part in this research but your contribution may help us to gain knowledge about how recovery unfolds over time. The knowledge developed through this process will have an impact on future clinical practice. Contributing to this process, through taking part in the study might be perceived as a benefit, as might the experience of sharing information about your social relationships with a trained listener.

Will my time/travel costs be reimbursed?

You will receive £20 for participating in the study as compensation for your time and effort

What happens to the data provided?

We would like your permission to use anonymised data in future studies, and to share our research data (e.g. in online databases) with other researchers in other Universities and organisations both inside and outside the European Union. This would be used for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. All personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public.

Data sharing in this way is usually anonymised (so that you could not be identified)

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

Even after you have signed the consent form, you are free to withdraw from the study at any time without giving any reason. Any personal data will be destroyed.

[Please state what will happen to the data/information you have already collected if the participant chooses to withdraw. Please give participants a deadline by which they can easily withdraw their data i.e. after an interview/focus group. (i.e. before it is fully anonymised for analysis; before publication) make sure this is the same on your consent form].

If you withdraw we will no longer collect any information about you or from you but we will keep the anonymous research data that has already been collected and stored as we are not allowed to tamper with study records. This information may have already been used in some analyses and may still be used in the final study analyses.

Who will know that I am taking part in this research?

Data will be used for research purposes only and in accordance with the General Data Protection Regulations. Audio digital recordings and electronic data will be anonymised with a code as detailed above. Electronic storage devices will be encrypted while transferring and saving of all sensitive data generated in the course of the research. All such data are kept on password-protected databases sitting on a restricted access computer system and any paper information (such as your consent form, contact details and any research questionnaires) would be stored safely in lockable cabinets in a swipe-card secured building and would only be accessed by the research team.

Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data).

You can find out more about how we use your personal information and to read our privacy notice at:

https://www.nottingham.ac.uk/utilities/privacy.aspx/

Designated individuals of the University of Nottingham may be given access to data for monitoring and/or audit of the study to ensure we are complying with guidelines.

With your consent, we will keep your personal information on a secure database in order to contact you for future studies. [Amend above statements as necessary]

Anything you say during an interview group will be kept confidential, unless you reveal something of concern that may put yourself or anyone else at risk. It will then be necessary to report to the appropriate persons.

Due to the professional responsibilities of some University staff, if you mention something during the interview which may require reporting the research team will discuss it with you and decide on a course of action. This may involve implementing the University of Nottingham, Safeguarding policy.

What will happen to the results of the research?

The research will be written up as a thesis. On successful submission of the thesis, it will be deposited both in print and online in the University archives, to facilitate its use in future research. The thesis will be published open access.

Who has reviewed this study?

All research involving people is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests.

Who is organising and funding the research?

The research is organised by the Principle Investigator Mike Slade at the University of Nottingham and is being funded by Nottingham Biomedical Research Council.

What if there is a problem?

If you have a concern about any aspect of this project, please speak to the Emilia Deakin or the Principal Investigator Mike Slade, who will do their best to answer your query. The researcher should acknowledge your concern and give you an indication of how he/she intends to deal with it. If you remain unhappy and wish to complain formally, you can do this by contacting the FMHS Research Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen’s Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk.

Please quote ref no: FMHS 251-0521

Contact Details

If you would like to discuss the research with someone beforehand (or if you have questions afterwards), please contact:

Emilia Deakin
Recovery Research Team
D Floor
Institute of Mental Health
Email: Emilia.deakin@nottingham.ac.uk

Appendix 7: Participant Consent Form

Final version 1.0: DD.MM.YYYY

Title of Study: Unfold

REC ref: (please add when approved)

Name of Researchers:
Principle Investigator: Professor Mike Slade
Researcher: Emilia Deakin (PhD student)

Please initial box

Name of Participant:

I confirm that I have read and understand the information sheet version number 1.0 dated 01.05.2021 for the above study which is attached and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without disadvantage. ☐

I understand that relevant sections of my data collected in the study may be looked at by the research group and by other responsible individuals for monitoring and audit purposes. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

I understand that the interview will be audio recorded using a digital device and that anonymous direct quotes from the interview may be used in the study reports. ☐

I understand that information about me recorded during the study will be made anonymous before it is stored. It will be uploaded into a secure database on a computer kept in a secure place. Data will be kept for 7 years after the study has ended and then deleted. ☐

I agree that my anonymous research data will be stored and used to support other research in the future and shared with other researchers including those working outside the University. ☐

I understand that what I say during the interview will be kept confidential unless I reveal something of concern that may put myself or someone else at any risk. It will then be necessary to report this to the appropriate persons. ☐

I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Appendix 8: Systematic review full references of included studies

Reference number	Full reference
1	Ben-Zeev, D., Frounfelker, R., Morris, S.B. and Corrigan, P.W., 2012. Predictors of self-stigma in schizophrenia: New insights using mobile technologies. Journal of Dual Diagnosis, 8(4),305-314.
2	Ben-Zeev, D., McHugo, G.J., Xie, H., Dobbins, K. and Young, M.A., 2012. Comparing retrospective reports to real-time/real-place mobile assessments in individuals with schizophrenia and a nonclinical comparison group. Schizophrenia Bulletin, 38(3), 396-404.
3	Ben-Zeev, D., Morris, S., Swendsen, J. and Granholm, E., 2011. Predicting the occurrence, conviction, distress, and disruption of different delusional experiences in the daily life of people with schizophrenia. *Schizophrenia Bulletin*, *38*(4), 826-837.
4	Granholm, E., Ben-Zeev, D., Fulford, D. and Swendsen, J., 2013. Ecological Momentary Assessment of social functioning in schizophrenia: Impact of performance appraisals and affect on social interactions. *Schizophrenia Research*, *145*(1-3),120-124.

5	So, S.H.W., Peters, E.R., Swendsen, J., Garety, P.A. and Kapur, S., 2013. Detecting improvements in acute psychotic symptoms using experience sampling methodology. *Psychiatry Research*, *210*(1), 82-88.
6	Brenner, C.J. and Ben-Zeev, D., 2014. Affective forecasting in schizophrenia: Comparing predictions to real-time Ecological Momentary Assessment (EMA) ratings. *Psychiatric Rehabilitation journal*, *37*(4),316.
7	Hartley, S., Haddock, G., e Sa, D.V., Emsley, R. and Barrowclough, C., 2014. An experience sampling study of worry and rumination in psychosis. *Psychological Medicine*, *44*(8),1605-1614.
8	Kimhy, D., Vakhrusheva, J., Liu, Y. and Wang, Y., 2014. Use of mobile assessment technologies in inpatient psychiatric settings. *Asian Journal of Psychiatry*, *10*, 90-95.
9	Edwards, C.J., Cella, M., Tarrier, N. and Wykes, T., 2016. The optimisation of experience sampling protocols in people with schizophrenia. *Psychiatry Research*, *244*,289-293.

10	Mulligan, L.D., Haddock, G., Emsley, R., Neil, S.T. and Kyle, S.D., 2016. High resolution examination of the role of sleep disturbance in predicting functioning and psychotic symptoms in schizophrenia: A novel experience sampling study. *Journal of Abnormal Psychology*, *125*(6),788.
11	Reininghaus, U., Kempton, M.J., Valmaggia, L., Craig, T.K., Garety, P., Onyejiaka, A., Gayer-Anderson, C., So, S.H., Hubbard, K., Beards, S. and Dazzan, P., 2016. Stress sensitivity, aberrant salience, and threat anticipation in early psychosis: an experience sampling study. *Schizophrenia Bulletin*, *42*(3),712-722.
12	Kimhy, D., Wall, M.M., Hansen, M.C., Vakhrusheva, J., Choi, C.J., Delespaul, P., Tarrier, N., Sloan, R.P. and Malaspina, D., 2017. Autonomic regulation and auditory hallucinations in individuals with schizophrenia: an experience sampling study. *Schizophrenia Bulletin*, *43*(4),754-763.
13	Klippel, A., Myin-Germeys, I., Chavez-Baldini, U., Preacher, K.J., Kempton, M., Valmaggia, L., Calem, M., So, S., Beards, S., Hubbard, K.

	and Gayer-Anderson, C., 2017. Modeling the interplay between psychological processes and adverse, stressful contexts and experiences in pathways to psychosis: an experience sampling study. *Schizophrenia Bulletin*, *43*(2),302-315.
14	Moitra, E., Gaudiano, B.A., Davis, C.H. and Ben-Zeev, D., 2017. Feasibility and acceptability of post-hospitalization ecological momentary assessment in patients with psychotic-spectrum disorders. *Comprehensive Psychiatry*, *74*, 204-213.
15	Dupuy, M., Misdrahi, D., N'Kaoua, B., Tessier, A., Bouvard, A., Schweitzer, P., Auriacombe, M., Serre, F., Fatseas, M. and Swendsen, J., 2018. Mobile cognitive testing in patients with schizophrenia: A controlled study of feasibility and validity. *Journal de Thérapie Comportementale et Cognitive*, *28*(4),204-213.
16	Steenkamp, L., Weijers, J., Gerrmann, J., Eurelings-Bontekoe, E. and Selten, J.P., 2019. The relationship between childhood abuse and severity of psychosis is mediated by loneliness: an experience sampling study.

	Schizophrenia Research. 241, 306-311.
17	Swendsen, J., Ben-Zeev, D. and Granholm, E., 2011. Real-time electronic ambulatory monitoring of substance use and symptom expression in schizophrenia. *American Journal of Psychiatry*, *168*(2), 202-209.
18	Ainsworth, J., Palmier-Claus, J.E., Machin, M., Barrowclough, C., Dunn, G., Rogers, A., Buchan, I., Barkus, E., Kapur, S., Wykes, T. and Hopkins, R.S., 2013. A comparison of two delivery modalities of a mobile phone-based assessment for serious mental illness: native smartphone application vs text-messaging only implementations. *Journal of medical Internet research*, *15*(4), e60.
19	Moran, E.K., Culbreth, A.J. and Barch, D.M., 2017. Ecological momentary assessment of negative symptoms in schizophrenia: Relationships to effort-based decision making and reinforcement learning. *Journal of Abnormal Psychology*, *126*(1),96.
20	Kimhy, D., Delespaul, P., Ahn, H., Cai, S., Shikhman, M., Lieberman, J., Malaspina, D., Sloan, R., 2010. Concurrent measurement of “real-world” stress and arousal in

	individuals with psychosis: assessing the feasibility and validity of a novel methodology. Schizophrenia Bulletin 36, 1131–1139.
21	Blum, L.H., Vakhrusheva, J., Saperstein, A., Khan, S., Chang, R.W., Hansen, M.C., Zemon, V. and Kimhy, D., 2015. Depressed mood in individuals with schizophrenia: a comparison of retrospective and real-time measures. *Psychiatry Research*, *227*(2-3),318-323.
22	Edwards, C.J., Cella, M., Emsley, R., Tarrier, N. and Wykes, T.H., 2018. Exploring the relationship between the anticipation and experience of pleasure in people with schizophrenia: An experience sampling study. *Schizophrenia Research*, *202*,72-79.
23	Cella, M., He, Z., Killikelly, C., Okruszek, Ł., Lewis, S. and Wykes, T., 2019. Blending active and passive digital technology methods to improve symptom monitoring in early psychosis. *Early Intervention in Psychiatry*. 13(5), pp.1271-1275.
24	Visser, K.F., Esfahlani, F.Z., Sayama, H. and Strauss, G.P., 2018. An ecological momentary assessment evaluation of emotion regulation abnormalities in

	schizophrenia. Psychological Medicine, 48(14), 2337-2345.
25	Granholm, E., Holden, J.L., Mikhael, T., Link, P.C., Swendsen, J., Depp, C., Moore, R.C. and Harvey, P.D., 2019. What Do People With Schizophrenia Do All Day? Ecological Momentary Assessment of Real-World Functioning in Schizophrenia. *Schizophrenia Bulletin*. 46(2), pp.242-251
26	Johnson, E.I., Grondin, O., Barrault, M., Faytout, M., Helbig, S., Husky, M., Granholm, E.L., Loh, C., Nadeau, L., Wittchen, H.U. and Swendsen, J., 2009. Computerized ambulatory monitoring in psychiatry: a multi-site collaborative study of acceptability, compliance, and reactivity. *International journal of methods in Psychiatric Research*, *18*(1), 48-57.
27	Fielding-Smith, S.F., Greenwood, K.E., Wichers, M., Peters, E. and Hayward, M., 2020. Associations between responses to voices, distress and appraisals during daily life: an ecological validation of the cognitive behavioural model. *Psychological Medicine*, 52(3), 538-547 1-10.
28	Harvey, P.D., Miller, M.L., Moore, R.C., Depp, C.A., Parrish, E.M. and

	Pinkham, A.E., 2021. Capturing Clinical Symptoms with Ecological Momentary Assessment: Convergence of Momentary Reports of Psychotic and Mood Symptoms with Diagnoses and Standard Clinical Assessments. *Innovations in Clinical Neuroscience*, 18(1-3), p.24.
29	Hanssen, E., Balvert, S., Oorschot, M., Borkelmans, K., van Os, J., Delespaul, P. and Fett, A.K., 2020. An ecological momentary intervention incorporating personalised feedback to improve symptoms and social functioning in schizophrenia spectrum disorders. *Psychiatry research*, *284*,112695.
30	Ben-Zeev, D., Buck, B., Chander, A., Brian, R., Wang, W., Atkins, D., Brenner, C.J., Cohen, T., Campbell, A. and Munson, J., 2020. Mobile RDoC: Using Smartphones to Understand the Relationship Between Auditory Verbal Hallucinations and Need for Care. *Schizophrenia Bulletin Open*, *1*(1), 060.
31	Bell, I.H., Rossell, S.L., Farhall, J., Hayward, M., Lim, M.H., Fielding-Smith, S.F. and Thomas, N., 2020. Pilot randomised controlled trial of a brief coping-focused intervention for

	hearing voices blended with smartphone-based ecological momentary assessment and intervention (SAVVy): Feasibility, acceptability and preliminary clinical outcomes. *Schizophrenia Research*, *216*, 479-487.
32	Durand, D., Strassnig, M.T., Moore, R.C., Depp, C.A., Ackerman, R.A., Pinkham, A.E. and Harvey, P.D., 2021. Self-reported social functioning and social cognition in schizophrenia and bipolar disorder: Using ecological momentary assessment to identify the origin of bias. *Schizophrenia Research*, *230*, pp.17-23
33	Reininghaus, U., Oorschot, M., Moritz, S., Gayer-Anderson, C., Kempton, M.J., Valmaggia, L., McGuire, P., Murray, R., Garety, P., Wykes, T. and Morgan, C., 2019. Liberal acceptance bias, momentary aberrant salience, and psychosis: an experimental experience sampling study. *Schizophrenia bulletin*, *45*(4),871-882.
34	So, S.H.W., Chung, L.K.H., Tse, C.Y., Chan, S.S.M., Chong, G.H.C., Hung, K.S.Y. and Sommer, I.E., 2021. Moment-to-moment dynamics between auditory verbal hallucinations and negative affect

	and the role of beliefs about voices. *Psychological Medicine*, *51*(4), 661-667.
35	Ludwig, L., Mehl, S., Krkovic, K. and Lincoln, T.M., 2020. Effectiveness of emotion regulation in daily life in individuals with psychosis and nonclinical controls—An experience-sampling study. *Journal of Abnormal Psychology.* 129(4), p.408
36	Hermans, K.S., Myin-Germeys, I., Gayer-Anderson, C., Kempton, M.J., Valmaggia, L., McGuire, P., Murray, R.M., Garety, P., Wykes, T., Morgan, C. and Kasanova, Z., 2020. Elucidating negative symptoms in the daily life of individuals in the early stages of psychosis. *Psychological Medicine*,1-11.
37	Strassnig, M.T., Harvey, P.D., Miller, M.L., Depp, C.A. and Granholm, E., 2021. Real world sedentary behavior and activity levels in patients with schizophrenia and controls: an ecological momentary assessment study. *Mental Health and Physical Activity*, *20*,100364.
38	Jongeneel, A., Aalbers, G., Bell, I., Fried, E.I., Delespaul, P., Riper, H., Van Der Gaag, M. and Van Den Berg, D., 2020. A time-series network approach to auditory verbal

	hallucinations: Examining dynamic interactions using experience sampling methodology. *Schizophrenia research*, *215*,.148-156

Appendix 9: Published systematic review

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Design decisions and data completeness for experience sampling methods used in psychosis: systematic review

Emilia Deakin[1,2,3*], Fiona Ng[1], Emma Young[3], Naomi Thorpe[3], Christopher Newby[4], Carol Coupland[4], Michael Craven[2,5,6] and Mike Slade[1,2,7]

Abstract

Background: The experience sampling method (ESM) is an intensive longitudinal research method.

Participants complete questionnaires at multiple times about their current or very recent state. The design of ESM studies is complex. People with psychosis have been shown to be less adherent to ESM study protocols than the general population. It is not known how to design studies that increase adherence to study protocols. A lack of typology makes it is hard for researchers to decide how to collect data in a way that allows for methodological rigour, quality of reporting, and the ability to synthesise findings. The aims of this systematic review were to characterise the design choices made in ESM studies monitoring the daily lives of people with psychosis, and to synthesise evidence relating the data completeness to different design choices.

Methods: A systematic review was conducted of published literature on studies using ESM with people with psychosis. Studies were included if they used digital technology for data collection and reported the completeness of the data set. The constant comparative method was used to identify design decisions, using inductive identification of design decisions with simultaneous comparison of design decisions observed. Weighted regression was used to identify design decisions that predicted data completeness. The review was pre-registered (PROSPERO CRD42019125545).

Results: Thirty-eight studies were included. A typology of design choices used in ESM studies was developed, which comprised three superordinate categories of design choice: Study context, ESM approach and ESM implementation. Design decisions that predict data completeness include type of ESM protocol used, length of time participants are enrolled in the study, and if there is contact with the research team during data collection.

Conclusions: This review identified a range of design decisions used in studies using ESM in the context of psychosis. Design decisions that influence data completeness were identified. Findings will help the design and reporting of future ESM studies. Results are presented with the focus on psychosis, but the findings can be applied across different mental health populations.

Keywords: Experience sampling methods, ESM, Ecological momentary assessment, EMA, Psychosis, Smartphone

Background

The experience sampling method (ESM) is an intensive longitudinal research method [1]. ESM is conducted in real world settings as a participant goes about their daily life [2]. Participants complete self-report questions about transient experiences at multiple times, typically

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*Correspondence: emilia.deakin@nottingham.ac.uk

[1] School of Health Sciences, Institute of Mental Health, University of Nottingham, Triumph Road, Nottingham NG7 2TU, UK
Full list of author information is available at the end of the article

followed by questions relating to current environment or context [3]. Prior to the advent of digital technologies, ESM involved filling in a diary or booklet [4]. Most ESM designs are now computerised and allow researchers to identify the exact time a momentary assessment was completed [5]. The review will focus specifically on digital ESM because paper-based approaches are increasingly redundant and the review focus on data completeness is likely to be strongly influenced by data collection approach.

ESM can provide an accurate assessment of phenomena as they occur [2]. It allows researchers to gain more ecologically valid insights into the impact of daily events on participants, which are difficult to measure under laboratory conditions [6]. ESM can be used to examine temporal precedence between variables [2]. By asking participants to report experiences over a period of time, researchers can investigate fluctuations between variables which may not be captured using other methods [7].

ESM has been used widely in mental health research [8], and a review of its use has identified a number of applications including improving understanding of symptoms and social interactions, identifying causes of symptom variation and evaluating treatments [9]. ESM is a valid approach when capturing mental health states in participants with psychosis [10].

Data completeness is a particular challenge in ESM. Missing data is common in research using ESM methods [11]. Data incompleteness can occur for a number of reasons, such as participants finding ESM burdensome and time consuming [2], leading to reduced adherence to the study protocol, resulting in reduced data quantity [12] and quality [13]. Incomplete data sets can cause important aspects of experience to be overlooked by researchers and also bias statistical models used for analysis [14]. People with psychosis have been shown to be less adherent to ESM study protocols than the general population [13]. Studies that recruit people with psychosis have higher rates of participant withdrawal, resulting in fewer participants included in final analyses [15].

ESM design

Conducting an ESM study involves making several design decisions [16]. For example, deciding when and how frequently participants answer questionnaires. A questionnaire prompt may be sent to participants at predefined intervals (time contingent protocol), scheduled at random times (signal contingent protocol) or carried out when a predefined event has occurred (event contingent protocol) [17]. Studies can also use hybrid designs, which combine sampling protocols [9]. Setting the frequency of questionnaire prompts involves consideration of participant burden as well as how rapidly the target phenomenon is expected to vary [4].

There is evidence that design decisions influence completion rates. For example, longer questionnaires have been associated with higher levels of participant burden [18]. Protocol adherence has been shown to reduce over time, and also to be dependent on the time of day a questionnaire is received [13]. A systematic review investigating compliance with study protocols and retention in ESM studies in participants with severe mental illness found that frequent assessments and short intervals between questionnaires reduce data completeness, and increasing participant reimbursement increases data completeness [15].

There is a need for greater consistency in the design of ESM studies [9]. ESM is a collection of methods and is usually reported in relation to general characteristics rather than a defined set of design options [4]. When designing an ESM study, researchers have insufficient evidence on which to base design decisions [18]. Designs of ESM studies are often based on individual research questions [16], leading to a large heterogeneity of designs [15]. Additional methodological research is needed in order for studies to be replicable and standardised [9].

Developing consistency in design is impeded by the absence of a typology of design decisions. No typology for ESM design choices currently exists. A typology could help to define and classify ESM research methods [19], increasing both methodological rigour in developing and reporting individual studies and the ability to compare or combine findings.

Review aims

The aim of this systematic review is to characterise the design choices made in digital ESM studies monitoring the daily lives of people with psychosis. The objectives in relation to ESM studies involving people with psychosis are:

(1) to develop a typology of design choices used in digital ESM studies and
(2) to synthesise evidence relating data completeness to different ESM design choices.

Methods

A systematic review of the literature was carried out following PRISMA guidance [20]. Studies published in academic journals that met inclusion criteria were assessed for methodological quality. The constant comparative method [21] was used to identify design decisions to produce a typology. Weighted regression was used to identify design decisions that predicted data completeness.

Eligibility criteria

Inclusion criteria:

- Participants: papers that reported on participants with a clinical or research diagnosis of psychosis, either as a category or by specific diagnosis, e.g., schizophrenia either as the study population or as a separately reported and disaggregable sub-group
- Methods: Studies using ESM to monitor participants with psychosis
- Studies which used digital technology to administer ESM
- Studies which included experience sampling as part of a wider design, e.g. as part of an intervention
- English language full text articles, reviews and conference abstracts
- Papers published from January 2009 to July 2021
- Studies which either reported the completeness of data or gave sufficient data to allow calculation of data completeness where not specifically reported

Exclusion criteria:

- Studies recruiting non clinically diagnosed adults, i.e. participants self-reporting psychosis without clinical or research validation
- Studies using non-digital approaches to data collection
- Lifelogging, quantified self and other self-tracking approaches used by individuals to record personal data, since these are not research methodologies used to collect data for scientific purposes

Data sources and search strategy

A systematic search was developed and conducted in collaboration with two information specialists with expertise in systematic review searches (authors EY and NT). These data sources and associated search strategy are described below.

Six sources were used.

First, the following electronic databases were searched with a date limit of January 2009 to July 2021 (date of last search): Medline, Embase, PsycInfo (all via Ovid), Cochrane Library, and Web of Science Core Collection. The search terms are described in detail in additional file 1.

Second, the table of contents for the following journals were hand searched: Journal of Medical Internet Research, Journal of Medical Internet Research (Mental health), Journal of Medical Internet Research (mHealth and uHealth), Journal of Methods in Psychiatric Research, Psychiatric Rehabilitation Journal, Psychiatric Services, Psychological Assessment Schizophrenia Bulletin and Schizophrenia Research. Issues from 2009 to July 2021 were searched. These journals were chosen as they regularly published recovery-related papers.

Third, web-based searches were conducted using: Google Scholar, ResearchGate and Academia.edu. They were searched using the terms 'experience sampling' and 'psychosis', 'ecological momentary assessment' and 'psychosis', 'experience sampling' and 'schizophrenia' and ecological momentary assessment and 'schizophrenia.' Due to the large number of results found on Google Scholar only the first five pages (100 results) per search string were searched.

Fourth, grey literature searches were conducted using OpenGrey. This was conducted using the same search terms used for the web-based searches.

Fifth, reference lists of included papers were hand-searched. Backward citation tracking was conducted by hand-searching the reference lists of all included papers. Forward citation tracking of papers citing included studies was conducted using Scopus and Google Scholar.

Finally, a panel of five experts with expertise in experience sampling methods was consulted for additional studies meeting the inclusion criteria.

Data extraction and appraisal

Eligible citations were collated and uploaded to EndNote, and duplicates were removed. The titles of all identified citations were screened for relevance against the inclusion criteria by ED and FN, who rated all of the studies for inclusion. Data were extracted into an Excel spreadsheet developed as a Data Abstraction Table (DAT) for the review. The complete DAT can be found in (Additional file 2). Full text was obtained for potentially relevant papers and eligibility decided by the lead author.

Quality assessment

In the absence of a typology for reporting of ESM studies, recommended reporting criteria for ambulatory studies [22] were used. Studies were assigned points based on whether they had reported elements of the study design recommended by the guidelines. Examples of recommended reporting criteria include 'explanation of the rationale for the sampling design' and 'full description of the hardware and software used to collect data.' Corresponding to the number of items on the reporting criterion, the maximum possible score was 12 points. Studies scoring 0 to 6 were arbitrarily considered to be low quality, and studies scoring 7 to 12 were considered high quality. This rating was carried out by ED.

Subgroup analysis was undertaken for studies included in Objective 2 (predictors of data completeness).

Subgroup analysis was not undertaken for the Objective 1 typology because the aim was to develop an exhaustive typology [23].

Data analysis

To meet Objective 1 (design typology), design decisions were iteratively identified from the included papers. A preliminary typology of design decisions was developed by analysts who were familiar with the field of ESM (ED, MC, MS). This preliminary typology was used as headings in the initial version of the Data Abstraction Table (DAT). The constant comparative method [21] was used to refine the preliminary typology, by combining inductive category coding with simultaneous comparison of incidents observed [24]. Included papers were coded using existing DAT headings, and further or combined categories were iteratively identified [25]. The DAT was then structured using all identified design decisions and corresponding data extracted from each study [26]. Extending and combining of the preliminary typology was achieved through discussion amongst researchers ED, MC, FN, MS.

To meet objective 2, the outcome of data completeness was defined as the percentage of questionnaires completed by participants in each study out of a possible total allowed by each study protocol. This was taken directly from the paper where possible. Where percentage of data completeness was not reported, completeness was calculated by converting the total questionnaires completed during the study into a percentage using the total possible questionnaires allowed by the study protocol. The percentage represents the total data completeness for each study. Each study had a different number of questionnaires to report and different number of participants The percentage therefore includes variation between participants and within participants as questionnaire completion was completed over time. Each of the categories from the typology were used as predictor variables. Additional predictor variables included in the analysis were mean age of study participants and percentage of male participants.

A weighted regression was carried out. This approach assumes that the completeness is a summary statistic from a study with unknown variance and this standard error. Each completeness percentage statistic is weighted by how many participants were in each study. The number of questionnaires (denominator variable) was also included as a predictor to see if this predicted completeness. The completion outcome is analysed as a standard regression but where each estimate of completeness is given weight dependent on its sample size.

Predictor variables were entered into the weighted regression model. Design features not used in any included study, such as 2.1.1 ESM protocol: signal contingent, were excluded. For continuous predictor variables, cut-points were used to produce broadly equal sized categories: Participant gender (0%—32% male, 33%-65% male, 66%-100% male). For each predictor variable, the first category was then used as the reference category and each of the other categories individually and where relevant in grouped combinations were compared with the reference.

A *p*-value for each predictor was calculated using the ANOVA function comparing the difference in model fit (*R* squared value) for each predictor and the intercept model (i.e. no variables). Significant predictors were then further explored by comparing beta values in their models with their corresponding p-values. These were reported and tabulated to see the impact on completeness and to explore which differences between categories of the predictor were significantly associated with completeness.

Results

Thirty-eight publications were included in the review. The study selection process is summarised in Fig. 1 using the PRISMA flowchart [27].

Characteristics of included publications are presented in Table 1.

Quality assessment

All 38 studies were assessed for quality. Overall, 14 (37%) were evaluated as high quality and 24 (63%) as low quality.

Participants

The 38 included studies recruited a total of 2,722 participants with psychosis. Overall, 51% ($n = 1{,}380$) of participants were male. The mean age was 41 years. Other participant demographic variables were reported inconsistently across studies. Data were collected from 2,643 (97%) participants in the community and 79 (3%) were inpatients at the time of data collection. Participants had diagnoses including schizophrenia, spectrum disorder, psychosis, non-affective psychotic disorder, bipolar disorder, schizophreniform disorder, schizo-affective disorder, delusional disorder, or psychotic disorder not otherwise specified (NOS), depression with psychotic symptoms, delusional disorder, first episode psychosis and major depression.

ESM design choices

Design choices are summarised in Table 2. Not all design decisions were reported across all studies.

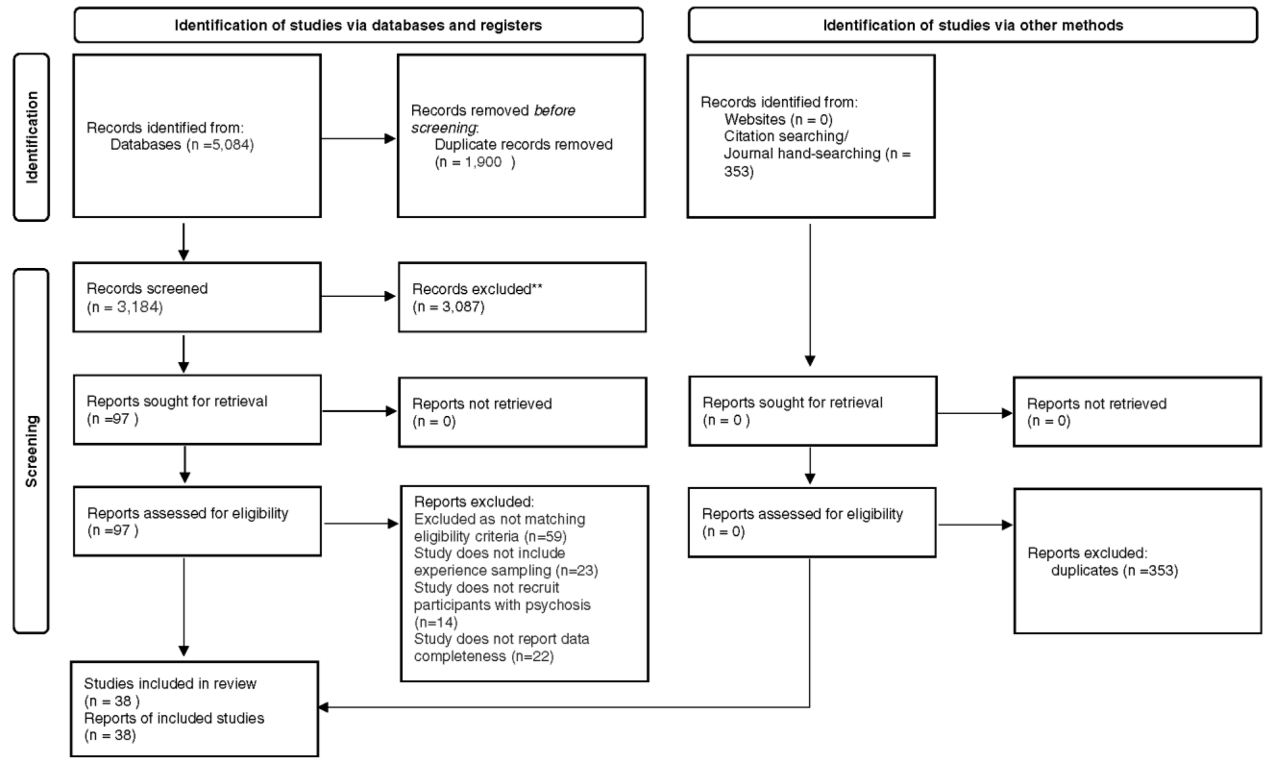

Fig. 1 Flowchart of study selection

Data completeness

Percentage of data completeness was obtained for 29 studies. The remaining nine studies expressed data completeness as either a percentage or number of participants who completed more than a predefined threshold amount, meaning it was not possible to determine the exact data completeness percentage. Data completeness across included studies in summarised in Fig. 2.

Objective 1: Typology of design choices used in ESM studies

Analysis of included publications identified 24 design decisions. Three superordinate themes were identified from the designs: Study context, ESM approach and ESM implementation.

Superordinate theme 1: Study context The Study Context theme describes decisions made when designing an ESM study which are not ESM-specific decision. These are shown in Table 3.

Superordinate theme 2: ESM Approach ESM approach describes the design decisions relating specifically to experience sampling and are shown in Table 4.

Superordinate theme 3: ESM Implementation The theme of ESM implementation is shown in Table 5.

Objective 2: Predictors of data completeness

A weighted regression of design decisions included in the typology was conducted, and the significance of each design choice as a predictor of data completeness is shown in Table 6.

The regression identified six candidate predictors of data completeness: ESM protocol, length of time per measurement, total time in the study, research team contact, accepted response rate and collecting other data. The findings from the weighted regression for specific values of these six candidate predictors are shown in Table 7.

Table 7 shows that using a time contingent protocol rather than a signal contingent protocol was significantly associated with reduced data completeness by around 12%. Greater data collection burden was consistently associated with reduced data completeness: every extra hour in measurement duration reduced data completeness by 2%, every additional day enrolled in the study reduced data completeness by 0.5%, and collecting extra data alongside ESM data reduced data completeness by 19%. Finally, researcher-initiated contact with

Table 1 Summary of included papers ($n = 38$)

#	Ref	Sample size	Length of data collection	Time period per day	Notification frequency	Hardware used	Data completeness
High quality studies							
		n	**Days**	**Hours**	**n per day**		**%**
1	[28]	24	7	13	6	PDA	88%
2	[10]	24	7	Not reported	6	PDA	97.7%
3	[29]	130	7	12	4	PDA	130/190 participants completed 2 full days or more
5	[30]	26	14	12	7	PDA	60%
11	[31]	$N = 150$ 51 First episode psychosis 46 at risk mental state 53 controls	6	Not reported	10	Data collection platform	51/59 particpants completed more than 20 valid responses
13	[32]	$N = 150$ 51 First episode psychosis, 46 At risk mental state, 53 controls	6	Not reported	10	Data collection platform	90.9%
14	[33]	65	28	12	4	PDA	28%
15	[34]	$N = 49$ 22 schizophrenia, 27 controls	7	Personalised to each participant	5	Smartphone application	87%
18	[35]	24	6	12	4	Smartphone application	69%
25	[36]	171	7	12	7	Smartphone application	85%
31	[37]	34	6	12	10	Smartphone application	72
33	[38]	97	10	15	6	Electronic device	97 participants completed > 20 questionnaires
34	[39]	47	6	Varied	10	Smartphone application	41 participants completed at least 18 out of 60 questionnaires
38	[40]	95	6	14.5	10	Electronic device	56%
Low quality studies							
4	[41]	145	7		4	PDA	72.10%
6	[42]	24	7	13	6	PDA	98.10%
7	[43]	32	6	15	10	PDA	27 participants completed more than half of questionnaires
8	[44]	31	2	12	10	PDA	81%
9	[45]	53 schizophrenia, 58 controls	6	13.5	7	Data collection platform	72.10
10	[46]	22	7	Personalised for each participant	5	PDA	77.40%
12	[47]	$N = 40$	3	12	10	PDA	89.80%
16	[48]	59	5	Not reported	10	Data collection platform	98.4%
17	[49]	199	7	12	4	PDA	72.10%
19	[50]	31	7	9	4	PDA	80%
20	[51]	20	1.5	12	10	PDA	79%
21	[52]	73	1.5	12	10	PDA	74%
22	[53]	76	6	13.5		Data collection platform	71%
23	[54]	15	10	10	4	Smartphone application	76%
24	[55]	56	6	12	4	PDA	90.2%
26	[56]	141	7	12	4	PDA	69%
27	[57]	31	9	Varied	10	Smartphone application	88.5% provided ⩾30 valid responses
28	[58]	173	30	Varied	3	Smartphone application	80

Table 1 (continued)

High quality studies

#	Ref	Sample size	Length of data collection	Time period per day	Notification frequency	Hardware used	Data completeness
		n	Days	Hours	n per day		%
29	[59]	64	21	21	6	Smartphone application	61.5
30	[60]	384	30	12	4	Smartphone application	60
32	[61]	173	30	12	3	Smartphone application	76.5
35	[62]	71	6	Not reported	10	Smartphone application	71/80 completed > 10% questionnaires
36	[63]	110	6	15	10	Electronic device	13 participants excluded as less than 20 responses completed
37	[64]	100	7	12	7	Smartphone application	85%

participants increased data completeness by 17.5% when compared to participant-initiated contact.

Sensitivity analysis

The analysis was repeated only including the 10 studies rated as high quality that expressed the data completeness as a percentage. The quality assessment ratings for studies is shown in Additional file 2. 14 studies were rated as high quality. The quality criteria met by fewest studies was justification of sample size (met by 3 studies) and rationale for the sampling design (met by 5 studies). The weighted regression identified 3 design decisions that predicted of data completeness: sample size (p: 0.012), other data collected (p: 0.006) and hardware used (p: 0.045). The statistically significant predictors with beta values, standard errors and p-values can be found in additional file 3.

Discussion

This systematic review identified design decisions used in experience sampling studies of people with psychosis. The resulting typology identified three superordinate themes relating to design decisions in ESM studies: Study context, ESM approach and ESM implementation. Weighted regression was then used to identify six design decisions that predicted data completeness: ESM protocol, other data collected, length of time in study, measurement duration, accepted response rate and contact with the research team.

Objective 1: Typology of design choices used in digital ESM studies

A systematic search of published literature on ESM allowed the creation of a typology that accurately represent the methods used in the field [65]. The resulting typology can help researchers to choose designs, help establish a common language and help to provide the field of ESM research with organisational structure [66].

Four ESM protocols were included in the typology. Event-contingent assessments, Signal-contingent assessments, Time-contingent assessments, and hybrid assessments. Three ESM protocols are commonly cited in ESM literature [67]. A questionnaire prompt may be sent to participants at pre-defined intervals (time contingent), scheduled at random times (signal contingent) or carried out when a predefined event has occurred (event contingent) [17]. 'Hybrid assessment' has been used to describe combined protocols.

A sampling protocol is often selected based on the variables of interest [16]. Choice of protocol may depend on whether the variables are discrete, relating to distinct events such as social interactions, or continuous events with less identifiable parameters, such as mood [4]. Discrete events are well suited to event contingent protocols as they have definable beginning and end points. Rather than waiting for a signal or prompt, participants fill out a questionnaire when a discrete event occurs. Time contingent and signal contingent protocols are better suited to measurement of continuous variables. Participants are not required to identify the beginning or end of a predefined event in order to complete a questionnaire in time contingent or signal contingent designs [9].

Signal and time contingent protocols can be carried out at fixed or flexible time points [9]. Some authors described their signal contingent designs as stratified [37, 39, 43] or semi-random [16]. In stratified sampling, questionnaires are sent at random time points within pre-programmed time windows. These parameters are unknown to the participant [58]. An example of this is a protocol with a range of 90 min within which at least one beep

Table 2 Design decisions used in included studies ($n = 38$)

Design decision	n
Study design	
Cohort study	19
Case control study	17
Crossover trial	1
Randomized repeated measures crossover design	1
Sample size	
Mean	73.6
SD	74.7
Data collection setting	
Hospital	3
Community	34
Recruitment setting	
Hospital	3
Community	30
Hospital and community	2
ESM Protocol	
Event-contingent	0
Signal-contingent assessments	27
Time-contingent assessments	7
Stratified	3
Type of prompt	
Auditory (beep)	2
Vibrate	25
Auditory (beep) and vibrate	0
Technology used	
Personal Digital Assistant (PDA)	16
Smartphone application	14
Data collection platform	5
Electronic device	3
Device ownership	
Provided by researcher	34
Participants provided with device if they didn't have one	2
Time taken to complete measures (minutes)	
Mean	3.5
SD	1.22
Type of data being collected	
Experience data	12
Context data	0
Behavioural data	1
Cognitive data	1
Experience and context data	11
Experience and behavioural data	6
Experience, context and behavioural data	0
Behavioural and context data	2
Experience, context, behavioural and cognitive data	0
Design of the questionnaire	
Derived from validated scale/scales	6
Uses non validated scales	19
Combination of both	8

Table 2 (continued)

Design decision	n
Other data collected	
Yes	9
No	29
Total length of time per day sampling took place (hours)	
Mean	12.3
SD	1.3
Questionnaire availability (minutes)	
Mean	16.4
SD	13.2
Data collection frequency (Number of prompts per day)	
Mean	6.8
SD	2.7
Study duration (days)	
Mean	9.3
SD	7.8
Terminology used	
Experience Sampling Methods or ESM	23
Ecological Momentary Assessment or EMA	12
Ambulatory assessment	0
EMAc	1
Mobile phone based assessment	1
Self assessment	0
Computerised ambulatory monitoring	1
Data access	
Researchers	37
Participants	0
Researchers, Participants and clinicians	1
Accepted response rate (%)	
Mean	27.8
SD	9.0
Contact with research team during data collection	
Researcher initiated	16
Participant initiated	1
Both	5
Participant training	
Yes	33
No	0
Additional support	
Initial contact after commencing data collection	5
Initial contact after commencing data collection + technical support on request	5
Initial contact after commencing data collection + additional support on request	1
Technical support on request	3
Technical support on request + motivational support + emotional support	1
Motivational support + technical support	1
Initial contact after commencing data collection + motivational support	2
Motivational support	4
Initial contact after commencing data collection + technical support + motivational support	1
Participant reimbursement (£)	
Mean	60.7

Table 2 (continued)

Design decision	n
SD	38.7
Data completeness %	
Mean	76.8
SD	15.2

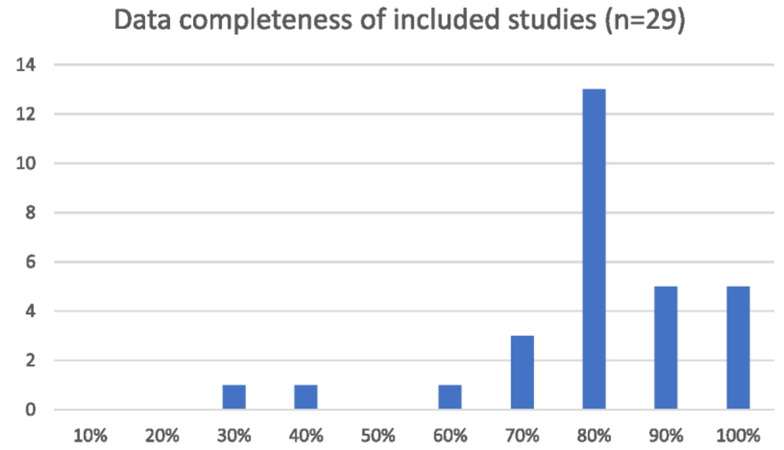

Fig. 2 Data completeness of included studies

Table 3 Superordinate theme 1: Study context

Theme	Definition	Categories
1.1 Study design	Design of the overall study within which the ESM study is nested	Cohort Case control Crossover trial Pilot RCT
1.2 Sample size	Intended number of participants completing ESM measures	N
1.3 Data collection setting	Location of ESM data collection	Hospital (currently an in-patient) Community (not an in-patient)
1.4 Recruitment setting	Location of participant recruitment	Hospital Community Hospital and community

occurred with a minimum of 15 min and a maximum of 3 h between each beep. The intention of the stratified protocol is to balance the requirement for collecting variable and valid data with participant burden [43]. The data may be more variable than a time contingent protocol, as the timing of the signal cannot be anticipated by participants. Participants will not therefore be less likely to alter their daily life or habits to incorporate the sampling. Some stratified sampling protocols included personalising the daily measurement period to each participant's waking hours [39, 58].

Another design choice relating to ESM approach is whether the digital technology used for data collection was provided by the researchers or participants were required to use their own smartphones. The present review found there to be no significant difference in data completeness between studies which provided a device and those in which participants used their own phone. There is conflicting opinion about this in

Table 4 Superordinate theme 2: ESM Approach

Theme	Definition	Categories
2.1 Data collection method		
2.1.1 ESM protocol	Data collection trigger	Event-contingent assessments: carried out when a predefined event has occurred, for example attending a social event
		Signal-contingent assessments: scheduled at random times
		Time-contingent assessments: involve prompting the individual to make an assessment at pre-defined intervals
		Hybrid assessments: a combination of more than one data collection trigger
2.1.2 Type of prompt	Alert to promote participant response	Auditory (beep)
		Vibrate
		Visual prompt
2.1.3 Hardware used	The hardware used to collect data	Personal Digital Assistant (PDA)
		Online data collection platform
		Smartphone
2.1.4 Software used	The software used to collect data	Smartphone application
2.1.5 Device ownership	Owner of the device used to collect data	Provided by researcher
		Pre-owned by participant
2.2 Measures		
2.2.1 Questionnaire completion time	Total time taken by participants to complete one round of questions	minutes (n)
2.2.2 Type of data	Type of data being collected	Cognitive data (e.g., Mobile word task)
		Behavioural data (e.g., instance of cannabis use)
		Experience data (e.g., current mood)
		Context data (e.g., immediate physical environment)
2.2.3 Questionnaire design	Were questions derived from psychometrically validated scales?	Derived from validated scale/scales
		Uses non-validated scales
2.2.4 Other data collected?	Was other participant data collected during the ESM data collection period?	Yes
		No
2.3 Schedule		
2.3.1 Measurement duration	Time period within each day that data collection takes place, i.e., gap between earliest and latest time	Hours (n)
2.3.2 Questionnaire availability	How long was the questionnaire available for participant response after each prompt?	Minutes (n)
2.3.3 Data collection frequency	Number of prompts per day	n
2.3.4 Length of time in study	Length of time ESM data collection is conducted	Days (n)

ESM literature [22]. Disadvantages of using participant-owned devices may include increased distractions from other applications on the phone and decreased uniformity of study procedures [68]. Advantages may include reduced study costs and also reduced requirement for participants to meet researchers face to face [69], which could reduce participant burden. A meta-analysis on ESM protocol compliance in substance users found no significant difference in adherence rates for participants who used their own phone compared with participants who used researcher provided devices [70].

The typology identified measures used for ESM studies that were derived from psychometrically validated scales and others that were not validated. Many of the measures which were not validated were created by the research team for the purpose of the study. In ESM studies, researchers have often selected items from longer, validated measures and adapted the questions to fit the study time frame [22]. This is often due to the lack of validated measures available for use in ESM studies [71]. Researchers should consider that adding "right now" to a questionnaire item does not necessarily mean that it is appropriate for measuring momentary states

Table 5 Superordinate theme 3: ESM Implementation

Theme	Definition	Categories
3.1 Terminology	What was the method of data collection called in the study?	Experience Sampling Methods or ESM Ecological Momentary Assessment or EMA Ambulatory assessment Computerised ambulatory monitoring Mobile phone-based assessment Self-assessment Computerised ecological momentary assessment (EMAc)
3.2 Data		
3.2.1 Data access	Who can access collected ESM data?	Researchers Participants Clinicians
3.2.2 Accepted response rate	Amount of questionnaires completed in order to be eligible for inclusion	Continuous: %
3.3 Participation		
3.3.1 Participant training?	Was training provided for participants prior to commencing ESM data collection?	Yes No

Table 5 (continued)

Theme	Definition	Categories
3.3.2 Contact with research team	Who initiates additional contact between the research team and participants during the ESM period?	Researcher Participant Either
3.3.3 Additional support	Support offered to participants by the research team after commencing data collection	None Initial contact after commencing data collection Technical support Technical support on request Motivational support Emotional support
3.3.4 Participant reimbursement	Compensation provided to each participant	Continuous: £

Table 6 Weighted regression of design choices as predictors of data completeness (29 studies)

Design Choice	Significance (overall *p*-value)
1.1 Study design	0.221
1.2 Sample size	0.159
1.3 Data collection setting	0.737
1.4 Recruitment setting	0.741
2.1.1 ESM protocol	**0.021**
2.1.2 Type of prompt	0.310
2.1.3 Hardware used	0.078
2.2.2 Type of data	0.978
2.2.3 Questionnaire design	0.540
2.2.4 Other data collected?	**< 0.001**
2.3.1 Measurement duration	**0.033**
2.3.2 Questionnaire availability	0.210
2.3.4 Length of time in study	**0.021**
3.2.2 Accepted response rate	**0.035**
3.3.2 Contact with research team	**0.014**
3.3.3 Additional support	0.390
Participant gender	0.435
Participant mean age	0.450
Number of questionnaires	0.165
2.1.5 Device ownership	0.320
3.1 Terminology used	0.984
3.2.1 Data access	0.869
3.3.4 Participant reimbursement	0.313

Bold = $p < 0.05$

[3]. Measuring momentary experiences is different from measuring phenomenon included in cross-sectional questionnaires that occur generally and retrospectively [9]. When considering what questionnaires to use in ESM studies, researchers should take into account the momentary nature of the phenomena and develop items that accurately capture how they are experienced over the course of the study duration [72].

The typology also identified support offered to participants once data collection has commenced. This is a common method of encouraging protocol adherence [13]. It can take the form of technical support, motivational support, or emotional support.

This study found no significant association between data completeness and reimbursement to participants. However, reimbursement can involve a number of different strategies, including providing added incentives to participants who achieve high levels of protocol adherence, withholding payment if compliance falls below a certain threshold, and providing payment at regular face to face meetings [22]. The value of participant reimbursement has been found to be positively associated with protocol adherence [15]. However, the authors note that they did not consider the strategy used to provide the incentives. Instead, a total incentive was calculated for each study. Another study investigated studies which provided reimbursement proportional to the number of questionnaires completed. No increase in protocol adherence was found [70]. The difference in findings indicate that more research is needed in this area, particularly on the influence of different reimbursement strategies on data completeness.

Applicability to different populations

Design choices included in the typology are consistent with those described in suggested ESM reporting guidelines for research in psychopathology [22]. This suggests

Table 7 Weighted regression for candidate predictors of data completeness (29 studies)

Design Choice	Beta-value	Standard error	p
2.1.1 Protocol			
Signal contingent	-11.82		
Time contingent vs Signal contingent	-0.25	4.24	**0.010**
Hybrid vs signal contingent		5.18	0.962
2.2.4 Other data collected			
Yes	19.26		
No vs yes		3.57	**< 0.001**
2.3.1 Measurement duration (hours)	-2.16	0.94	**0.033**
2.3.4 Length of time in study (days)	-0.438	0.18	**0.021**
3.2.2 Accepted response rate (% of questionnaires)	68.07	28.70	**0.035**
3.3.2 Contact with research team			
Researcher initiated	-17.49		
Participant initiated vs Researcher initiated	-4.84	5.06	**0.004**
Both vs Researcher initiated		7.85	0.549

that the typology can be applied across different mental health populations. Future research is required to validate the typology for use with transdiagnostic groups. For example, when being used to collect data from participants with depression, or measuring discrete variables such as self-harming behaviours [73]. This suggests that event contingent protocols may be used more frequently with this population [4].

Objective 2: Design decisions that predict data completeness

The ESM protocol used predicted data completeness. Using a signal contingent protocol compared to a time contingent protocol was shown to increase data completeness by around 12%. This is in contrast with previous research which has shown that signal contingent sampling may be perceived as more burdensome by study participants [74] leading to lower levels of adherence compared to other protocols [75]. The authors suggest that higher levels of predictability afforded by time contingent protocols may increase adherence as participants are able to integrate responding to questionnaires into their daily routine [75]. Knowledge of when to expect the questionnaire prompts may allow participants to plan their daily tasks in accordance with the scheduled questionnaires [15].

A study of ESM in participants with substance dependence found that participants may prefer to isolate themselves, or to be in quiet environment when responding to questionnaires [76]. In this case, the additional burden of anticipating the signal at a certain time and finding a quiet environment may account for lower data completeness with a time contingent protocol. Similarly, the psychosis population in our review may have more cognitive impairments such as reduced attention, meaning that the potential for integrating data collection into daily life is reduced, so a signal contingent assessment is easier to provide an immediate response to. As there are advantages and disadvantages to each ESM protocol and inconsistent findings regarding their effects on data completeness, it has been suggested that the choice of protocol should be based on the requirements of the study [15]. This may involve choosing a protocol that is based on the nature of the variables of interest [4].

Design decisions relating to scheduling were found to influence data completeness. Longer study lengths and longer daily measurement duration predicted lower levels of data completeness. For every day participants were enrolled in a study, data completeness reduced by 0.5%. Similarly, every additional hour of measurement duration per day reduced data completeness by 2%. These findings are consistent with previous research. A study analysed predictors of adherence to ESM protocols in a pooled data set of 10 ESM studies. The sample consisted of 1,717 participants, of whom 15% had experienced psychosis. The results showed that ESM protocol adherence declined over the duration of study days [13]. More generally, the problems experienced by people living with psychosis, such as negative symptoms and amotivaton, may require lower burden data collection procedures.

Some studies have customised the time period per day that sampling took place for each participant. This has included personalising the daily measurement period to each participant's waking hours [29, 34, 36]. Sampling took place for the same number of hours per day for each participant but began and ended at different times. This review only included the total number of hours per day sampling took place in the analysis. Future research could investigate the relationship between personalised scheduling and data completeness. Completeness, to allow diurnal variation in symptomatology to be integrated into the data collection schedule. For example, an individual who is more preoccupied with hallucinatroy experiences in the morning may be more able to respond to data collection prompts later in the day.

Monitoring participants once ESM has commenced has been recommended in order to encourage protocol adherence [22]. Support from researchers during the data collection phase is either initiated by researchers or by participants. Researcher initiated contact with participants throughout the duration of the study increased data completeness by 17.5% compared to participant-initiated contact. These findings support active researcher support once data collection has commenced. This is something which may be particularly beneficial if participants find the study procedures burdensome.

Strengths and limitations

One strength of this study is the rigorous search strategy. This was designed in collaboration with two information specialists with expertise in conducting systematic review searches in the field of mental health. Another strength is the use of several analysists with differing expertise. Areas of expertise include clinical expertise, mental health services research and technology research and design.

Several limitations can be identified. Studies were only included which reported data completeness, or studies where it was possible to calculate this. Studies that did not report this could have been included for Objective 1, which may have increased generalisability of the findings. Similarly, studies were only included if they used digital ESM which may also have limited generalisability. The title, abstract and full paper sifting was only carried out by one author (ED), which may introduce inclusion bias. In the absence of an appropriate quality checking tool, recommended reporting guidelines were used instead, which may not have been fully capturing quality. Finally, a meta regression could not be carried out, and the weighted regression that was conducted instead does not account for given estimates of variance, meaning that conclusions drawn from the analysis need to be interpreted with caution. Additionally, a small number of studies ($n=10$) were included in the sensitivity analysis.

Conclusions

The study addresses a knowledge gap related to design decisions for ESM studies recruiting people with psychosis. The typology of design choices used in ESM studies identifies key design decisions to consider when designing and implementing an experience sampling studies. The typology could be used to inform the design of future experience sampling studies in transdiagnostic mental health populations. The review also identifies a number of predictors of data completeness. This knowledge could help future researchers to increase the likelihood of achieving fuller data sets.

Future research might seek to add additional design choices to the typology and to refine design decisions as the field advances. Future research may also examine how the typology is used by researchers when designing ESM studies. Researchers may also validate the typology for use with different mental health populations.

Abbreviations

ESM: Experience Sampling Method; DAT: Data abstraction table.

Supplementary Information

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Additional file 1. Sources, search strategy, and study selection.

Additional file 2. Data abstraction table.

Additional file 3: Additional Table 1. Overall p-values for predictors of percentage completeness for high quality studies only ($n=10$). **Additional Table 2.** Statistical significant predictors with beta values, standard errors and *p*-values, for high quality studies ($n=10$).

Additional file 4. Quality assessment.

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Not applicable.

Authors' contributions

This systematic review was planned and designed by ED, MS, CC and MC. The literature search was carried out by E.Y and N.T. The screening was carried out by ED. Quality checking was performed by ED. Data was analysed by ED, FN, CC, MC, CN and MS. All the authors have read and approved the manuscript.

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Availability of data and materials

All data generated or analysed during this study are included in this published article and its supplementary information files.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

Author details

[1]School of Health Sciences, Institute of Mental Health, University of Nottingham, Triumph Road, Nottingham NG7 2TU, UK. [2]Nottingham Biomedical Research Centre, University of Nottingham, Nottingham, UK. [3]Nottinghamshire Healthcare NHS Foundation Trust, Nottingham, UK. [4]School of Medicine, University of Nottingham, Nottingham, UK. [5]Human Factors Research Group, Faculty of Engineering, University of Nottingham, Nottingham, UK. [6]Institute of Mental Health, NIHR MindTech MedTech Co-Operative, University of Nottingham, Nottingham, UK. [7]Nord University, Postboks 474, 7801 Namsos, Norway.

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Publisher's Note

Appendix 10: Interview topic guide

UNFOLD interview topic guide

Introduction

- Ensure the participant has read the information sheet and understands that participation is voluntary and that they are free to withdraw at any time
- Explain the aims and purpose of the interview and give a brief description of the interview structure.
- Provide an opportunity for participant to ask any questions
- Describe audio recording of the interview. Turn on the recorder/set Microsoft Teams to 'record'. Read out the UID so that it is recorded.

Questions (In line with qualitative methodology, topic guides may be updated after each interview). Ask the participant to describe their social experiences at the time of their first social identity map and then the present day. This may include influences their social groups have had on their lives during this time period. Encourage participants to use their social identity map as a prompt. Give them plenty of time, listen carefully. Reply if asked (e.g. "Is this okay?" – "Yes, you're doing great") and use minimal prompts if needed (e.g. "Do go on") but try to let the participant answer in their own words.

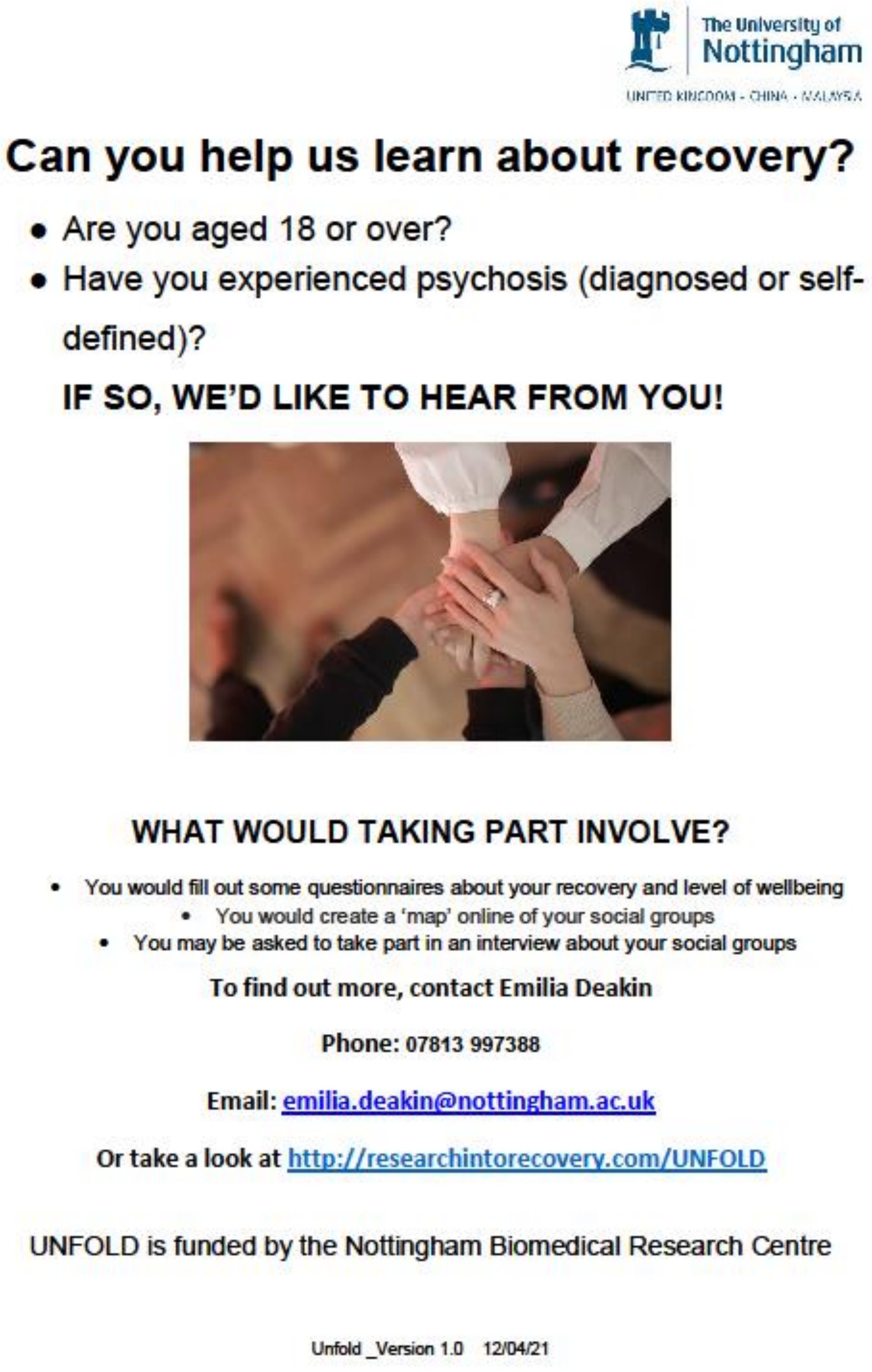
Follow up with questions about changes to group memberships, e.g.
1. How have the groups you use to describe yourself/define yourself changed between the two maps/timepoints?
2. How have groups influenced your recovery?
3. Were any groups maintained from the first map to the second, if so, how did this influence your recovery?
4. What is the impact on your recovery of any new groups?
3. If there was a particularly prominent change to group membership/relationships ask specifically about the impact of relevant relationships.
4. Were any groups mental health focused?

If the participant becomes distressed during the interview, ask if they would like to take a break or stop. If the participant reveals information which is of concern and may need reporting i.e. potential risks to another person or to themselves, or criminal behaviour, then continue the interview if you feel *comfortable to, but discuss these with the PI at the earliest opportunity and where appropriate report accordingly.*

End of interview

Explain the interview is now over and ask if the participant has any final questions. Give information about timeline for the study and how publications can be accessed. Thank the participant for their participation.

Appendix 11: Recruitment poster



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Can you help us learn about recovery?

- Are you aged 18 or over?
- Have you experienced psychosis (diagnosed or self-defined)?

IF SO, WE'D LIKE TO HEAR FROM YOU!

WHAT WOULD TAKING PART INVOLVE?

- You would fill out some questionnaires about your recovery and level of wellbeing
- You would create a 'map' online of your social groups
- You may be asked to take part in an interview about your social groups

To find out more, contact Emilia Deakin

Phone: 07813 997388

Email: emilia.deakin@nottingham.ac.uk

Or take a look at http://researchintorecovery.com/UNFOLD

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